STATE OF THE SCIENCE CONFERENCE PROCEEDINGS 2013

Tools for System Transformation for Young Adults with Psychiatric Disabilities

The Learning & Working During the Transition to Adulthood
Rehabilitation Research & Training Center

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Dear Distinguished Colleagues and Guests,
Welcome to our state-of-the-science conference, "Tools for System Transformation for Young Adults with Psychiatric Disabilities." We are the Rehabilitation Research and Training Center on Learning and Working During the Transition to Adulthood (aka Transitions RTC) of the University of Massachusetts Medical School. We are honored that you are taking time from your very busy schedule to take part in this important endeavor with us.
We have two goals for this conference. Our first goal is to share and discuss with you the current state of research knowledge regarding practice and policy supports for strong educational and employment outcomes in young adults (ages 18-30) with psychiatric disabilities. We will focus on implications for adult mental health and rehabilitation service systems, and the young adults with psychiatric disabilities in those systems. Our second goal is to engage you in prioritizing the knowledge that future research should address, to guide these systems' efforts, to better launch and support these young adults' long-term careers.

We thank our funders, the National Institute on Disability and Rehabilitation Research, the Substance Abuse and Mental Health Services Administration and the University of Massachusetts Medical School as well as our conference sponsors, the National Technical Assistance Center for Children's Mental Health Georgetown University and the Annie E. Casey Foundation.

We look forward to your participation in our conference, and in what we hope will be, a lively discussion about the service system implications of the state-of-the-science knowledge and needed future research directions.
Thank you for being with us today. Enjoy the conference!

Best Wishes,

Maryann Davis, Ph.D
Director, Transitions Research and Training Center
University of Massachusetts Medical School

ABSTRACT

The Learning and Working During the Transition to Adulthood Rehabilitation Research & Training Center, University of Massachusetts Medical School, successfully conducted a state of the science conference, "Tools for System Transformation for Young Adults with Psychiatric Disabilities." The conference was held at Georgetown University National Technical Assistance Center for Children's Mental Health on September 24-25th, 2013.

We had two goals for this conference. Our first goal was to share and discuss the current state of research knowledge regarding practice and policy supports for strong educational and employment outcomes in young adults (ages 18-30) with psychiatric disabilities. We focused on implications for adult mental health and rehabilitation service systems, and the young adults with psychiatric disabilities in those systems. Our second goal was to engage all attendees in prioritizing the knowledge that future research should address, to guide these systems' efforts, to better launch and support these young adults' long-term careers. The process of the conference included, presentations of three state of the science papers that were written and completed prior to the event in the domains of employment, education, and system and policy as well as an introductory framework paper. Subsequently, a summary of written responses to each paper were prepared and presented by a panel of stakeholders which included: researchers, young adults, family members, and individuals representing underserved populations. The papers, responses, and an introductory framework were made into a compendium which was distributed to all conference participants, both before, and at the conference.

In attendance at the state of the science conference were federal and state directors and administrators of disability service systems, especially in the areas of employment and education, as well as those with experience and expertise as family and young adult representatives and researchers.

The structure of the conference included:
- Welcoming remarks from Charlie Lakin, Director, National Institutes on Disability Rehabilitation Research (NIDRR),
- Welcoming remarks from Jim Wotring, Director, National Technical Assistance Center for Children's Mental Health,
- Welcoming remarks from Paolo Del Vecchio, Director, Substance Abuse and Mental Health Services Administration,
- Presentation by Maryann Davis, Director, Transitions Research and Training Center, on conference goals and framework for understanding young adults with psychiatric disabilities,

- Keynote address by Judith Cook, Director, Center on Mental Health Services Research.
- Three conference papers in each domain were presented by lead authors and a panel of responders in addition to comments by:
- Sue Swenson, Deputy Assistant Secretary, Office of Special Education and Rehabilitation services, U.S. Department of Education,
- Jennifer Sheehy, Deputy Assistant Secretary, Office of Disability Employment Policy, U.S. Department of Labor.

Additionally, a young adult panel shared their lived experience with us. Audience and break-out discussion groups were also built in and served to identify the key research questions of the field moving forward. A highlight of the conference was a video montage prepared by Transitions RTC Young Adult Project Assistants and staff. The conference concluded with a wrap up and conclusions. The proceedings herein include all conference papers and responses as well as final considerations for the future research directions in education, employment and policy and practice.

OPENING REMARKS

September 24, 2013
Paolo del Vecchio, M.S.W.
Director of the Substance Abuse & Mental Health Services Administration Center for Mental Health Services

I want to thank the National Technical Assistance Center for Children's Mental Health at Georgetown University and the Transitions Research and Training Center for convening this meeting. I want to thank, particularly, the National Institute on Disability and Rehabilitation Research, our partner for almost 30 years in supporting rehabilitation research training centers for people with mental health disabilities. I want to thank you, the presenters and participants contributing to this meeting, for taking your time. A special thanks to our Substance Abuse and Mental Health Services Administration staff as well who've joined us here today. Particularly, thanks to the leadership of Diane Sondheimer for her outstanding leadership. Thank you, Diane.

Topic of this meeting: State of the Science Education, and Employment Outcomes for Young Adults. It's one that certainly, for myself, hits home. And as my introduction notes, I'm a person who self-identifies as an individual in recovery. And for me, the young adult years were the most important times, frankly, in my life and a changing point in my life. And for many of us, after a childhood of trauma, of dealing with criminal justice, addictions, mental health disabilities, I found myself as a young adult in my early 20's in college in North Philadelphia and at my worst time in my life. A time where I couldn't get out of bed for days at a time, where I wouldn't interact with my peers. I would hide in the stairwells instead of talking to the students. Not saying a word during semesters at a time.

And my life, I thought at that point, wasn't worth living. So I made a decision that I was going to end it. I found myself on the Broad Street subway platform and ready to take that step. As I saw the light coming down the tunnel and the rumble of the trains, something pulled me back. And that was my mom, the thought of my mom, my heroine in my life. A woman who knew mental health issues very well, was institutionalized during younger parts of her life, subject to the evidence-based practices of the day, insulin-shock treatment. But went on to raise four kids in poverty, went on to get a masters degree in philosophy, was a nationally published poet and social activist in her own life. She passed away last year and God rest her soul.

But the thought of her pulled me from that platform and I made a decision there that I was going to try to get some help. So I went to the counseling center at the college campus. I

told them what was going on. They said, "Come back in a month. We have an opening then." But what I found there changed my life and that was a sign on the door for a job and it was for a work study job of manning an information and referral phone for a local mental health group. And frankly, I found my calling. I found what employment brings to people, a purpose in life and a life of purpose.

And through that experience, I also found two other things. One is that I wasn't alone with what I was going through and being able to talk to folks in the community who were experiencing what I was. And then secondly, I found that by helping other people, you help yourself and that concept of what that does to your own self worth and self esteem. And I went on and dedicated my life back to working in mental health. I want to say, again, particularly, the importance of jobs, importance of family supports is crucial for young adults as it is for all of us.

Just to note a couple of data points here. As we know, for people with psychiatric disabilities, some of the lowest rates of employment of any disability group. Those who are employed earn an average of $16,000 less per year than their counterparts who do not have a diagnosis. I've heard it said that empowerment is a good paycheck at the end of the week. And in our report here that you all have, again, just to note a couple other data points here about the importance of the topic. And you folks know this data very well, but again, 30% of young adults have a mental health problem in the past year. Two-and-a-half million have an issue so serious that it impacts their ability to function. Young people are more likely to experience homelessness, be arrested, drop out of school, be unemployed. The greatest disability within this age group is mental health disorders. Almost a quarter have experienced four or more types of potential traumatic events. Four or more, one quarter. Almost a half felt they did not have an adult to whom they could talk about important things. A tenth, one in ten experienced a period of homelessness, 16% neither in school or employed, 10% have made a suicide attempt. A quarter have been arrested, 12% with a serious substance abuse problem.

See, just a word or two again about employment, and that is that we have it backwards when it comes to psychiatric disabilities and employment in this country. We don't have to become less symptomatic before returning to work, that work reduces our symptoms. It provides that sense of purpose and belonging, gives us the opportunity to contribute, to share in goals.

Along this line, I also want to say that our work is even more difficult today than it was a week ago. Experiences of the navy yard shootings just downtown D.C. here, just a few miles from us. Obviously, last December as well with the horrible shootings in Newtown,

Connecticut, the names of Adam Lanza and Aaron Alexis just give further burden to the lives of those of us with psychiatric disabilities and that scarlet letter has gotten even worse. What this means, particularly for social inclusion, what it means for us about employment opportunities, when the kind of fear that these kind of incidents can produce, and what can we do as a community to try to address those issues in the days, weeks, years to come. Frankly, it's a huge issue for us.

Part of this also is the culture of diminished expectations from people and young adults with mental health problems. We have to recognize that a diagnosis does not have to become a destiny, as my friend, Russell Pierce, has said. We are not doomed to a life of less health, less enjoyment, less money, less status. We have to break the Prozac ceiling when it comes to employment in mental health.

I'm gonna end my remarks by, again, just relaying my own personal experience. When I started at SAMHSA almost 20 years ago, the then special assistant to the director of the center, Bernie Aarons, told me this a few years later, that she was going to make it, as I started the job, her goal to take care of this mental patient that she saw coming to work at the agency. She expected, in her head, she told me, someone coming in drooling and shuffling, not really being able to function on the job. To make a long story short, three years later we were married and 16 years later, we take care of each other. We have three beautiful children and a home and a mortgage and two dogs. So it's about, again, recovery. It's about keeping that hope for all of us and particularly for young adults. So thank you. I wish you well in your meetings next day or so.

Enhancing Successful Transitions to Adulthood for Young Adults with Psychiatric Disabilities
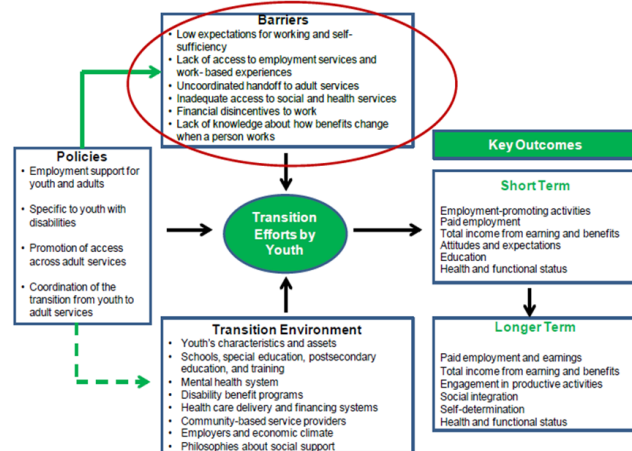
Judith A. Cook, PhD

Professor, Department of Psychiatry
University of Illinois at Chicago

Presented at Tools for System Transformation for Young Adults with Psychiatric Disabilities
Washington, DC, September 24, 2013

UIC COLLEGE OF
MEDICINE

Figure ES.1. Conceptual Framework for Policies and Programs Serving Transition-Age Youth

Barriers
- Low expectations for working and self-sufficiency
- Lack of access to employment services and work- based experiences
- Uncoordinated handoff to adult services
- Inadequate access to social and health services
- Financial disincentives to work
- Lack of knowledge about how benefits change when a person works

Policies
- Employment support for youth and adults
- Specific to youth with disabilities
- Promotion of access across adult services
- Coordination of the transition from youth to adult services

Transition Efforts by Youth

Transition Environment
- Youth's characteristics and assets
- Schools, special education, postsecondary education, and training
- Mental health system
- Disability benefit programs
- Health care delivery and financing systems
- Community-based service providers
- Employers and economic climate
- Philosophies about social support

Key Outcomes

Short Term
Employment-promoting activities
Paid employment
Total income from earning and benefits
Attitudes and expectations
Education
Health and functional status

Longer Term
Paid employment and earnings
Total income from earning and benefits
Engagement in productive activities
Social integration
Self-determination
Health and functional status

Moreno et al., 2013

Emphasis on Transition-Age Youth in State VR Agencies, 2004-2006

- 26% - State VR plan contains goals & plans related to youth
- 76% - State has VR counselors with dedicated transition caseload
- % counselors w dedicated transition caseloads
  - 0%   24% (12)
  - 1-10%   41% (20)
  - 11-20%   20% (10)
  - 21+%   14% (7)
- Effort has shown some success - aggregate cross-disability, post-school employment rate 2-5 years after school exit rose about 9 percentage points from late 1980s to 2003 (NLTS)

Figure III.3. Employment Ratio (Ratio of VR Youth with Positive Employment Outcomes to Youth Served), by State
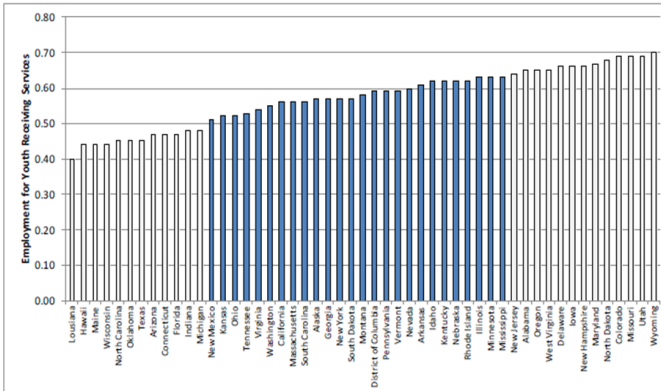
Source: RSA-911 closure records, fiscal years 2004 through 2011.

Honeycutt et al., 2013

State VR & Youth with Psychiatric Disabilities

- RSA 911 data indicate that transition age youth (ages 14-24) were 1/3 of all the eligible clients whose cases were closed in 2011
- After youth with learning disabilities, youth with psychiatric disabilities were the next largest group within the youth category, accounting for 16% of total closures
- The success rate for youth with MH problems (45%) was significantly lower than almost any other disability or age group.

Marrone & Taylor, 2013; Berry & Caplan, 2010

SSI & Transition to Adulthood

- Poor outcomes for youth on SSI *prior to age 18*
  - by age 19-23 years only 22% were employed, and 39% had dropped out of school (Loprest & Wittenburg, 2007)
- More positive outcomes for youth entering the SSI rolls *at 18-19 years* of age
  - better employment outcomes than any other age group, followed by those 20-35 years of age when they enter the rolls (Ben-Shalom et al., 2012)

7

Annual Percentage of 1996 SSI Award Cohort with Positive Countable Earnings, by Age at Award, 1996–2007
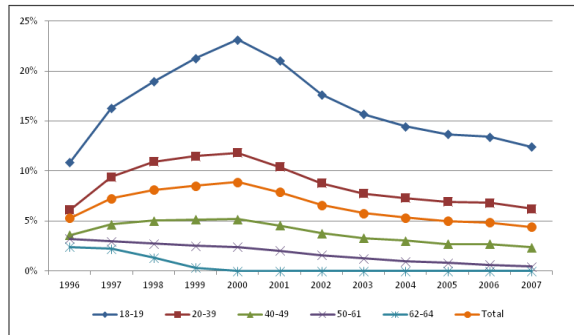
Ben-Shalom et al., 2012

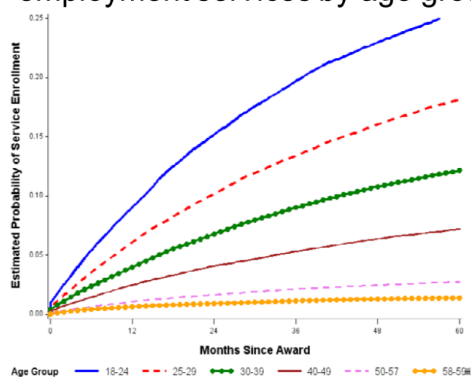## Research on Transition Age SSDI Beneficiaries

- Young adults with disabilities enroll in employment services at much high rates than older groups of workers

DI beneficiaries first enrollment for employment services by age group

Ben-Shalom & Mamun, 2013

Research on Transition Age SSDI Beneficiaries

- In the first 5 years after enrollment, young adults are more likely to enter their trial work period than older groups of workers
- In the first 5 years after enrollment, young adults more likely than older workers to have cash benefits suspended or terminated due to work

DI beneficiaries suspended or terminated for work 5 years post-award by age group
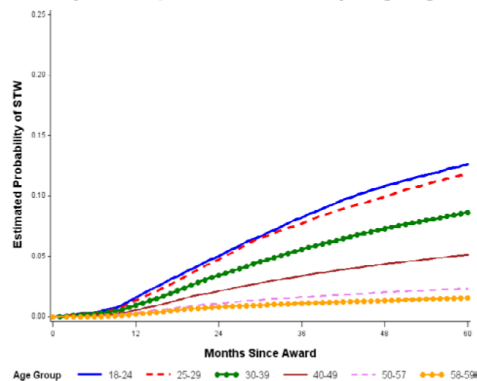
Ben-Shalom & Mamun, 2013

Multivariate Analysis of Positive Vocational Outcomes Among DI Beneficiaries

- *Younger age at award* associated with higher probability of achieving positive service engagement & work outcomes within 5 years after DI award.
  - e.g., compared to beneficiaries age 50–57, those age 18–24 are 20.4 % points more likely to have started their Trial Work Period
- In addition, the probability of achieving the milestones is increased by having a *greater number of years of education*

30 Occupations with Largest BLS-Projected Percentage Employment Increases, 2010 - 2020

- 17 require Associates degree or above
- Of those that pay above the median annual wage of $33,840, all require an AA, BA, or advanced degree
- Of those that pay below the median, the average annual salary is $25,340

Lockard & Wolf, 2012

SSA's Youth Transition Demo Model Components

- individualized work-based experiences
- youth empowerment
- family supports
- system linkages
- social & health services
- SSA work incentive waivers
- benefits counseling

Rise of "New Capitalism"

- increased competition, often leading to closures, takeovers or mergers, with consequent shedding of labor (increased lay-offs and unemployment)
- volatility of markets, requiring adaptability of workers to adjust to new skills needed to provide new products and services
- more efficient use of labor by employers to reflect fluctuating patterns of demand, involving increased use of temporary and other forms of non-standard labor

Sennett (1998)

Usefulness of transition concept?

- Early adulthood now characterized by multiple transitions, or shifting, between full time, part-time, temporary work & self employment; unemployment; education; travel; breaks for motherhood; & other domestic labor
- Transitions have become differentiated & individualized. The notion of a collective "transition" into the work force no longer applies due to plural education options & precarious labor market.

Bradley & Davadason, 2009; Goodwin & O'Connor, 2005

Typology of career trajectories, young adults age 20-34 (Bradley & Davadason, 2009)

Shifting - frequent changes between work statuses & jobs

Sticking - pursuit of single type of job or career

Switching - after some time in a particular occupation, making a conscious choice to change direction

Settling - After a period of shifting, making a conscious choice to pursue a single occupation or career

Mostly low wage jobs, hi family interdependence, attitude of "internalized flexibility" allows for optimism

U.S. Labor Force Mobility – 1st 12 years after entry into the LF (Fuller, 2008)

- By 12th year after labor-market entry, men average 6.4 employer changes while women average 5.7
- Men are laid off & discharged more often than women, while women more often experience family-related quits that are followed by unemployment
- Job changing positively impacts wages earlier in careers but not later in careers
- In the 1st 5 years of a job, each year of tenure increases wages by 2% but this stops after 5 yrs
- Lay-offs, discharges & family-related separations associated with lower wages
- Workers with high mobility see wage advances from job changes eroded by decreases in job tenure
- Marriage & family depress women's earnings, not men

Life Timeline – Late Teens & Twenties What Kind of Interventions?

Late teenage years

End of 20s

High School or Post-Secondary Education

Labor Force Entry

Average of 6 job changes

12 Years After LF Entry

Wage advantage from job changing greatest earlier in career

First 5 years of tenure at a specific job have biggest payoff

Re-entry into education or training at any time
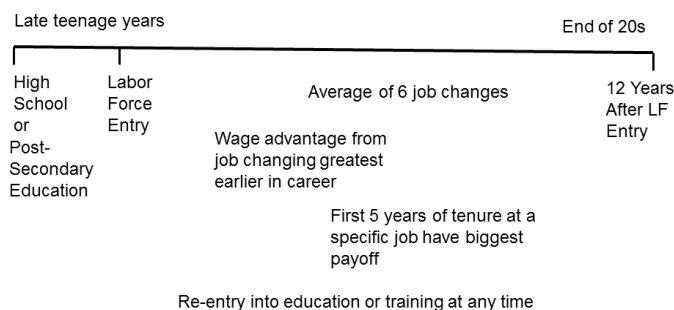
Context of Services for Young Adults with Psychiatric Disabilities

- Substance use & abuse
- Pregnancy & early parenthood
- Leaving the foster care system
- Juvenile justice involvement
- Housing instability or homelessness
- Transportation barriers

Strengths & Resiliency

- Importance of peer group
- Connection with family
- Use of social media offers networking possibilities
- IT sophistication creates job skills
- Societal recognition of young adult under- and unemployment
- Openness to service use for self-determination

Judith Cook Keynote SoS References
January 8th 2014

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FRAMEWORK

By: Maryann Davis, PhD

CAREER DEVELOPMENT IN YOUNG ADULTS WITH PSYCHIATRIC DISABILITIES: FRAMEWORK FOR THE STATE OF THE SCIENCE PAPERS

This paper is part of a compilation of papers summarizing the state of the science in career development among young adults (ages 18-30) with psychiatric disabilities, entitled *Tools for System Transformation for Young Adults with Psychiatric Disabilities.* The purpose of these papers is to provide a summary of research-based knowledge about supports to help this population pursue postsecondary education and training and successfully move into adult working careers. These papers focus on knowledge that can inform the services these young adults can access in adult mental health and vocational rehabilitation systems, or other systems that provide them educational, training, or career supports at this age. These papers also propose future research agendas to strengthen this knowledge base.

Specifically, this paper is a "framing paper" that highlights issues shared across subsequent state of the science papers in three areas: one each on education, employment, and system/policy issues. For your convenience, these papers are available for download as individual papers. However, you will likely find it most useful to refer to all the papers available on our website at **http://labs.umassmed.edu/TransitionsRTC.**

Suggested Citation:
Davis, M. (2013). Career Development in Young Adults with Psychiatric Disabilities: Framework for the State of the Science Papers. In M. Davis (Ed.), *Tools for system transformation for young adults with psychiatric disabilities: State of the science papers*. Worcester, MA: University of Massachusetts Medical School, Department of Psychiatry, Center for Mental Health Services Research, Transitions RTC.

Introduction

The goal of this paper is to provide a general framework that shapes the discussion in the subsequent state of the science papers. This framework includes an overview of definitions that will be used in the subsequent papers, a description of some of the important characteristics of young adults with psychiatric disabilities related to supports for their career development, and a brief review of considerations for evaluating the knowledge generated through research.

Some Definitions

Young adults are also referred to as "emerging adults" (Arnett, 2000) or "transition-age youth" (Davis & Vander Stoep, 1997). Emerging adults are generally considered those who are age 18 up to some developmental point before "mature" adulthood, most consistently age 25 or 30. Transition-age youth begins at ages 15 or 16 and most commonly ends at age 25. **We will use the term *young adults* to mean individuals who are ages 18-30.**

There are numerous terms used to describe people who have mental health disorders that impair their functional capacities. *Mental health disorders* are mental, behavioral, or emotional disorders in the Diagnostic and Statistical Manual (DSM) with the exception of "V" codes (temporary conditions that may be the focus of treatment), substance use disorders, and developmental disorders (i.e. autism spectrum disorders, learning disorders, mental retardation). *Mental illness* is the most common term used for adults with mental health disorders, whereas *emotional disturbance* is the term most often used for children and youth. For a review of how these terms are used to define eligibility for public services see Davis, 2003 and Davis & Koroloff, 2005. *Mental illness* is sometimes used to define a narrow range of the most impairing mental health conditions (i.e. psychotic disorders, bipolar disorder, and major depressive disorder). *Psychiatric disability* is a term used to describe when mental health disorders have produced significant functional impairment in areas such as basic daily living skills, instrumental living skills or functioning in social, family, and vocational/educational contexts. Typically, individuals in the early stages of schizophrenia do not qualify as having a psychiatric disability because the illness has not progressed sufficiently to produce various definitions of "significant functional impairment". However, given the course of the illness, and that the early stages of it typically occur during young adulthood, we include this population in our considerations of the needed supports for this age group. **We will use the term psychiatric disability to describe those with mental health disorders that have caused significant functional impairment.**

Career development is comprised of the learning and cognitive elements that influence career choices, activities, performance and attainment. By definition, career development includes formal education or training, as well as the learning that comes from experience and the

influence of factors such as parental expectations and modeling. We use the term *career* to describe occupations with opportunities for growth that are undertaken for a significant period of a person's life. **We will use the term career development to refer to career activities, performance and attainment, and the learning and cognitive elements that influence them.**

Developmental Considerations

An essential characteristic of young adults is the ongoing change in psychosocial development. This includes cognitive, moral, social, and psychosexual development, and identity formation. These developmental changes allow young adults to meet society's expectations of them. Developmental characteristics that can affect young adult service provision include distrusting authority, experimentation, social immaturity, sexual behavior, concrete cognitive operations, *enacting* the good judgment they *understand* is appropriate, and needing to fit in with peers. The younger and more seriously an individual's psychiatric disability develops, the more delayed their psychosocial development will typically be. Typically, there is more rapid psychosocial development in the youngest period of adulthood, with a plateau having occurred by age 30.

Social roles also rapidly evolve in young adulthood. Roles as student, worker, spouse/partner, parent, and the like typically undergo many changes as they are picked up, changed, or are dropped on the path to established adult role functioning. Some of the most important developmental and role change considerations for educational, training, and vocational supports for young adults are described below.

Self-determination skills are developing during young adulthood. As the safety nets of childhood are withdrawn, one of the most important skills that young adults refine is self-determination (i.e. the ability to identify one's own needs, identify goals to address the needs, and set and pursue a course to achieve those goals). The cognitive maturation to accomplish each of these steps typically comes to fruition during this stage of life, but is not mature at the outset of it. Thus, young adults will need varying levels of support for the self-determination aspects of career development. Perhaps the most important implication of developing self-determination is the need for services and interventions to be appealing to young adults because they can easily walk away from those that aren't appealing, even when the service is viewed as critically important by others.

It is age-typical to pursue educational goals in young adulthood. It is important to keep in mind that young adulthood is a time when many young adults pursue postsecondary educational or training goals, and this greatly benefits their careers. Access to careers that allow for financial independence increasingly requires education or training

beyond high school (Settersten, Furstenberg, & Rumbaut, 2005). For many, especially those whose families cannot support their singular pursuit of postsecondary education/training, working is a concurrent goal. The pursuit of education/training concurrently with working is far less common in mature adults than in young adults.

Career development immaturity. Many mature adults with psychiatric disabilities have fairly extensive work histories (Baron & Salzer, 2000). As described earlier, the strongest predictor of vocational outcomes in adults with mental illness is their work history (Bond, Drake, & Becker, 2008; MacDonald-Wilson, Rogers, & Anthony, 2001). Young adulthood is when those positive work histories can begin. Thus, an obvious difference between mature and young adults is the immaturity of young adults' career development. Young adults will likely have less crystalized vocational identities, less informed outcome expectations, still need career exploration, and accumulate career activities to hone skills and cognitive elements of career development (e.g. career self-efficacy beliefs).

Family involvement. Families are important to career development in young adults in the general population, and family resources (emotional and instrumental) are increasingly important to young adult career success in the U.S. (Settersten et al., 2005). Young adults more frequently move back in with their families after some initial independent living (e.g. after college). The ability to move back home can give young adults an advantage in pursuing high achievements (e.g. pursuing higher degrees) and avoiding risk factors (e.g. homelessness). Family involvement is diverse among young adults with psychiatric disabilities, with some families very involved and others compromised, unavailable, or unhelpful. Families may view age 18 as a time for their young adult child to move out of the family home and take care of themselves. Other families view this as a time for greater involvement as the safety nets of childhood are systematically removed.

Peer influence. Peer influence is stronger in young than in mature adulthood, and strongly influences many aspects of career development choices including pursuit of postsecondary education/training opportunities, career exploration, occupational choices, and types and amount of career activities. Peer influence can also impact decisions to seek or remain in services or treatment. Group settings that have very few same-age peers are often unappealing.

Stigma. While mental health treatment is generally viewed more positively in younger age groups, there remains significant stigma associated with mental illness. This can influence help seeking and intervention completion. Young adults are generally more susceptible to perceived stigma from peers because of the central role of peer relations for them. Conversely, peer support for pursuing career development help can be a powerful factor in successfully accessing help.

Other important youthful factors. Other important factors that disproportionately impact young adults with mental illness include pregnancy (Vander Stoep et al., 2000), substance use (Sheidow, McCart, Zajac, & Davis, 2012), and arrests (Davis, Banks, Fisher, Gershenson, & Grudzinskas, 2007; Fisher et al., 2006), each of which can contribute to stunted career development in typical young adults (Green & Ensminger, 2006). Torres-Stone and colleagues (under review) also found that young adults in vocational support programs desire readily available workplace supports that are not provided by vocational program staff, and among the Latino young adults, social skills training.

The degree to which each of these aspects of young adulthood affects the success of career development supports is a matter for research to clarify. Until it is more closely examined, we consider it likely that the degree to which supports address these features will influence their effectiveness.

Research considerations

<u>The strength of research evidence about a phenomenon is largely determined by the rigor of the research methods used to examine the phenomenon and by the amount of research conducted on the various aspects of the phenomenon</u>. Thus, simply answering the question "how many young adults have a psychiatric disability in the U.S.?" requires a rigorous method to obtain a good representative sample of young adults in the U.S. (e.g. representing different geographic regions, racial/ethnic groups, subpopulations that are difficult to recruit) and a sound method for assessing psychiatric disability. "Sound" methods need to consider the information source (e.g. self-report only, inclusion of records or others' reports), the measure used to obtain the information (e.g. the psychometric features of the "structured interview"), and the process (e.g. in-person, phone-based, or web-based "interviews"). The evidence from any single study generally requires replication to increase the strength of the evidence.

The strongest evidence comes from large randomized clinical trials in real-world settings. Typically we come to know scientifically if an intervention works through an established process that includes clearly describing the intervention in detail (through a manual), then applying that intervention to one group of individuals and comparing their 3 outcomes to those of another group of individuals that are not treated with that intervention (the other group may be treated with another intervention/s, not treated, be on a wait list for the intervention, or given a "placebo"). An *intervention* is a treatment, service, or other set of specific activities designed to change something for the individuals receiving it. The most rigorous way to compare the two groups is to randomly assign each study participant to the experimental or other group (essentially deciding which group the study participant is assigned to by a flip of a coin). The most rigorous way to ensure that the experimental

intervention has been provided as designed is to compare what the providers of the intervention actually did to what they were supposed to do. This is called assessing *fidelity*. This collective group of procedures is called clinical trials. It is through clinical trials that interventions' efficacy are directly tested.

Once an intervention has been shown through at least two randomized clinical trials conducted by different researchers to produce meaningfully better outcomes compared to a placebo or alternative treatment, or outcomes that are equivalent to interventions that are already *well established* for their efficacy, its efficacy is deemed *well established* (*Lonigan, Elbert & Johnson, 1998*). However, clinical trials are often conducted under "ideal" conditions, such as using only treatment providers who are well-trained, well-supervised, and enthusiastic regarding the treatment, and study participants that meet a narrow range of characteristics. Real life situations are rarely so simple and, for that reason, "effectiveness trials", which most closely mimic the way interventions are conducted in ordinary settings, often follow efficacy trials. Many interventions, both psychosocial and pharmacological, that work well in efficacy trials sometimes fail to produce under these less ideal conditions.

Evidence from other types of studies is strengthened by replication and the accumulation of confirming findings from other study methods. Clinical trials research evidence about how well an intervention works is not always available for a given intervention. Sometimes randomization to intervention groups is not possible. Statistical methods can help reduce the impact of factors that shape which group an individual ends up in the absence of randomization. Sometimes groups are randomized, but the intervention is not well specified, or the fidelity of its implementation is not measured. Sometimes the research base comes only from the individuals who were exposed to the intervention, and the only comparison available is their status before the intervention compared to after the intervention is completed. The findings from these types of studies are weaker evidence about an intervention's efficacy, though the accumulation of several such studies using different methodologies increases confidence in the evidence.

Evidence is strongest when the research has focused on this population. Weaker evidence comes from other age, disability, vulnerability, or general populations. One final consideration about the research evidence on career development supports for young adults with psychiatric disabilities is the relevance of the samples that contribute to this knowledge. Though research specifically on this population has increased in recent years, studies of this specific population are still rare. Clinical trials that simply included this age group (e.g. studies of "adults" ages 18-55), or are of this age group but for a broader group of young adults with disabilities, are not sufficient to establish efficacy.

In order to establish efficacy, the sample size of young adults compared to that of older or younger age groups needs to be large enough to detect an age effect. Few published studies have presented age comparisons, though some report significant differences between younger and older adults in the outcomes or relative efficacy of psychosocial interventions (e.g. Haddock et al., 2006; Rice, Longabaugh, Beattie, & Noel, 1993; Uggen, 2000). We are often left connecting the dots of available research from other age groups or other disability or vulnerability groups to develop informed estimates for this population.

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SUPPORTING THE EDUCATION GOALS OF YOUNG ADULTS WITH PSYCHIATRIC DISABILITIES

TRANSITIONS RTC STATE OF THE SCIENCE PAPER
September 2013

By: Marsha Langer Ellison, Ph.D.,
E. Sally Rogers, ScD., and
Amanda Costa, A.A.

This paper is part of a compilation of papers summarizing the state of the science in career development among young adults (ages 18-30) with psychiatric disabilities, entitled Tools for System Transformation for Young Adults with Psychiatric Disabilities. The purpose of these papers is to provide a summary of research-based knowledge about supports to help this population pursue postsecondary education and training and successfully move into adult working careers. These papers focus on knowledge that can inform the services these young adults can access in adult mental health and vocational rehabilitation systems, or other systems that provide them educational, training, or career supports at this age. These papers also propose future research agendas to strengthen this knowledge base.

Specifically, this paper is one of four papers: a framing paper that highlights issues shared across the subsequent papers, and three major papers, one each on education, employment, and system/policy issues. In order to provide multiple perspectives, a panel of various stakeholders reviewed each major paper. The reviewers' comments were then synthesized by one of the panel members into a response paper that is also included in this compilation.

For your convenience, these papers are available for download as individual papers. However, you will likely find it most useful to refer to the framework paper as well as the other two major papers available on our website at **http://labs.umassmed.edu/TransitionsRTC.**

SUPPORTING THE EDUCATION GOALS OF YOUNG ADULTS WITH PSYCHIATRIC DISABILITIES

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EXECUTIVE SUMMARY

The opportunity:

Over time, higher educational attainment leads to better employment, higher wages, and opportunities for careers, among all adults, including young adults with psychiatric disabilities.

The challenge:

Students with psychiatric disabilities struggle with educational attainment at the high school and post-secondary levels including high drop-out rates and poor retention in college. The educational trajectory of post-secondary outcomes for students in special education with psychiatric disabilities suffers compared to typical students.

While increasing numbers of students with psychiatric disabilities attend college, many barriers to successful college completion exist, such as, unsupportive campus policies, cultures, or services.

Current attempts to improve education outcomes:

Research has shown recent gains in high school completion among special education students with serious emotional disturbances and there are other promising interventions in the secondary education arena.

There are numerous recommendations made for campus based initiatives to improve the retention of college students with psychiatric disabilities. However, none have undergone systematic evaluation or rigorous testing. Some of these initiatives include: modification of campus policies regarding mental health, adjustments to "campus culture" such as communication to increase awareness of mental health needs, efforts to reduce stigma, and improved provision of supports such as educational accommodations, peer support groups, and suicide prevention efforts.

There may be significant opportunities for increasing young adults' educational outcomes through the services offered by state agencies of vocational rehabilitation.

Supported education services for young adults with psychiatric disabilities is a critical policy and research issue. Supported education has the potential to address normal young adult developmental tasks, as well as to prepare young adults for careers rather than low-wage jobs. However, there is no systematic body of evidence demonstrating its success, nor its long –term impact on employment and careers.

Testing of some adaptations of supported education to meet the specific needs of young adults is underway, but more innovation is needed to address the sub-populations of young adults with psychiatric disabilities and the variety of systems that serve them.

Future Research Needs:

1. **Additional data about the barriers to and facilitators of increased educational attainment for youth**
2. **New models of educational support services that address the needs/wants of this stage of life**
   a. Combining supported education and supported employment to address the many young adults with SMHC who need to alternate between school and work, or do both simultaneously
   b. Developing more supports for high school dropouts with serious emotional disturbance
   c. Continued testing and evaluation of transition services for secondary students with serious emotional disturbance
3. **Specification and rigorous testing of supported education services for young adults**
   a. Supported education needs adaptation and trials for different populations of young adults with SMHC (high school drop-outs, foster care, criminal justice involvement) and in systems other than mental health.
   b. Adaptation of supported education for secondary education to have a remedial focus and thus improve high school completion rates.
   c. Long-term longitudinal follow up studies of supported education services through college completion (certificate/2 year/4 year) and through to employment and career launch.
4. **Innovation and rigorous evaluation of approaches for supporting students with psychiatric disabilities on campuses. Approaches such as:**
   a. Modification of campus mental health policies to better support the retention of students with psychiatric disabilities
   b. Changes in campus culture such as communication strategies, training of "frontline" staff and faculty anti-stigma campaigns, and campus "mental wellness" programs

I. INTRODUCTION

In this brief report the authors attempt to canvass and synthesize the array of research, knowledge, and practice information that is available in the landscape of supports for students with psychiatric disabilities who have higher education goals or who are in educational settings. We do this in order to inform policy and system planners in the adult rehabilitation systems who are serving this population. Through this canvass, we also aim to generate an agenda for future research. Our topic is broad and covers many complex issues such as outcomes of postsecondary special education, policies and practices of colleges, and impact of supported education approaches. Thus, it is not possible to treat any one topic in great depth. The paper is divided into sections on: the scope of the challenge, current attempts to improve education outcomes among transition age youth and young adult students, lessons learned, and next steps for research.

This specific topic has a fairly limited peer reviewed literature, and in many instances the state of knowledge can be characterized as "pre-scientific." Thus we review understandings available in the peer reviewed literature and we describe program and policy innovations available in the "grey literature."

Though our age range is 16-30, we focus on young adults who are leaving the post-secondary system and are entering institutes of higher education. This is varied group with sub-populations such as young adults with first episode psychosis, special education graduates with serious emotional disturbance, or college students with significant mental health concerns. Given the intended brevity of review, we do not treat the sub-populations or specific cultural groups distinctively, though we acknowledge that their circumstances and needs are unique. Future research and practice innovations will need to take these sub-population variations into account.

II. SCOPE OF THE CHALLENGE

The Bureau of Labor statistics clearly demonstrates the relationship between educational attainment and employment outcomes for the general population and the fact that in aggregate, the higher the educational attainment, the lower the unemployment rate and the higher the wages a person receives (United States Department of Labor, 2010). Even before the current economic downturn, analysis of the impact of shifts in economic and other societal factors on the development of careers, demonstrated an increasing requirement for higher levels of postsecondary education or training (Settersten et al., 2005). In addition, career efforts during the young adult years in particular, have been found to be predictors of later career success (De Vos, De Clippeleer, & Dewilde, 2009). We consider valuable post-secondary educational settings to include vocational training schools, career colleges,

community colleges, on-line education, and apprenticeships. We use the term career to describe occupations undertaken for a significant period of a person's life, with opportunities for progress.

Educational attainment is likewise important for those with psychiatric disabilities. Indeed, educational attainment is a consistent predictor of later employment achievements (Burke-Miller et al., 2006; Cook et al. , 2005; Ellison, Russinova, Lyass, & Rogers, 2008; Rogers, Anthony, Lyass, & Penk, 2006; Tsang, Lam, Ng, & Leung, 2000). However, the onset of a psychiatric condition can be accompanied by a myriad of cognitive, emotional, symptomatic, social and academic difficulties. Serious mental health conditions (SMHC) translate into functional limitations that impact educational performance, such as, sustaining concentration, screening out stimuli, maintaining stamina, handling time pressure and multiple tasks, interacting with others, and test anxiety (Souma et al., 2006). When that onset occurs at a young adult age , (Corrigan, Barr, Driscoll, & Boyle, 2008; Nuechterlein et al., 2008; Waghorn, Still, Chant, & Whiteford, 2004), or during adolescence (Wagner, Newman, Cameto, et al. 2006) disruptions to educational attainment and vocational plans can result in a trajectory of unemployment, disability and poverty.

> Strong educational attainment supports better employment, and opportunities for careers that sustain employment, over time in all young adults.

Students with psychiatric disabilities (SPD) struggle at every level of education. Over 50% of students with a mental disorder (ages 14 and older) drop out of high school, which is the highest dropout rate of any disability group (U.S. Department of Education, 2009, data for 2003-4). While 40% of the general population of young adults go on to attend a four year college, college attendance is only 11% among special education students with psychiatric disabilities , (Wagner & Newman, 2012), and 7-26% among other adolescents with psychiatric disabilities (see Davis & Vander Stoep, 1997). There are also longer delays in entering college (Newman, 2011). College students with SMHC have higher rates of part-time student status (Newman, 2011), high dropout rates (86%) and low graduation rates compared to typical college students (Kessler, Foster, Saunders, & Stang, 1995; Salzer, Wick, & Rogers, 2008).

Despite these outcomes, there are growing numbers of students on college campuses with mild to significant mental health problems (Eudaly, 2003; Heiligenstein & Keeling, 1995; Meaespitsel, 1998; Sharpe et al., 2004), with prevalence estimates ranging from 9% to 18% of all college students (Lewis, Farris, & Greene, 1999; Mowbray et al., 2006;. Sharpe, Bruininks, Blacklock, Benson, & Johnson, 2004; Souma, Rickerson, & Burgstahler, 2006; U.S. Department of Education, 2004). There are also substantial increases in the number

of students seeking services for psychiatric conditions (Sharpe & Bruininks, 2003) and high proportions of students reporting mental health symptoms or disorders (The American College Health Association's 2006 National College Health Assessment). Increases in college participation among student with serious mental health conditions are attributed in part to improving mental health treatment and medications, and improved access to effective services (Collins & Mowbray, 2008; Mowbray et al., 2006; Salzer et al., 2008; Watkins, Hunt, & Eisenberg, 2012).

Among students with SMHC in higher education, challenges to their success include: unwillingness to seek help (Osberg, 2004); or not getting needed help for reasons such as perceptions that student disability services offices are unknowledgeable or incompetent (Eisenberg, Golberstein, & Gollust, 2007; Collins & Mowbray, 2008). Cutting down on the amount of time spent doing/completing college work because of emotional problems is common among students with SMHC (Megivern, Pellerito, & Mowbray, 2003). Students with SMHC are also the most likely of any disability group to not inform the school of their disability status (21% do not report vs. 3 to 15% of students in other disability categories; Newman et al., 2011). Salzer (2012) found that among current and former college students with SMHC who obtained any type of academic support, the majority reported a fear of being stigmatized by faculty, and that faculty was uncooperative or unreceptive to their requests for accommodations or support. Further, these students reported less engagement on campus and poorer social relationships than their peers; factors that were also associated with lower graduation rates.

Finally, the scope of the challenge includes, students with pre-existing mental health conditions, or those who develop mental health problems during college years who are at higher risk for suicide ideation and attempts on campus (National Mental Health Association, 2002). Of great concern are the numbers of student suicides that are occurring on campus. Estimated rates of making a suicide plan are as high as one in 12 U.S. college students, and 7.1 deaths by suicide per 100,000 college students aged 20 - 24 (Neumann University, 2013). One study found the reported suicide rate to be higher in college students than non school-attending young adults (Mowbray et al., 2006).

> Students with serious mental health conditions struggle with educational attainment at the high school and post-secondary levels. While increasing numbers of students with SMHC attend college, many barriers exist, such as stigma, ineffective disability services, and the impact of symptoms on successful college completion.

III. CURRENT ATTEMPTS TO IMPROVE EDUCATION OUTCOMES AMONG TRANSITION AGE AND YOUNG ADULTS STUDENTS

1II.A. Attempts to improve education outcomes in secondary school

Special Education. One of the largest efforts to improve secondary education outcomes for students with serious emotional disturbance (SED)[1] is the Individuals with Disabilities Education Act (IDEA; PL 94-142). This federal special education law mandates transition planning efforts and participation of youth starting at age 16. Transition planning involves, "a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability, to facilitate the child's movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education (Johnson, 2004). Recent analysis of the National Longitudinal Transition Studies (Wagner & Newman, 2012) examines the outcomes of students with emotional disturbance (ED) enrolled in special education services as they enter early adulthood. (The population of special education students with SED is considerably smaller than the whole population of students with mental disorders, many of whom are not enrolled in special education and do not receive special education services (Forness, et al., 2012).

Comparing results from 1990 to 2005 researchers found that the rate of high school completion among special education students with SED increased from 47.4% to 78.1%, and that the 2005 rate did not differ significantly from that of general education peers. Further, the percent of ED special education students who enrolled in post-secondary education (including training) jumped from 18% to 35% (though the latter rate is low compared to the 62.6% rate in the general population (Wagner & Newman, 2012).

Check and Connect. Check and Connect is a secondary education intervention designed to reduce dropout by pairing mentors to work with students and their families for two years. Mentors monitor attendance, grades, and problems ("Check"), and talk with students about school progress, relationship between school engagement and school completion, the importance of staying in school, and problem-solving steps to resolve conflict and cope with life's challenges ("Connect"). Mentors also maintain close communication with families.

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[1] IDEA defines emotional disturbance as follows: "…a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree that adversely affects a child's educational performance: (A) An inability to learn that cannot be explained by intellectual, sensory, or health factors. (B) An inability to build or maintain satisfactory interpersonal relationships with peers and teachers.(C) Inappropriate types of behavior or feelings under normal circumstances.(D) A general pervasive mood of unhappiness or depression.(E)A tendency to develop physical symptoms or fears associated with personal or school problems. Retrieved from http://nichcy.org/disability/specific/emotionaldisturbance#def

When implemented with secondary students with emotional or behavioral disabilities in a randomized controlled trial, students involved in Check and Connect were less likely than their counterparts to have dropped out of school, and attended school with fewer prolonged absences (Sinclair, Christenson & Thurlow, 2005). In addition, a small randomized trial also produced encouraging results (What Works Clearinghouse, 2007). This model is currently being tested with special education students with SMHC in a large clinical trial.

1II.B. Attempts to improve outcomes at or by institutes of higher education (IHE)

Over the past twenty years several strategies have been used by, or recommended to institutes of higher education (colleges and universities) for promoting the successful academic outcomes and retention among students with SMHC. These recommendations reflect colleges as whole communities within a larger community, such as a city or county, and therefore incorporate recommendations for policies, leadership, infrastructure, mental health literacy and support within the college community, as well as coordination with the surrounding community. The following section describes developments in these areas. However, it is important to note that these developments to date, have undergone no rigorous testing and very limited evaluation. Thus, the stage of research is best characterized as pre-scientific speaking to the need for specification of the intervention and intended population, and rigorous testing of outcomes.

**Policies.** Some college policies make it difficult for students with SMHC to complete their degree, such as forced absences for self-injuries or suicide attempts, or retracting student financial aid because of mental health issues (Clay, 2011). Other policies can also be deleterious for students with SMHC; highly restrictive or punitive policies for withdrawals, discriminatory application of medical leave policies, and arbitrary return policies after illness (Bazelon Center for Mental Health Law, 2008). Various authors have suggested alternatives that provide a blue print for policy revisions (Bazelon Center for Mental Health Law, 2008; Gruttadaro & Crudo 2012; Smith, Ackerman, & Costa, 2011) including:

1. Leave-of-absence protocols
2. Policies for self-harm other than zero tolerance
3. Individualized re-entry requirements
4. Protocols that encourages campus wide, multi departmental communication about a student in distress.
5. An emergency contact notification protocol where students are encouraged to sign release of information allowing notifications under specified circumstances
6. Memoranda of understanding with a local hospital for students in psychiatric crises.

**Campus culture**. Analyses of student experiences and college practices have produced

recommended steps to improve general mental health well-being on campus (Gruttadaro & Crudo, 2012; Mowbray et al., 2006) and include:

- *Improving communication about mental health and campus supports*
  - Mental health education on college websites
  - More information on campus behavior, rules and policies
  - Ready access to information on counseling services such as, their location and hours
  - College websites displaying on-line screening tools with links informing students about the availability of accommodations
- *Educating the college community*
  - For college staff, faculty, staff of disability student services, and campus police
    - recognition of early warning signs
    - approaching students in need
    - recognizing conditions
    - crisis training
  - For students
    - the importance of getting help
    - resources for dealing with stress
    - events to encourage help-seeking before the onset of psychiatric crises
- *Campaigning to de-stigmatize mental illness*
  - Provide model success stories
  - Provide information on the commonness of mental health needs and success with treating it
  - Strategies to get students to reveal "secrets" about their mental health difficulties (Friday, 2011)
  - Make vivid and apparent the toll of campus –based suicides (Active Minds, 2013)

Good Supports and Interventions

Educational accommodations. Accommodations are, "any change in the work environment [orinstructional setting] or in the way things are customarily done that enables an individual with a disability to enjoy equal opportunities" (Costa, 2011). Similar to employment, reasonable accommodations are available for students with a qualifying disability by the Americans with Disabilities Act and later amendments (Souma et al., 2006). The types of educational accommodations used by students with SMHC include: extended time to complete assignments and tests, private feedback, and use of tape recorders in class (Salzer et al., 2008). Surveys have shown increasing awareness and use of educational accommodations over time among students with SMHC and use of accommodation are associated with better student outcomes (Salzer et al., 2008; Gruttadaro & Crudo, 2012). Barriers to accommodations use include:

- Lack of awareness of accommodations or their rights to receive them (Collins &

Mowbray, 2008; Dobmeier et al., 2011; Salzer et al., 2008)
- Fear of the consequences of disclosing their condition (mtvU, 2006; Salzer et al., 2008)
- Student disability offices that are ill-prepared to handle requests from students with SMHC (Collins & Mowbray, 2005; Collins & Mowbray, 2008)
- The "hidden" and episodic nature of psychiatric disabilities contributing to the need for creative and thoughtful assessment.

Research on student disability office practices suggests that the following practices are associated with higher enrollment of students with SMHC: staff in the office with a specific qualification in psychiatric disability, referrals to the office coming from student services, a specific and larger office, and access and knowledge of supported education services (Collins & Mowbray, 2008).

College-based mental health counseling. Counseling for students with a mental health condition is available to students on nearly all campuses. Such services are a frequently used resource for students with psychiatric conditions (The Jed Foundation, 2012). Campus counseling centers typically provide students free short term therapy or counseling, access to on-campus psychiatric evaluation and medication, and referrals to longer-term community mental health resources, and consultation to teachers and administrators.

The number and severity of problems among students seeking help from campus counseling centers are rising (Mowbray et al., 2006, Gallagher, 2012). Challenges that campus counseling centers face in addressing these emerging needs include: deficiencies in accessibility, issues related to confidentiality, emergency response capability, staff training in young adult development, and resistance from administrators to these centers embracing a truly therapeutic treatment role (Mowbray et al., 2006).

Several improvements for college counseling services have either been made (noted with a * from Gallagher, 2012) or recommended including:

- Making services easier to obtain (Watkins et al., 2012)
- Greater accessibility (such as weekend and evening hours) (Watkins et al., 2012)
- Using qualified mental health staff (not graduate students) (Watkins et al., 2012)
- Providing an on-call psychiatrist (Watkins et al., 2012)
- Better crisis management and prevention procedures/earlier identification*
  - Aggressive outreach (Watkins et al., 2012)
  - Anonymous online screening tools to enable campus mental health clinicians to reach out to students exhibiting warning signs (Watkins et al., 2012)

- – Communication campaigns as described above under campus culture (Watkins et al., 2012)
    - – Peer counseling or peer education programs to take advantage of students' willingness to talk to peers (Watkins et al., 2012)
    - – Providing 24/7 crisis teams or hotlines (Gruttadaro & Crudo, 2012)
    - – Training, as described under Campus culture, especially around suicide issues (Watkins et al., 2012)
- Providing a complete diagnostic, psychosocial and functional assessment (Watkins et al., 2012)
- Providing seamless referrals to student health and disability services (Mowbray et al., 2006)
- More long–term services and expanded external referral networks*
- Improved coordination and follow-up with referrals to community based treatment (Watkins et al., 2012)
- Behavioral intervention team that meet to discuss students at risk or of concern (Gruttadaro & Crudo, 2012)
- Skills training for students to help them learn to tolerate and manage mild to moderate emotional discomfort without medication*
- Adjustments for changing student demographics*

Suicide prevention. There is little empirical examination of systematic college suicide prevention efforts (Joffe, 2008). One suicide prevention campaign has been evaluated. This campaign included a suicide prevention team, and mandated the use of a suicide incident report form, an assessment after incident, and four weekly counseling sessions following the incident. The team gave students with suicidal ideation consequences for not adhering to uniform university standards of "self-welfare" and "self-care". Team members also clarified for students referred for assessment that they may lose student status if they do not attend counseling sessions and if they had another suicide attempt. The evaluation examined the suicide rates over the 20 years during which the campaign was implemented and found a 45% reduction in the number of deaths by suicide among all students (Joffe, 2008). There were no comparable concurrent reductions in the county or for all other colleges.

An unevaluated, but notable college suicide prevention model comes from the JED foundation via their "Guide to Mental Health Action Planning". This guide describes a step by step program for mental health promotion and suicide prevention that targets social and environmental risk factors associated with student mental health. The guide includes steps that involve different levels of system change (e.g., campus policy, counseling center practices) (Jed Foundation, 2008; Joffe, 2008).

There are current federal efforts to identify and test strategies to reduce campus suicide rates, such as the Garrett Lee Smith (GLS) Memorial Act that has provided 74 college campus grants for suicide prevention efforts (Goldston et al., 2010), and the Campus Suicide Prevention program funded by the Substance Abuse and Mental Health Services Administration (Clay, 2011; Joffe, 2008). These programs support colleges and universities in their efforts to prevent suicide among students and to enhance services for students with depression, substance abuse, and other behavioral health problems that put them at risk of suicide. One such program is the "Student Support Network". This is a training program for student peer leaders (e.g., sports team captains, fraternity/sorority leaders) on recognizing mental health issues in students and providing that important first line of response (Morse & Schulze, undated).

**Peer advocacy and peer support.** An untested but promising strategy for supporting students with SMHC at college is college student peer groups on mental health issues. One such group is "Active Minds" a national organization of students that sponsors college based chapters. Through campus-wide events and national programs, Active Mind aims "to remove the stigma that surrounds mental health issues, and create a comfortable environment for an open conversation about mental health issues on campuses nationwide" (Active Minds, 2012). Another student peer group is "NAMI on Campus," which tackles mental health issues on campus. By joining a NAMI on campus club, students are part of a broader mental health grassroots movement, and are provided with direct support and exclusive access to national resources (NAMI, 2013).

In addition to providing peer groups on mental health issues, including the perspective of young adults in the decision-making process for design of new programs and policies can be an effective use of advocacy on campus. While not yet tested on a college campus, incorporating youth voice has been shown to improve student outcomes and the success of school reform in secondary education settings (Mitra, 2004). When the conditions are in place, involving youth in decision-making is a powerful strategy for positive change (Zeldin, McDaniel, Topitzes & Calvert, 2000).

> Institutes of higher education may improve educational completion among students with SMHC through changes in policies, infrastructure, training, communication, coordination with surrounding services when needed, and improvements in disability office and counseling center services. The impact of specific approaches has yet to be measured in systematic ways.

III. C. Attempts to improve education outcomes by state agencies of vocational rehabilitation

State agencies of vocational rehabilitation (VR) are designed to promote employment of people with disabilities. When creating an Individualized Plan for Employment (IPE) VR will consider providing any service that is needed to achieve an agreed upon vocational goal, such as payment for education or training, including college tuition and related supplies (Whitney, Smith, & Duperoy, 2012). VR agencies are seen as one important resource for the transitioning of youth from special education to employment as adults. There are standards specific to youth as a special population in VR agency annual reports. Moreover, youth (ages 16 -24) represent nearly one third of the population that VR agencies serve (Honeycutt, Thompkins, Bardos & Stern, 2013), and on average 25% of the youth population served by VR has a primary disability that is psychiatric. For some states, youth with psychiatric disabilities comprises the largest proportion of the youth population served (Honeycutt, Thompkins, Bardos & Stern, 2013). Thus, there is a significant opportunity to increase young adults' educational outcomes through the VR system. Analysis of VR outcomes for 2011 shows a modest application of educational programming for young adult VR participants with psychiatric disabilities[2]. Approximately 10%, or nearly 3500, young adults with a primary psychiatric disabling condition served in VR (ages $14 - 26$ upon entrance to services), were provided educational assistance for college. Among these young adult clients, 47.6% were successfully closed by VR services, meaning that they had achieved their IPE goal and had been employed for 90 consecutive days (the standard for VR closure of services). A comparison with 2006 data showed similar findings. Although, we do not know if the educational services provided were directly related to the later employment goal.

> There may be significant opportunities for increasing young adults' educational outcomes through the VR system.

III.D. Attempts to improve education outcomes in supported education rehabilitation programs.

Supported education (SEd) can be broadly described as services provided largely to individuals with psychiatric disabilities, that enable a person to define an educational goal, pursue activities needed to achieve the goal, and then maintain those steps and activities until the goal is achieved (Soydan, 2004).

Service components of SEd can include educational counseling, assistance with financial aid, development of educational accommodations, preparatory coursework, assistance with organization of school tasks and activities, as well as others (Mowbray, Collins, & Bybee,

[2] Frank Smith. Personal Communication. Analysis of Vocational Rehabilitation State Agency Data, Institute forCommunity Inclusion, Boston, MA

1999; Waghorn et al., 2004). According to Waghorn et al. (2004), there are ten components of supported education: 1) coordination of supported education with mental health services; 2) use of specialized supported education staff (not just generic case managers); 3) availability of career counseling, vocational counseling and planning; 4) assistance with financial aid; 5) assistance to develop skills needed to cope with a new academic environment; 6) provision of on-campus information about rights and resources; 7) on or off campus mentorship and personal support during the educational training period; 8) facilitation of access to courses and within-course assistance; 9) access to tutoring, library assistance and other academic support; 10) access to general support (e.g., referral for mental health services).

Collins and Mowbray (2005) describe 4 models of supported education, some of which have been subject to research and evaluation:

- The classroom model in which students with psychiatric disabilities attend closed classes on campus designed for the purpose of providing supported education services;
- The onsite model which is sponsored by a college or university and provides supported education in an individual rather than group setting;
- A mobile support model that provides services through a mental health agency;
- And a more recent classification or model they call the "free-standing model," which is located at the organizational setting sponsoring the supported education program, such as a clubhouse or on site at a college.

For the most part, supported education models have been developed and tested in the adult mental health system, but may be applicable with adaptation for young adults. For example, the values and principles of supported education such as the need to develop educational goals, to exercise choice and self-determination, to develop skills and supports to achieve educational goals, may be applicable across the lifespan. However, the activities, the supported education providers, the likely educational settings, the means of supporting and communicating with young adults, all may differ. Existing supported education programs and services can be adapted so that they are instrumental in assisting young adults to re-engage with critical developmental tasks, to explore their vocational identity, to pursue educational roles and subsequent career development. Thus focusing on supported education among young adults appears to be a critical policy and research issue

Effectiveness of Existing Supported Education Models
In a recent systematic review of SEd programs and services, researchers found a dearth

of rigorous studies on SEd and very little data to support its effectiveness. There are numerous descriptions in the literature of innovative models of SEd service delivery (Isenwater, Lanham, & Thornhill, 2002; Lieberman, Goldberg, & Jed, 1993; Mowbray et al., 1999; Unger, 1993) but no randomized or quasi-experimental study which suggested that participation in an SEd intervention resulted in significantly greater educational attainment or vocational success (Rogers et al., 2006; Rogers, Kash-Macdonald, & Maru, 2010). In addition, many older studies focused on models that are no longer considered feasible or integrated (e.g., the "classroom" model) (Mowbray et al., 1999). In the one large randomized trial of SEd, Mowbray and colleagues found no significant difference in the employment rates at follow-up of individuals participating in a SEd intervention versus those not participating (Mowbray et al., 1999). Other uncontrolled evaluations of SEd have suggested improvements in employment and educational status as a result of participation in a supported education intervention but these data are methodologically weak and the majority of studies are not current (Best, Still, & Cameron, 2008; Cook & Solomon, 1993; Hoffmann & Mastrianni, 1993; Unger et al., 1991; Unger, Pardee, & Shafer, 2000; Unger & Pardee, 2002). Missing in the literature are longitudinal tests of supported education on the longer term impacts, especially for career outcomes.

Studies and data speak to the need to develop and test new models of supported education. More recently, measures of the fidelity of supported education interventions have been developed (Manthey, et al., 2012; Unger, 2013) which may be useful in guiding program development and assessing outcomes. However, no published research studies could be found that incorporate these fidelity measures to date.

Anecdotally, SEd is viewed as a viable intervention for many individuals to meet their goals for educational advancement, personal development, and better jobs (Mowbray, Bybee, & Shriner, 1996), but the data are insufficient to strongly support these assertions. Studies and data speak to the need to develop and test new models of supported education. In addition, the majority of studies on supported education have been carried out with adults in the mental health system and there is no evidence or information testing the effectiveness of these interventions with young adults.

Need for new models and research that focuses on the young adult
There are several studies underway that promise to provide more methodologically sound data. This includes a program housed at UCLA that integrate supported employment (see related paper on career development supports) and SEd for persons with recent onset schizophrenia (Nuechterlein et al., 2008). A simple version of integrated SEd and supported employment for early psychosis has produced positive vocational outcomes in a small randomized trial in Australia (Baksheev et al., 2012). The NIMH-funded RAISE

project (Recovery After Initial Schizophrenia Episode) has a SEd component within a quasi-experimental study, but no data are currently available on the effectiveness of those services[3] Most individuals in early stages of schizophrenia are young adults. A recently funded randomized study of SEd (Salzer, 2013) with a special emphasis for young adults is also underway (Transitions Research and Training Center, 2012), but effectiveness data are not yet available. The Center for Psychiatric Rehabilitation is conducting an exploratory study of a combined supported education and employment model service delivery for young adults, but that study is underway and does not yet have information about its effectiveness.[4] Also, supported education trials to date have not focused on specific sub-populations of young adults with psychiatric disabilities, such as those emerging from foster care or from juvenile justice systems.

> Supported education has the potential to address normal young adult developmental tasks, prepare young adults for careers rather than minimum wage jobs, and perhaps disrupt the path of disability and poverty. Adaptations of SEd for young adults is needed as is rigorous testing of specific SEd models, with longitudinal examination of career outcomes.

IV. LESSONS LEARNED

We summarize the numerous "lessons learned" and next steps in promoting the educationalattainment and eventual employment success of young adults with psychiatric disabilities.

- Policy innovation in special education appears to have had a beneficial impact on high school students with SMHC, through the precise "active ingredient" of this innovation is unknown.
- Nonetheless high school and post-secondary outcomes of students with SMHC still lag behind those of the general population as well as behind other disability groups.
- Students with SMHC are increasingly on college campuses, but college campuses seem unprepared to assist with the challenges these students face.
- The literature includes descriptions of a variety of strategies to support students with SMHC on campuses, but almost none are tested.
- Supported education needs considerable innovation and testing to assure that is a feasible,appealing service for young adults with SMHC, as most studies were completed with mature adults and with adults in the mental health system.

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[3] E.S. Rogers, Personal communication with Kim Mueser on status of the RAISE project, August
[4] E.S. Rogers, Personal communication with Dori Hutchinson, on the Supportive Employment and Supported Education project, August 2013.

- Further innovation is needed for those young adults who are transitioning from foster care and juvenile justice systems.

- There are virtually no supported education studies that capture long-term outcomes including degree completion or especially career outcomes.

V. NEXT STEPS FOR RESEARCH

The information gleaned from labor statistics, developmental psychology, surveys of campus mental health issues, and information about both education and employment for young adults with mental health conditions, point to the strong need for:

1. Additional data about the barriers to and facilitators of increased educational attainment for youth.
2. New models of services that address the needs/wants at this stage of life, for example:
   a. Combining supported education and supported employment to address the many young adults with SMHC who need to alternate between school and work, or do both simultaneously.
   b. Developing more supports for high school dropouts with serious emotional disturbance.

   c. Continued testing and evaluation of transition services for secondary students with serious emotional disturbance.
3. Specification and rigorous testing of supported education services for young adults, for example:
   a. Supported education needs adaptation and trials for different populations of young adults with SMHC (high school drop-outs, foster care, criminal justice involvement) and in systems other than mental health.
   b. Adaptation of supported education for secondary education to have a remedial focus and thus improve high school completion rates.
   c. Long-term longitudinal follow up studies of supported education services through college completion (certificate/2 year/4 year) and through to employment and career launch.
4. Innovation and rigorous evaluation of approaches for supporting students with psychiatric disabilities on campuses. Approaches such as:
   a. Modification of campus mental health policies to better support the retention of students with psychiatric disabilities.
   b. Changes in campus culture such as communication strategies, training of

"front line" staff and faculty, anti-stigma campaigns, and campus "mental wellness" programs.

c.   Campus based supports for students with SMHC e.g., educational peer support, campus mental health counseling centers, provision of educational accommodations, and student disability support services.

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SUMMARY OF RESPONSES TO PAPER:
"SUPPORTING THE EDUCATION GOALS OF YOUNG ADULTS WITH PSYCHIATRIC DISABILITIES"

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Michelle Mullen

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8/5/13

The following reflects the reactions of the seven reviewers. Most comments were made by a single reviewer. Attempts were made to indicate when comments were made by more than one reviewer. I did not identify any conflicts in the comments made by the reviewers. Most reviewers commented on the incredible complexity of the issues that are being discussed and the lack of depth in many places.

Strengths and key points of agreement

- Excellent synopsis of the importance of higher education to employment.
- Good discussion of the current state of educational attainment for this population.
- Described great resources and programs that will be helpful for young adults.
- Good start at a review of lessons learned and future research directions.

Identify any omissions and why important

- One reviewer commented on the significant heterogeneity of the target population and the need to adequately address this heterogeneity.
- Concerns were expressed about the brevity of the review of the current literature and brief section on lessons learned and next steps for research.
- There was concern about mentioning programs where there is no peer-reviewed research (e.g., Active Minds, etc.). Could mention, but express caution about the lack of demonstrated effectiveness. The description of efforts by post-secondary educational institutions includes lists of possible policies and recommended lists to improve general mental health and barriers to accommodation. If this is a summary of the "state of the science" in this area, we can say that the work is in the pre-scientific phase. No data are presented, no analytic framework, and no conclusions about what appears to work.
- Provide more of a discussion in the introduction about the importance of higher education for career development rather than just focusing on employment.
- At least two reviewers commented that the mention of suicide on page 2 seems disconnected from the rest of the Introduction. This is an important topic that needs to be effectively connected.
- Good SEd should actually be similar for young adults and mature adults. Not sure that adaptation for young adults is necessary. A stronger case needs to be made, with evidence, if you are advocating for adaptation of current SEd models for young adults.
- The section on the role of the state VR system in helping young adults achieve educational goals provides the statistic that about 10% of all young adults with a primary psychiatric disabling condition receive help with educational goals and that almost half of these "achieve" their educational goal. While these data are informative, they do not provide much guidance regarding policy recommendations, nor do the authors offer any

insight whether VR's role is relatively minor or major or whether VR should do more, do less, or continue as is.

- There is a good review of the SEd outcome research, but more attention is needed on the program models studied, the fidelity scales used (or not used) to assess adherence, the designs and outcome measures used, or the actual findings.
- One reviewer made some suggestions on additional areas to cover and references to add
  – More rigorous review of recent early psychosis literature, which includes an accumulating number of rudimentary program evaluations and rigorous studies (Rinaldi et al., 2010).b Miles Rinaldi in England, Geoff Waghorn in Australia, Tamara Sale in Oregon all have pertinent data. Killackey now has two recent studies (Killackey et al., 2012; Killackey, Jackson, & McGorry, 2008). My reading of that literature is that, outside Nuechterlein's study, early psychosis programs have a disappointing track record in the education area. But a careful systematic review is needed.
  – There have been a couple surveys attempting to document the prevalence of support education in the mental health field; these data seem pertinent (Manthey et al., 2012; Mowbray, Megivern, & Holter, 2003).
  – Linda Carlson and colleagues have made trenchant comments regarding the difficulty measuring outcomes in this area (Carlson, Eichler, Huff, & Rapp, 2003). Also should include a solid review by Chandler (2008).
- First section switches back and forth between data for students served in special education, general college student population with mental health needs, and those with new diagnoses versus those with long histories of psychiatric disabilities. Related to this, it needs to be clear that the paper is focusing on addressing the educational needs of students with mental health issues rather than the mental health needs of students. The mention of suicide and counseling programs on college campuses, for example, seems to confuse the reader on the focus of the paper. If it is the latter, than need to mention the numerous school-based mental health programs in secondary educational settings.
- Expand discussion about the mechanisms used to help the 48% served by VR to obtain their education and or employment goals. Additionally, do VR counselors have specific training on how to best meet the educational/vocational needs of transitioning youth adults with serious mental health conditions? In general, more discussion about how VR can uniformly support educational goals could be useful.
- Include the mention of more peer and self-advocacy programs.
- Need to provide a more detailed discussion about the rationale for targeting young adults separately from more mature adults. What are the developmental factors and illness career factors that make this specific focus important?

Present the points of views of special considerations
(some of the topical representatives)

- Document was easy to read and was written very clearly, which is very important to multiple stakeholders who are not necessarily researchers
- Perspectives of young adults need to be considered in the design of new programs, especially program goals.
- More attention is needed on the potential impact of racial, gender, and other sociodemographic factors on educational attainment for this group, especially identifying potential disparities.
- More attention is needed to students from marginalized cultural groups as students who are over-identified or under-identified for Special Ed services.
- Interventions must attend to cultural differences.

Final summary, what we still need to know/research

- More than one reviewer believes that if supported education is ever to move beyond description, and conduct higher quality outcomes studies, than researchers will need to rigorously define program models. Unger's fidelity scale is widely used, but there are others (e.g., Manthey et al., 2012). More work is needed to define and measure the critical ingredients. Evaluations of the effectiveness of programs need to consider the perspectives of young adults.
- What is the policy innovation in special education that has had a beneficial impact? Are you suggesting that having a transition plan in place by age 16 is the key? What do we know about these transition plans? Who do they work for and what should be included in them?
- Need research on the lack of academic preparedness of classified students in high school and the need for higher academic standards and early vocational preparation for this group
- Need more research and discussion about lack of knowledge/skill of the students with SMHC advocate on campus, i.e, Office of disability services, and the potential long-term impact of lack of advocacy, expertise and protections for this group on campus.
- More research is needed to examine differences in educational attainment, access to services, outcomes, etc. by gender, race/ethnicity, socioeconomic status to identify disparities.

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ADDENDUM TO THE EDUCATION DOMAIN.

This addendum provides a summary of the salient points discussed during the state of the science conference presentation on the education domain. We review the discussion by the audience and break-out groups, break-out group balloting results, and present final conclusions for future research directions.

State of the Science conference audience and breakout discussions. Several overall themes emerged from the audience discussion. There was widespread affirmation and recognition of the importance of higher education and training for career development for young adults with SMHC. At the same time there were passionate recountings of the many profound obstacles to academic /training completion, derailing many dreams of achieving ones potential in schooling and employment. The audience seconded issues of how concerns about stigma will prevent student help-seeking, academic policies that were inflexible and punitive, campus mental health counseling that was unable to respond to significant mental health needs, and student disability offices that lacked knowledge of how to accommodate mental health conditions. The audience also noted the profound lack of rigorous research in this area and the need to specify education models and outcomes to promote better testing and to establish evidence for practices.

Discussions in the break out session touched on many of the numerous and complex issues raised in the presentations and papers. Among them was the importance of including vocational/technical secondary and post secondary training in any education research going forward. The audience was interested in a better understanding of what state vocational rehabilitation agencies can do to support those with education goals. Workgroup members also stressed that viewing educational supports through a cultural lens was imperative to understanding disparities and "what works for whom". Workgroup members were interested in promoting self-advocacy skills, and in attention to building networks of support among students with SMHC, and to improve outreach and engagement of these youth with available supports. Needs for better knowledge about transition planning for secondary schools to higher education was noted as was preparing students for the absence of supports in post-secondary schools relative to special education supports in high school.

Balloting results. During the breakout session in which there was balloting , among 14 research needs listed on the ballot, the one with the highest number of endorsements was the need for longitudinal follow-up studies of supported education through post secondary education and training and through to employment (N=14). Such studies could empirically test the assertion that supported education will eventually lead to greater employment and career achievements. Very close behind this research need (N=13), was endorsement of

the need for rigorous evaluation of innovations to campus culture (such as better training of staff, anti-stigma campaigns, or improved communication of mental health needs.)   Four other research needs were rated highly rounding out the upper half of research needs endorsed: a) examining differences in educational attainment by culture and demographics to better identify disparities in educational attainment (N=11); b) testing models of supports that combine supported education and supported employment (N=10); c) developing more supports for high school dropouts with SMHC (N=9); and, d) assessing the impact of improved self-advocacy and peer supports on student outcomes (N=9) .

Conclusions for future research directions. Taken together, the overall conclusions were that there is a need for more research in the education domain at all points in the education trajectory (secondary, transition from secondary to post secondary, and within post secondary colleges and training programs, through to later employment and career development). There is a need for research that examines the effects and outcomes on the individual level (such as disparities according to individual characteristics or individualized rehabilitation strategies such as supported education) as well as how external and environmental supports (such as stigma reduction and improved campus policies) can improve student achievements. Problems for the conduct of this research reside in need for greater specification of intervention models and of educational outcomes. A problem that bedevils education research is that the outcomes tend to be long in the making (such as college completion) whereas research funding tends to be more time limited. Nonetheless, there is a call to find a way to conduct longitudinal research for this domain.

EDUCATION TOTALS TALLY

	Orange Mark Salzer	Green Nancy Koroloff	Blue Chuck Lidz	Red Krista Kutash	Yellow Kathryn Sabella	Total
1. Additional information about the barriers to and facilitators of increased educational attainment for youth and young adults such as:						
1a. Examine differences in educational attainment, access to services, outcomes, etc. by gender, race/ethnicity, and socioeconomic status to identify disparities	4	2	1	3	1	**11**
1b. Discern the "active ingredients" responsible for recent gains in special education outcomes among students with serious emotional disturbance		1	1	1	2	**5**
1c. Examine transition plans for special education. Are they effective, who do they work for, and what should be included in them?				1	2	**3**
2. New models of educational support services that address the needs of this stage of life:						
2a. Assess the impact of higher academic standards and early vocational preparation			1			**1**
2b. Develop more supports for high school dropouts with psychiatric disabilities.		1	3	4	1	**9**
2c. Combine supported education and supported employment to address the many needs of young adults with psychiatric disabilities (such as needing to alternate between school and work, or do both simultaneously).	1		3	4	2	**10**
3. Specification and rigorous testing of supported education services for young adults:						
3a. Clearly describe supported education program models and its components in order to be able to conduct replicable and rigorous tests	1	1				**2**
3b. Adapt supported education models and test them among difference populations of young adults with psychiatric disabilities (high school drop-outs, foster care, criminal justice involvement) and in systems other than mental health.	1	1	1	1	2	**6**
3c. Adapt supported education for secondary education to have a remedial focus and thus improve high school completion rates				2		**2**
3d. Conduct long-term longitudinal follow up studies of supported education services through college completion (certificate/2year/4yea) and through to employment and career launch	6	1	4	3		**14**
3e. Consider the perspectives of young adults in all evaluations and research of supported education services		3	1	1		**5**
4. Rigorous evaluation of innovative approaches that support students with psychiatric disabilities on campuses:						
4a. Modify and test campus mental health policies so as to better support the retention for students with psychiatric disabilities	1	2			1	**4**
4b. Implement changes that effect campus culture such as communication strategies, training of staff, anti-stigma campaigns, and campus "mental wellness" programs.	3	6	3		1	**13**
4c. Improve and assess the impact of greater student self-advocacy and peer supports on…		2	2	3	2	**9**

Write in's/Question Edits/Flipchart Notes By Group:

Orange	**Write In's:**
	• None
	
	Question Edits:
	• 1a. Add "culture" (noted 2x)
	   3a. For other educational efforts other than college
	• 3d. Add "any post education" (noted 2x)
	• 3d. Add "Vocational/Technical (noted 2x)
	• 4. Add all post secondary education
	• 4b. Add "culture"
	
	Flipchart and Notes:
	• Rehabilitation rights
	    o How do we change the college campus especially for students with PD?
	    o Networks to change campus disability services common
	    o What are the barriers and facilitators?
	• What are the service supports needed of students with PD?
	• What are the learning designs and supports (e.g. WDL) that can increase access to all students
	• What supports are being eliminated resulting from FERPA
	• What are the implications of when parents attend service meetings
	• Topics are not helpful when applying the cultural lens (e.g. tribal community)
	• What are the considerations of culture and race
	    o Considerations of when one leaves their community and are in environment where they are considered "other)
	• Large discussion of dead end jobs and career development
	• How do we change campus culture? This includes disability workers
	• What are universal design supports and learning methods that can be utilized by students with SMHC
	• Looking at new models focused on choices and self-determination

Green	**Write In's:** • Understanding skill set young adults with PD will need to self manage, advocate and participate in institution
	Question Edits: • 1b. Is this specific to Wagner? • 1d. Functional classifications needed because diagnosis information is needed • 3e. Should engage young adults in all levels • 4b. Examine models of family support • 4b. Assess capabilities to self advocate via Myers Briggs • 4b. Who is taking psychiatric disability well on campus? • 4e. How can you preserve confidentiality and still incorporate perspectives of family in supporting students? • 4b should add faculty and staff. **Flipchart and Notes:** • Who is doing PD well across all educational environments • When we refer to educational attainment should refer to all post secondary educational settings and not just college. • Can we get access to functional information from large datasets that are often used to address questions about education and functioning? • Transition plans should include health related goals and concerns • We need to consider alternative modes of education—what are the alternative models in HS and beyond and how do we support people in those alternatives? Examples are online forms of high school and post secondary ed. Long list of testing SEd • Need a participatory approach to conducting research-need to involve young adults in research and design of services. • Need to better identify kids in public schools who are at risk for failing particularly for reasons due to their psychiatric disability. • How do we change the culture of campuses? • What about characteristics of students themselves that allow them to advocate for themselves to get needed support? • We need to extend the support in #4 to be across educational environments not just campuses.
Blue	**Write In:** • More Research on the impact of family support and connectedness • Assess(?) role of engaging students (17-22) in social _____ development (writing issues) • Assess(?) impact of work-based learning, career exploration, career planning (writing issues) **Flipchart Comments:** • Trauma informed issues: what is the role of trauma in education? • Supported education at a high school level

	• High school dropout rates are high: why is it so high and how do we work on prevention? • Research on youth and t-he impact of family support • Youth involvement- helping to identify what works and what is helpful • What is the key to engagement and how do we use engagement and technology to reach youth?/how do we create social connectedness in youth? • Research needed on on-campus groups (i.e. Active Minds/NAMI on campus) • What modalities of learning work best with this group (pd)? • What happens with lots of high school supports dropping to no supports after high school? • Follow up with dropouts- what are they doing with their time • How to improve resilience in YA's • How do you create community connection and engagement • Is there a higher rate of success in young adults if there is social community connectedness?
Red	**Write In's:** • Combine supported education and supported employment **Question Edits:** • 1a. Add "expectations" • 1b. What we learn could help us reach those we don't know about potentially • 3b. Change among to "within" different population groups • 4c. Add design
Yellow	**Write In's:** • Stakeholder driven research CBPR • Look at the general population for key elements then divide into <u>A</u> based specifically on that • Base 2 on the supported employment en-base • Career technical education • Transitions between environments: I.e. high school to college • What does the research tell us about factors that generate problems and success • Elements from supported employment that can be generalized/combo since supported employment has better en-base **Question Edits:** • 2. Base on supported employment en-base • 3. Don't do because there's not a model unified of supported education

	Flipchart and Notes: • Stakeholder- driven needs assessment, what are the processes we need to target? • ID elements for supported employment that can be generalized to supported education or combined due to large evidence base of supp emp. • Does the research tell us what factors generate/sustain education/work problems and education/work successes? Especially general population research • Develop intervention that targets those factors (in bullet above) using ways that the individual can target the factors (individual meaning the EA and family/adult allies) • Non college assistance seem to be missing. Technical education? Is this under supported employment umbrella? • Self-determination issues: effective transition planning needs to include specific skill development • Secondary Education level mental health needs of youth not identified in special education • Looking at community colleges and veterans • Difference in disorders and outcomes, programs that work for each

EMPLOYMENT AND CAREERS IN YOUNG ADULTS WITH PSYCHIATRIC DISABILITIES

TRANSITIONS RTC STATE OF THE SCIENCE PAPER
September 2013

By: Maryann Davis, Ph.D.,
Jonathan Delman, Ph.D., J.D., M.P.H., and
Tania Duperoy, B.A.

"I always wanted to land a career instead of job. I remember searching for a job for a long time. I would hesitantly apply to jobs at supermarkets or restaurants, hoping that no one would accept me there before I found a career-type job to apply to. I finally found one in the Social Sciences, where I ultimately want to be in, and I got it. If I was working anywhere else, I'd be very scared for me future because I'd feel stuck without any experience gained in the field I like."
-Young adult with lived experience of psychiatric disability

This paper is part of a compilation of papers summarizing the state of the science in career development among young adults (ages 18-30) with psychiatric disabilities, entitled Tools for System Transformation for Young Adults with Psychiatric Disabilities. The purpose of these papers is to provide a summary of research-based knowledge about supports to help this population pursue postsecondary education and training and successfully move into adult working careers. These papers focus on knowledge that can inform the services these young adults can access in adult mental health and vocational rehabilitation systems, or other systems that provide them educational, training, or career supports at this age. These papers also propose future research agendas to strengthen this knowledge base.

Specifically, this paper is one of four papers: a framing paper that highlights issues shared across the subsequent papers, and three major papers, one each on education, employment, and system/policy issues. In order to provide multiple perspectives, a panel of various stakeholders reviewed each major paper. The reviewers' comments were then synthesized by one of the panel members into a response paper that is also included in this compilation.

For your convenience, these papers are available for download as individual papers. However, you will likely find it most useful to refer to the framework paper as well as the other two major papers available on our website at http://labs.umassmed.edu/TransitionsRTC.

EMPLOYMENT AND CAREERS IN YOUNG ADULTS
WITH PSYCHIATRIC DISABILITIES

Table of Contents

The written response to this paper immediately follows the references section

We examined peer- and non peer-reviewed research, and communicated with other researchers to assess findings about the development of strong work lives during young adulthood (ages 18-30) among those with psychiatric disabilities, and practices during young adulthood that support strong career development. The following is a summary of the findings from that examination.

- Young adulthood is a critical time for launching careers, but employment is compromised in young adults with psychiatric disabilities. We use the term career to describe occupations undertaken for a significant period of a person's life that provide opportunities for growth. Developing the foundation of strong careers at this stage of life, when typical young adults are doing the same, should prevent or reduce later financial dependency and unemployment. Thus, interventions need to both support young adults' immediate employment goals and help them develop the necessary tools for successful careers and financial independence. Research is needed to better understand how to help young adults with psychiatric disabilities achieve strong careers.

- Adult vocational support interventions for those with psychiatric disabilities that have been researched include general vocational rehabilitation (VR) services, Clubhouses, Assertive Community Treatment, and supported employment focused on the Individualized Placement and Support (IPS) model. IPS is for individuals who want to work. One of the hallmarks of IPS is a place-then-train approach in which the aim is to help individuals succeed while on the job rather than delaying entry into work through lengthy preparatory activities.

- Because of the success of the place-then-train approach, adult vocational supports have moved away from historical practices that employed an array of "career development" approaches that slowly prepared individuals for competitive employment. In practice, these approaches appear to have non-beneficially delayed adults' entry into competitive employment.

- Though research has established that the IPS model and other supported employment improves employment in adults with psychiatric disabilities compared to usual services and other models, the jobs obtained remain mostly part time and low wage. Evidence supporting other widely available vocational interventions is nonexistent, or suffers from weak methods or outcomes.

- There is no evidence that any career or vocational intervention improves careers (i.e. satisfying jobs and income that improve over time) in individuals with psychiatric disabilities of any age.

- The impact of standard adult vocational models on the employment of young adults with psychiatric disabilities is not well studied. The limited research suggests that standard IPS produces better employment outcomes in young adults than standard services but, for the most part, these outcomes are still only part-time, low-wage jobs with many weeks not employed. Other research suggests that supported employment has no better impact than usual services in the youngest adults (i.e., ages 18-24), but heightened impact in older young adults (i.e. ages 25-30).

- An adaptation of IPS supports both employment and education in young adults with early psychosis (IPS-EP-1) and has encouraging evidence for its ability to improve employment outcomes among this group of young adults. Its ability to improve educational outcomes is less clear. The success of IPS-EP has not yet been examined in sites where these young adults are receiving typical (rather than cutting-edge) clinical services.

- Another IPS-EP model (IPS-EP-2) added a concurrent course in workplace skills and knowledge, and family information sessions to supported employment and education with encouraging outcomes in both schooling and working. Either version of IPS-EP may be a good basic model for other young adults with psychiatric disabilities. An IPS model is under development that adds Peer Mentors to assist young adults with a history of intensive mental health treatment in adolescence. Elements to specifically enhance career development, such as using the work experience to explicitly enhance cognitive underpinnings of careers (e.g. self-efficacy, outcome expectations) may also improve the long-term outcomes of IPS and its versions.

- Unnecessarily delaying employment for purposes of career development is detrimental at any age. However, typical young adults have access to a variety of career-enhancing activities, such as summer internships, apprenticeships, Job Clubs, career coaching/ mentoring, and formal career training through postsecondary education or training opportunities. These activities are based on a deeply researched theoretical literature on career development in typical individuals. Though not rigorously researched, there is consistent evidence in typical youth of the positive impact of some of these activities on important career elements such as making a good career choice, developing career-related skills, or conducting successful job searches. Some of these activities overlap with those viewed by VR counselors as centrally important for students transitioning out of

high school. The degree to which these types of career development activities enhance career outcomes is a promising avenue for future research in this age group.

■ Several new vocational approaches for young adults with psychiatric disabilities are in the early stages of research. These approaches share an emphasis on career exploration, assessment, and planning, and support of concurrent employment and education or training. These approaches put young adults in the captain's seat for making career choices, and teach skills for developing and implementing career plans. Several also actively include family members as potential supports. These models need to progress through the research stages of developing strong evidence for their efficacy for employment or careers in young adults with psychiatric disabilities.

Future Research Directions

1. Identifying factors unique to young adult career paths. It is difficult to develop interventions when the target[s] of the intervention is not well understood. Research to date does not reveal what the factors are in young adults with psychiatric disabilities that impede competitive employment, employment that supports fiscal independence, or strong longer term careers (i.e. satisfying employment that involves better jobs and better income over time). Many factors that have been found to relate to successful competitive employment in mature adults, such as job placement, likely apply to young adults as well, but should be confirmed. The factors associated with strong careers in typical young adults should be examined in young adults with psychiatric disabilities. Factors that may be unique to young adults or immature careers may hold the keys to more effectively helping them launch successful careers. Research should focus on factors that interventions could impact.

2. Applying research findings to improve interventions. Research from #1 should be used to develop or adapt interventions to target those factors. These interventions should undergo rigorous testing.

3. Research to improve young adult career outcomes with IPS. Since IPS has the strongest evidence of employment efficacy in young adults, several lines of research examining IPS could help elucidate alterations to it that could strengthen outcomes.
   a. The longitudinal impact of each IPS version on young adults' careers should be examined, including the quality of employment and the capacity for employment to improve over time.
   b. The research that can fully establish their efficacy should be completed for the young adult IPS versions.
   c. Research in young adults in IPS is needed to identify subgroups that experience better or worse outcomes, and/or conditions associated with better or worse

outcomes. Findings could inform IPS modifications, or the development ofalternative or complimentary approaches.

    d. Research is needed to illuminate the specific mechanisms of IPS that produce better employment outcomes in young adults. Findings would also help inform improvements in IPS or other approaches.

4. Continue research with developing models to test their career development efficacy. Current developing models that show promise need to establish their efficacy for improving current employment and developing careers. Those that establish efficacy and/or effectiveness should be further examined for the issues identified in points 3a, c, & d relative to the new intervention.

I. INTRODUCTION

This review asked the following questions about young adults, ages 18-30, with psychiatric disabilities (see overview paper for the definition of psychiatric disabilities used here):

1. What is known about their development of careers?
2. What is known about interventions that can help them launch successful careers?
3. What research is needed to improve their career launches?

To answer these questions, we reviewed the peer reviewed literature, and "gray" literature (e.g. online publications that had not undergone peer review, recent presentations at national research conferences). We also talked with researchers about developments in their research that are not yet published.

II. YOUNG ADULTS WITH PSYCHIATRIC DISABILITIES STRUGGLE WITH CAREER DEVELOPMENT

Working during young adulthood (i.e. ages 18-30 years) is different in important ways from working in mature adulthood and has implications for employment support services. This paper outlines what theory and research reveal about vocational supports for developing strong young adult careers. *We use the term career to describe occupations undertaken for a significant period of a person's life, with opportunities for growth.* It is not limited to professional careers. **The concept of career includes employment, but is broader and includes the quality and satisfactoriness of work, the capacity of work or educational experiences to lead to better work in the future, and self-concepts such as vocational identity** (Baron & Salzer, 2000; Lent, Brown, & Hackett, 1994). One can't have a career without employment, but only targeting employment without targeting broader career-related goals will not likely produce careers.

Moving from schooling into a career is an important step in becoming valued adult members of society for typical young adults. Conversely, unemployment as a young adult contributes to mental health and substance use problems (Fergusson, Horwood, & Lynskey, 1997), and criminal behavior (Baron, 2008; Hartnagel, 1997). Unsurprisingly, young adults with psychiatric disabilities also express desires to have careers, rather than simply getting jobs (Rinaldi et al., 2010; Torres-Stone, Delman, McKay, & Smith, Under review). They perceive of careers as an opportunity to be self-sufficient and to become valued adult members of society like their peers (Ryan, Marshall, Thorburn, LeDrew, & Hogan, 2006; Torres-Stone et al., Under review). Increasingly, careers require higher levels of postsecondary education or training (Settersten, Furstenberg, & Rumbaut, 2005). However, as opposed to typical

young adults (Osgood, Ruth, Eccles, Jacobs, & Barber, 2005), young adults with psychiatric disabilities are neither well employed nor on career paths.

- Among adults with psychiatric disorders, young adults are less often employed than mature adults (Waghorn, Chant, & Harris, 2009). Young adults that have psychiatric disabilities in adolescence have lower employment rates compared to same age peers in other disability groups or in the general population (Frank, 1991; Neel, 1988; Newman et al., 2011; Vander Stoep et al., 2000).

- Employment rates drop substantially, and in some studies drop to no employment, in young adults with psychosis in the 1-3 years after first episode or initial treatment (Ramsay, Stewart, & Compton, 2012; Rinaldi et al., 2010; Tandberg, Ueland, Andreassen, Sundet, & Melle, 2012; Turner et al., 2009).

- A third of individuals receiving Social Security Income (SSI) under age 65 are young adults, and almost a quarter (24.0%) of those young adults have psychiatric disabilities.[1] Receiving Social Security benefits is a strong disincentive to work (e.g. (Bond, Xie, & Drake, 2007; Burns, Catty, Becker, & et al, 2007; Frey et al., 2011).

- Unfortunately, other than the research list in the first 3 bullets, there are no published studies of employment rates or career development paths among young adults with psychiatric disabilities.

- The above research precedes the current world economic climate. This climate and its impact on youth and young adult entry into the labor force is of international concern (International Labour Organization, 2013), particularly for disadvantaged or vulnerable young people (Edelman & Holzer, 2013).

- Career development and career success, as opposed to employment status, has not been examined in young adults with psychiatric disabilities.[2]

Achieving employment is a struggle for young adults with psychiatric disabilities compared to nondisabled peers and older adults with psychiatric disabilities. Moreover, research on achieving employment alone misses critical elements of career development that can support financial independence throughout adulthood.

[1]Data analyzed from Supplemental Security Income (SSI) Recipients by Geographic Area, Sex, Age, Eligibility, and Diagnostic Group, 2010 Data, retrieved 5/31/13 http://www.ssa.gov/policy/docs/data/ssi-2010/SSI-Under65-Diag-2-2010.csv
[2]Footnotes will describe new relevant research that is underway, but not yet complete

In order to develop or modify strong career support interventions for young adults with psychiatric disabilities, we need research specifically in this population to help us understand causes of successful and impeded career development that interventions can affect and how this varies among subgroups (e.g. cultural minorities, young mothers, those with criminal justice involvement), at different ages, or at different points in career development (e.g. with or without any employment experience). Published research of this type is scant, though growing.[3] Because this research is limited, this review includes research on related populations that have relevance to our target group, either because of disability or because of age.

III. YOUNG ADULTHOOD IS WHEN CAREERS LAUNCH

There is a rich body of research and theory that describes the development of individual capacities and contextual and experiential factors that affect individuals' careers, mostly in "typical" individuals, though some vulnerable groups have also been examined. Career development actually begins before adolescence (Hartung, Porfeli, & Vondracek, 2005). Then, through repeated practice, modeling, and feedback from significant people, adolescents gradually develop skills, adopt personal standards, become capable of estimating their abilities and the outcomes of their efforts, and increasingly explore and hone their career interests (Zimmer-Gembeck & Mortimer, 2006). Paid employment also typically starts during secondary school (Shanahan & Flaherty, 2001). Career paths diverge greatly post-high school when adult careers are set in motion:

- By the mid-20's, there are significant career differences between those who pursue college degrees, and those who don't, and those who start families, and those who don't (Osgood et al., 2005; Sandefur, Eggerling-Boeck, & Park, 2005).
- By their mid-20's, most young adults are in long term or career-consistent jobs (Osgood et al., 2005).
- Important cognitive aspects of career development (e.g. career self-efficacy) crystallize
- during young adulthood (Swanson, 1999) and are difficult to change at older ages (Lent et al., 1994).
- Insufficient career activities (e.g. career exploration) can interfere with adult career roles (Herr, 1993; Super, 1988).
- Career efforts during young adulthood predict later career success (De Vos, De Clippeleer, & Dewilde, 2009).

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[3]Wagner, M., & Newman, L. are currently identifying individual, family, and school factors associated with positive career trajectories in special education students with serious emotional disturbance, to identify potential targets of high school based interventions to promote better career launches (Transitions RTC, study A1).

> Young adulthood is a critical window for establishing life-long careers. Subsequent adult career paths are largely extensions of the choices and opportunities of this period.

The dominant theory that guides career development research and interventions is the wellresearched Social Cognitive Career Theory (SCCT) (Betz, 2007; Lent, Brown, & Larkin, 1986; Ochs & Roessler, 2004; Patrick, Care, & Ainley, 2011), based on Bandura's social cognitive theory (Bandura, 1986). In SCCT, three central cognitive mechanisms exert primary influence on career success:

1. Career self-efficacy beliefs: confidence in performing career-enhancing tasks
2. Outcome expectations: beliefs regarding future benefits of current career-related behaviors
3. Clarity of career goals

Additional influences include; career interests, career activities, practice and refinement of skills, and contextual variables, such as discriminatory hiring practices. The learning from prior career experiences and attainment are the strongest influences on self-efficacy, expectations, and goal clarity, and therefore on career performance and attainment

Research on career development in young adults with other disabilities (Benz & Halpern, 1993; Capella, Roessler, & Hemmerla, 2002; Ochs & Roessler, 2001) or mature adults with psychiatric disabilities (Corbiere, Mercier, & Lesage, 2004; Regenold, Sherman, & Fenzel, 1999; Waghorn, Chant, & King, 2007) generally confirms the applicability of SCCT to understanding careers in individuals with disabilities. The consistent finding that prior employment is the strongest predictor of future employment in adults with psychiatric disabilities (Bond, Drake, & Becker, 2008; Cook et al., 2008; MacDonald-Wilson, Rogers, & Anthony, 2001) is also consistent with SCCT, which posits that career development is incrementally built from previous experience. We propose that attending to career development, rather than more narrowly on employment, will produce better long-term careers in young adults with psychiatric disabilities. Others have suggested a similar shift for adults with psychiatric disabilities (Mueser & Cook, 2012; Gioia 2005; Smith & Milson, 2011).

> Career development research suggests that interventions that target key career development elements in young adults with psychiatric disabilities should strengthen their initial and subsequent careers.

IV. IMPORTANT CHARACTERISTICS OF YOUNG ADULTS WITH PSYCHIATRIC DISABILITIES

Psychiatric disabilities. Some characteristics of young adults with psychiatric disabilities distinguish them from young adults who are either non-disabled or have other disabilities.

Psychiatric disabilities and associated characteristics. Symptoms of psychiatric disabilities can directly impact competitive employment in adults with psychiatric disabilities (Bond et al.,2008; McGurk & Mueser, 2003). *Competitive employment* is "jobs paying at least minimumwage, in regular, socially integrated community settings, not reserved for individuals withdisabilities, and held by patients rather than provider agencies" (Cook et al., 2005). Despite theabsence of research on the impact of symptoms on career development constructs like vocational identity formation, it is likely that symptoms, such as some of the cognitive symptoms of schizophrenia, or cognitive distortions of anxiety disorders, may impede the healthy development of these constructs. Psychiatric disabilities can interfere with the social aspects of working (Anthony & Jansen, 1984; Becker et al., 1998; Brekke, Hoe, Long, & Green, 2007) or social support for working (Norman et al., 2007). The stigma of psychiatric disabilities also impacts employment (Corrigan, Powell, & Rusch, 2012;Yanos, Lysaker, & Roe, 2010), and likely other aspects of career development.

> "I was once let go simply because I disclosed and not because I was symptomatic. They never told me upfront because of legal issues, but since my boss was friends with a family friend, I heard the truth of why I was let go soon after. My experience may make me afraid to disclose, but I always feel that honesty is the best policy. Finding the right fit with a job is thus very important."
> *-Young adult with lived experience of psychiatric disabilities*

Work disincentives. A significant work disincentive that many adults with disabilities, including those with psychiatric disabilities, face is the receipt of monthly Social Security Administration cash benefits provided to those who are unable to work because of a disability (Burke-Miller, Razzano, Grey, Blyler, & Cook, 2012; Bond et al., 2007; Burns et al., 2007; Frey et al., 2011). For some people who receive these benefits, the financial risk of losing benefits is too high in the face of uncertain job possibilities and job markets, to consider jobs that have the potential to increase their income substantially. Related disincentives include housing and food stipends. Employment disincentives will impede career development.
Differences between young and mature adults with psychiatric disabilities

> "My Senior year of college was tough. I had a full-time course load and worked as much as I could. Also, having recently acquired knowledge of having a mental health condition and

learning how to cope with it consumed much of my time and energy."
Recent college graduate (Young adult with lived experience)

As described in the introductory paper on this population, there are some important differences between young adults and mature (i.e. not young) adults with psychiatric disabilities. These reflect differences in the general population:

- It is age-typical to pursue educational goals in young adulthood, but less so in mature adulthood
- Young adults, as a group, will have less mature career development than mature adults
- Young adults will generally have more family involvement than mature adults
- Peer influence is stronger in young than in mature adulthood
- There are higher rates of pregnancy and early parenthood, substance use, and arrests in young than mature adults

To be useful for young adults with psychiatric disabilities, vocational supports designed for young adults in the general population or with other disabilities may need modifications for the presence of psychiatric disabilities and the impact of psychiatric disabilities symptoms, the stigma of psychiatric disabilities, and disability-related work disincentives. Interventions developed for mature adults with psychiatric disabilities may need modifications to address youthful needs for; immature career development, co-occurring educational pursuits, the greater influence of families, peers, substance use, and arrests, and developing careers while parenting young children.

V. SERVICES TO SUPPORT THE CAREER DEVELOPMENT OF YOUNG ADULTS WITH PSYCHIATRIC DISABILITIES

Because the focus of this conference is on services in "adult" systems that could better support career development in the young adults that access those systems (see Systems and Policy pre-meeting paper), our service review focuses on those provided in adult systems, and especially adult mental health and state vocational rehabilitation services. We also include those offered in child services for young adults (ages 18-21). We recognize that important career development work occurs prior to entry into adulthood, and would typically be offered within the "children's system" (e.g. child mental health, high school school), but will not review them here as they are designed for a younger age group. We will also not review care coordination models that could link individuals to services that support career development and employment. We assume linkage to strong interventions is beneficial. Thus, the focus of the interventions reviewed here are vocational rehabilitation (VR) services for those for individuals with psychiatric disabilities offered through state VR or adult mental health agencies, and career interventions that are typically offered in schools, colleges,

within businesses, or by private pay. We have selected approaches to review based on there being some data related to their employment or career related outcomes in the research literature (both peer- and non peerreviewed literature). We have tried to strike a balance between emphasizing scientific rigor and practicality. We emphasize what is known based on rigorous research, but also describe research findings from less rigorous approaches. In the first section we describe interventions and, in the second section, we review their attendant research.[4]

General vocational rehabilitation. State government vocational rehabilitation (VR) agencies administer the national VR Program. State VR agencies provide direct services to people with disabilities that support development of educational and vocational skills needed to live independently in the community, with priority given to individuals with the most severe disabilities. Services can be provided directly by VR counselors, or through contracted service providers. Typical services include:

- VR counselors who work with clients to develop an Individual Plan for Employment (IPE), organized around a specific client-chosen employment outcome. VR counselors also act as liaisons with high school special education staff, and offer services to eligible students (Marrone & Taylor, 2013).
- Services provided that may generally include assessment, counseling, resume development, employment coaching, therapeutic treatment, and employment-related transportation (Dutta, Gervey, Chan, Chou, & Ditchman, 2008).
- Services to high school students with disabilities, such as those that VR counselors rate as most important for them to provide (in order of importance): provision of career planning and counseling, provision of career preparation experiences (facilitate development of employment-related skills through community-based work experience), facilitation of connections to agency resources, facilitation of nonprofessional supports and relationships, development and maintenance of collaborative partnerships, promotion of access and opportunity for success as students, and conducting program improvement activities (Plotner et al., 2012).
- Services for VR clients that are in college or a training program, including job placement, job search assistance, and on-the-job training. A large subgroup of VR clients are in college or a training program, including 25,000 people with psychiatric conditions during FY06 (Boutin & Accordino, 2009).
- Specialized services for people with psychiatric disabilities, including IPS and Clubhouses (described below), that VR agencies can contract with providers to offer.

[4]Lidz, C. is conducting a qualitative study of the perceptions of employers and vocational support staff regarding the employment of young adults with mental illness, and perceptions of "recovered" adults regarding their vocational experiences (Transitions RTC Study B2).

<u>Guideposts for Success.</u> Guideposts for Success is a handbook developed by the National Collaborative on Workforce and Disability for Youth (2005), based on their review of the research, to provide guidance about services to help youth with disabilities transition from school to work. These are not specific to youth with psychiatric disabilities. The guideposts are broad, without a fidelity measure available, but are focused on several elements that fit with the developmental status of young adulthood; work-based experiences, youth empowerment, family involvement, and system linkages and benefits counseling. For example, in the second guidepost (career preparation and work-based learning experiences), one element calls for youth to be exposed to a range of experiences in order to identify and attain career goals. These experiences include the following:

- Opportunities to engage in a range of work-based exploration activities such as site visits
- Multiple on-the-job training experiences (paid or unpaid), including community service, that are specifically linked to the content of a program of study and school credit
- Opportunities to learn and practice their work skills (so-called "soft skills")
- Opportunities to learn first-hand about specific occupational skills related to a career pathway

The Social Security Administration (SSA) launched the Youth Transition Demonstration in 2003, that funded six sites to implement Guideposts for youth ages 14-25 with disabilities (i.e. those who were SSA income or insurance beneficiaries). Sites had to implement six elements in the guideposts: individualized work-based experiences, youth empowerment, family supports, system linkages and benefits counseling, and social and health services. Sites also offered these youths SSA waivers of disability program rules to allow them to keep more of their benefits as their earnings increased.

<u>Individualized Placement and Support (IPS).</u> The aim of IPS is to help people with psychiatric conditions achieve competitive employment. IPS clients work with an employment specialist, and employment specialists coordinate their efforts with that of the clinical team. It is a systemic approach based on eight supported employment principles;

1. A focus on *competitive employment* defined as jobs in the open job market at prevailing wages, and side-by-side with nondisabled employees, with supervision provided by personnel employed by the business (Bond, Drake, & Campbell, 2012)
2. Open to any person with a psychiatric disabilities who wants to work
3. Utilizes a rapid job search approach (job search occurs within 1 month, but according to client preference)
4. Is integrated with mental health treatment team
5. Potential jobs are chosen based on people's preferences

6. Service is provided for an unlimited time
7. Supports are individualized
8. Benefits counseling is provided to help address SSI's disincentivizing effect (Bond, 2004; Drake et al., 1999).

Two IPS versions for those with early psychosis, IPS-EP, have incorporated age-based modifications because most individuals with early psychosis are young adults. Both models integrated supported education with supported employment (Killackey, Jackson, & McGorry, 2008; Nuechterlein et al., 2008). Nuechterlein's group also added family information sessions and a group didactic training on workplace fundamentals that occurs while clients look for or obtain work or schooling.

Clubhouses. An International Center for Clubhouse Development certified Clubhouse is a place where a person with a psychiatric condition can receive rehabilitative supports, as a participating member, working side-by-side with paid staff to manage all clubhouse operations. Clubhouses offer a variety of group and individualized interventions for employment, and may also offer interventions for education, advocacy, housing, recreation, and wellness (McKay, Yates, & Johnsen, 2007). Work is seen as providing the foundation for recovery and community integration. Clubhouses provide various levels of vocational services;

- *The work-ordered day:* Members and staff work collaboratively to manage one of several Clubhouse functional units (e.g. the café, business office). Members working in the units develop skills for employment success (e.g. punctuality, responsibility) (Schonebaum & Boyd, 2012).
- *Transitional employment placements (TE)*: Members work in part-time market rate paid jobs for a limited time (6-9 months) for a Clubhouse-affiliated employer, who holds one or more jobs open for Clubhouse members. Clubhouses guarantee job attendance and performance (i.e. Clubhouses train members for the job, coach them, and fill in if they are absent). These positions are designed to enable members to try out a variety of positions and work settings (McKay, Johnsen, & Stein, 2005).
- *Supported employment,* which is similar to IPS, but without the requirement for integration with mental health treatment or benefits counseling, is offered to members.
- *Support of independent employment:* The Clubhouse community provides general support.

A qualitative study found that several clubhouses had, through trial and error, learned how to better engage young adults (McKay et al., 2012). These authors recommended the following approaches to engage young adults: develop referral and outreach strategies to welcome and

meet the needs of young adults, and provide opportunities to build on young adult strengths, particularly with technology, to contribute to clubhouse community and development.

Assertive Community Treatment (ACT). Assertive community treatment (ACT) is a community-based mental health service that provides integrated rehabilitation and clinical services. The multidisciplinary team typically includes case managers, clinicians (e.g. psychiatrist, substance abuse specialist) a peer counselor, and a vocational specialist. The goal of ACT is to provide holistic services and facilitate community integration (Stein, Santos, & Santos, 1998; Waynor & Pratt, 2011). The vocational portion of ACT contains many of the elements of IPS (Russert & Frey, 1991).

> The most common adult vocational services are general VR services, Clubhouses, and Individualized Placement and Support (IPS), only one of which, IPS, has been systematically modified for young adults.

Career interventions. *Career interventions*, as used here, consist of interventions that have generated from vocational psychology and are applied through the field of career counseling within counseling psychology (Savickas & Baker, 2005). Career interventions are rarely designed to address the needs of those with disabilities (Peterson & Elliott, 2008), but rather focus on typical young people and adults. The most common career intervention is one-on-one or group career counseling. As with psychotherapy, there are many different career counseling approaches that range from including psychotherapy, to those concretely focused on well-defined career-oriented activities. Career interventions also include workshops (Koivisto, Vinokur, & Vuori, 2011), courses (Reese & Miller, 2010), mentoring (Allen, Eby, O'Brien, & Lentz, 2008; Ensher, Thomas, & Murphy, 2001), coaching (Stelter, Nielsen, & Wikman, 2011), online career exploration programs (Betz & Borgen, 2009; Herman, 2010), and internships (Brooks, Cornelius, Greenfield, & Joseph, 1995).

Career interventions differ for youth and adults. Generally, for those still involved with schooling (e.g. high school, college), most career interventions focus on helping individuals develop the *precursors* for successful work lives. These include developing interests, relationship skills, self-evaluation skills, specific skills for working/careers, and skills to develop and follow career plans (Chope, 2012; Herr, Cramer, & Niles, 2004). Once adults begin to work, the focus is on helping adults find satisfying jobs or make workplace adjustments (satisfaction and success), linked to a larger goal of their "current and future happiness" (Chope, 2012, pg 549). Career interventions assume that strengthening career elements, such as developing better career choices, will lead to better careers, which includes obtaining employment.

VI. HOW WELL DO THESE VOCATIONAL AND CAREER DEVELOPMENT APPROACHES WORK FOR YOUNG ADULTS?

Overall, there are few published randomized trials examining specific vocational or career interventions in comparison to each other or usual services that have focused on young adults.

> No research has examined the impact of any intervention on the longitudinal patterns of employment or broader careers in individuals of any age with psychiatric disabilities.

This section summarizes the extant research on vocational and career interventions, using the framework on the rigor of research methodology described in the overview paper as a guide to the strength of the evidence.

General VR Services. Generally, it is difficult to fully assess the impact of the array of general VR services because they are applied and studied variability (Fleming & et al, 2013). Some specific components of VR general services are significantly correlated with competitive employment in individuals with mental disabilities (i.e. intellectual, learning, psychiatric disabilities). The greatest gains were from on-the-job supports, job placement assistance and vocational training (Dutta et al., 2008). College and university training supports, in adults with psychiatric disabilities, were associated with better competitive employment compared to similar individuals but without this VR support (Boutin & Accordino, 2011). While some studies have found beneficial effects of general VR services on the employment outcomes of adults with psychiatric disabilities (Rosenthal, Chan, Wong, Kundu, & Dutta, 2006), all studies that have compared general VR services (the "usual" VR services), or even specific VR services, to IPS have shown IPS to provide superior competitive employment outcomes for mature adults with psychiatric disabilities (Bond et al., 2007; Bond et al., 2008). IPS_EP-1 clients also had better competitive employment outcomes than those in standard VR services in Australia (Baksheev, Allott, Jackson, McGorry, & Killackey, 2012; Killackey et al., 2008). The occupations of the jobs that individuals with psychiatric disabilities hold at the end of VR services are low-wage occupations (e.g. janitorial, clerical, stock clerks; Martin et al., 2012). VR services have been unexamined in young adults with psychiatric disabilities (Marrone & Taylor, 2013). Similarly, the impact of VR services for special education students after high school on employment outcomes have not been rigorously researched (Hunnel, 2012). Thus, research is needed to establish which specific VR practices or combination of practices produce the best career outcomes (competitive employment, employment that supports financial independence, and satisfying employment that involves better jobs and better income over time) in young adults with psychiatric disabilities.

Guideposts for Success. The Social Security Administration launched the Youth Transition

Demonstration in 2003, that funded six sites to implement Guideposts for youth ages 14-25 with disabilities, generally those who were SSA income or insurance beneficiaries. Sites had to implement seven of the guideposts: Individualized work-based experiences, Youth empowerment, Family supports, System linkages, Social and health services, SSA work incentive waivers, and Benefits counseling. The demonstration also included SSA waivers of disability program rules to allow young workers to keep more of their benefits as their earnings increased. A random assignment evaluation was conducted and the findings suggest that individuals in programs that delivered more hours of employment services had significantly more hours and higher wages than individuals in the control groups. What was done within those employment service hours was not examined, thus relatively stronger versus weaker employment services could not be discerned. There was also no examination of any outcome differences for different disability groups. Unfortunately, there were no significant differences between the demonstration program and control group within the one site that targeted youth with serious emotional disturbance. The evaluation design precludes making conclusions about the particular factors that contributed to the lack of differences in this site, though this was a site that had fewer average hours of employment services (Wittenburg, Mann, & Thompkins, 2013; Fraker, 2013).

IPS. IPS has undergone extensive and rigorous research. The most recent reviews of controlled studies of the IPS model, generally with mature adults, found that IPS participants are two to three times more likely to obtain competitive jobs than participants receiving other types of employment programs (Bond, Drake, & Becker, 2012), and to work more hours than people using comparison services (Knapp et al., 2013). IPS is also likely cost-effective (Knapp et al., 2013). Like other VR models, the jobs that IPS produces for clients are typically part-time and most commonly 20 hours a week. It appears that few IPS clients work full-time due to fear of losing social security or other benefits, and the concern about the increased stress of full-time work (Bond et al., 2012). In a meta-analysis of four randomized control studies of IPS versus usual services, Bond, Drake and Campbell (2012) confirmed that standard IPS also produces better employment outcomes in young adults, producing almost double the employment rate, and about three times the total number of weeks with employment and wages earned. Yet, young adults in the IPS condition were not employed for most weeks, and the average number of hours worked per week was still less than 20. Thus, while IPS is more effective than usual services, these outcomes are still well below a desirable amount of work, or rate of pay. Moreover, *career* outcomes in IPS have not been examined (e.g. quality of occupation, job progression) in adults or young adults. Evidence supports the employment efficacy of the IPS-EP version tested in Australia (Killacky et al., 2008; Baksheev et al., 2012) that simply integrated supported employment with supported education. In a randomized trial design, this IPS-EP produced better employment outcomes for young adults with EP than standard services in Australia.

Australia has a time cap on services, so this IPS-EP version was not adherent to IPS principle #6, above. Results of the randomized efficacy trial of the version by Nuechterlein and colleagues (2008) have not yet been published, but appear strong as more than 80% of clients returned to school or work within six months of starting IPS-EP (Nuechterlein, personal communication, 8/29/11). It is important to note that young adults in both of these studies received clinical services from specialized teams for early psychosis, not from standard clinical care. It may be important that the clinical care that IPS integrates with be developmentally appropriate for young adults (i.e. appealing, engaging, effective).

Clubhouses. The Clubhouse model and its components do not have evidence from rigorous research that it is more effective for competitive employment than other approaches. Clubhouses were compared to IPS in a randomized trial before Clubhouses added the current supported employment program element. The competitive employment outcomes in that older trial were worse in the Clubhouse group (Bond & Dincin, 1986). While a randomized trial compared the more recent Clubhouse model to supported employment delivered through ACT, because the employment outcomes for the Clubhouse included those from employment that doesn't fully meet the criteria for competitive employment, comparison of the competitive outcome differences in the two conditions isn't possible (Macias et al., 2006). One study's finding suggests that participation in the training through employment in Clubhouses (e.g. working in the Clubhouse café) provides competitive employment benefit for those who enroll in it (Schonebaum & Boyd, 2012), but this element has not been tested in comparison to other approaches that target individuals who are not prepared for transitional, supported, or independent employment. No studies of Clubhouses have examined vocational outcomes specifically in young adults.

ACT. Research to date does not supported ACT as an effective vocational rehabilitation delivery mechanism in adults with psychiatric disabilities (Mueser, Bond, Drake, & Resnick, 1998; Waynor & Pratt, 2011). Adding a family component to ACT, along with the vocational component was found to produce positive employment outcomes in a small clinical trial (McFarlane et al., 2000), but no further research on this model has been published. None of these studies examined vocational outcomes specifically in young adults.

Age differences in the efficacy of these services. Several studies have found that younger adults with psychiatric disabilities have better competitive employment outcomes than older adults in vocational rehabilitation services (Salzer, Baron, Brusilovskiy, Lawer, & Mandell, 2011), supported employment services (Cook et al., 2008), or other vocational approaches (O'Brien, Price, Burns, & Perkins, 2003). Broad conclusions about the greater benefit for younger adults in these programs are not yet justified because many of these studies combined a broad age range of young adults (e.g. 18-34 yrs) within which important age

differences likely exist. For example, the finding of better supported employment outcomes for young adults was found to be true only for 26-30 year olds, while it produced no better outcomes than control conditions in 18-24 year olds (Burke-Miller et al., 2012).

> The only intervention with evidence of efficacy in improving employment outcomes in young adults is IPS. The IPS version for early psychosis has growing evidence that it benefits those for whom it was designed. The evidence supporting other established vocational interventions is either nonexistent, or suffers from weak methods or weak outcomes. *However, the IPS model does not appear to improve careers.*

Career Development Interventions. Given the vast research supporting career development theory, interventions that beneficially impact elements of career development associated with strong career performance should be a promising avenue for developing interventions that better benefit long term careers. However, before reviewing the research on career interventions it is important to acknowledge a historical controversy regarding the value of these types of services. We understand the term "prevocational activities" and related terms such as *career counseling* and *career development* in some circles have become associated with practices that delayed entry into competitive employment without clear evidence of benefit. Moreover, some of these practices included mandatory sequencing of activities prior to job placement, regardless of individuals' needs. Thus, in adult vocational rehabilitation, career development activities may be viewed as practices with little supportive evidence. However, despite this history, the fact is that most young adults are early in their career development and thus many are without firm employment or career direction. Simply helping them obtain competitive employment is a limited means of helping them develop the career elements that theory suggests is necessary. Therefore, it should be facilitative and not a hindrance for helpers to engage young adults in career exploration activities, depending on the needs and career status of each young adult. It remains important that these activities do not needlessly delay entry into competitive work. Research is needed to guide decisions about the amount and type of career strengthening activities that are beneficial at different levels of career maturity and for various subgroups of young adults with psychiatric disabilities.

Research in career interventions has not been rigorous. While many of the career interventions listed in the previous section have guidelines, and were examined in comparison to a randomly assigned control group, the guidelines are often not specific (making replication difficult), fidelity is rarely measured, and most interventions have only undergone a single study examining its effects (Brown & McPartland, 2005; Ethridge, Burnhill, & Dong, 2009; Perry, Dauwalder, & Bonnett, 2009). Further, the direct impact of these interventions on employment per se has rarely been examined. Other than job search interventions that have been examined for efficacy in obtaining jobs (e.g. Stidham & Remley,

1992), there is a dearth of research on interventions that improve work performance (Brown & McPartland, 2005). Because few career interventions have addressed the needs of individuals with disabilities (Peterson & Elliott, 2008), there is little research in this specific area. We are aware of Career Visions as being the only study that has examined the impact of a career intervention with young adults with psychiatric disabilities. Career Visions (Sowers, 2013) is undergoing an initial clinical trial, and has reported encouraging preliminary findings in career exploration, and career- and disability-related self-efficacy.

> The career development field has myriad interventions for young adults. Their targets are typically elements of career development, not employment per se. Their efficacy in young adults with psychiatric disabilities is largely unexamined, and the relationship of these elements to actual careers in this population is unknown.

VII. NEWER INTERVENTIONS AND SUPPORTING EVIDENCE

Psychosocial and career development differences between younger and older adults with psychiatric disabilities suggest several needed adaptations for adult vocational approaches. A qualitative study of young adults in the standard adult vocational support programs described above express three major desires: 1) career exploration, job preparation, and effective educational supports; 2) social skills training; and 3) supportive provider relationships and readily available workplace supports that don't involve provider staff (Torres-Stone et al., Under review). Standard adult approaches could build more explicit career development activities into the work they help young adults obtain (i.e. use the work experience to explicitly explore skills, career preferences, outcome expectations, career self-efficacy, etc.). For the career interventions used with typical young adults to be useful for young adults with psychiatric disabilities they may need to address the experience of disability or psychiatric disabilities, including education about the impact of symptoms on working or on self-efficacy beliefs, or provide information about disclosure of psychiatric disabilities or Americans with Disabilities Act accommodation requirements for employers.

Several studies are underway examining these types of age- and disability-tailored approaches. The interventions described in this section are uniformly in early stages of developing evidence regarding their efficacy with employment or other aspects of career development. They are described here to reveal interventions that may be found to be effective in the near future, and the young adult "themes" that emerge from them.

Career Visions. Career Visions is a career planning intervention for young adults with psychiatric disabilities (ages 18-30). Clients learn and use strategies to choose a career

or job, and develop and implement plans progressing toward their goals. They also learn practical skills (e.g. resume writing), and gain information and support directly related to mental health challenges. Preliminary findings from the small randomized trial indicate better career development outcomes in the Career Visions than in a control group (Sowers, 2013).

RENEW (Rehabilitation, Empowerment, Natural Supports, Education, and Work). This approach was developed for youth with emotional and behavioral disorders to provide an individualized and comprehensive planning and support process focused on high school completion, career development, employment, and post high school activities such as independent living, post-secondary education and training opportunities, and community inclusion (Hagner, Cheney, & Malloy, 1999). This approach has a manual (Malloy, Drake, Cloutier, & Couture, 2010). A small follow-along evaluation study (n=20) of special education students with emotional disturbance found an increase in competitive employment rates from 11% at baseline to 61% at follow-up among those enrolled in the program for at least two years (Hagner et al., 1999). No further research on this model has been produced.

Jump On Board for Success (JOBS). The JOBS program provides developmentally tailored wraparound services (VanDenBerg& Grealish, 1996) that focus on career development. JOBS specialists coordinate wraparound care and provide supported employment for youth, ages 16-22, with serious emotional disturbance, who have been served in the children's system or adult corrections (Clark, Pschorr, Wells, Curtis, & Tighe, 2004). In a follow-along evaluation study, among those that graduated from the program, positive engagement in attending school and/or competitive employment increased from 23% at baseline to 96% at graduation, with 76% engaged in competitive employment (Clark et al., 2004). While both RENEW and JOBS have positive outcomes, there are no outcomes from clients that didn't complete the program, no published fidelity measure, and no control group data available. These would be the next research steps necessary to further develop and test these interventions.

Social Enterprise Intervention for Homeless Young Adults. This twenty-month social enterprise intervention combines a community economic development approach with clinical supports to promote individuals' human and social capital (Ferguson, 2012). There are four elements to this intervention: 1) a 4-month course of vocational skill acquisition, 2) a 4-month small-business skill acquisition course, 3) a 12-month peer supported affirmative business formation phase, and 4) clinical services. A small randomized trial was conducted with homeless young adults (18-24 yrs old). Mental health condition was not a requirement of participation, though clinical services are part of the model. Early preliminary qualitative findings are encouraging.

IPS_Peer Mentors. Program developers at Thresholds in Chicago in partnership with researchers at the Transitions RTC, have developed a version of IPS_EP for young adults (ages 17-21) with long standing serious mental health conditions and intensive adolescent mental health service utilization, called IPS_Peer Mentors. The model adds peer mentors to the Killackey (2008) model. During weekly one-on-one interactions, peer mentors engage youth in specific recreational or relationship-building activities or teach curricula, available on a variety of topics that are chosen by the mentee, their supported education/employment specialist, and the peer mentor. The approach is manualized, with a fidelity measure, and has been examined in a single case series research project without a comparison group. Findings are not yet available.

MST-EA Coaches. Multisystemic Therapy for Emerging Adults (MST-EA) is an adaptation of an intervention with well-established efficacy to reduce juvenile recidivism (MST; Littell, Popa, & Forsythe, 2005), for use with 17-21 year olds with psychiatric disabilities and recent justice system involvement. MST-EA adds Coaches to the team of MST-EA therapists and clinical supervisor. Coaches are part-time lay positions utilizing individuals (usually young adults) who work well with this population to model good relationship skills, reinforce progress made in therapy, and teach and coach skills for independent living. Currently, Transitions RTC is conducting a randomized clinical trial of two Coach versions: Vocationally enhanced Coaches (VocC) versus No Vocational capacity Coaches+state VR services (NoVocC+VR). MST-EA and the Coach versions are manualized approaches with fidelity measures. Preliminary findings (N=21) indicate that using VocC yields better competitive employment outcomes post treatment (57% vs. 20% in competitive employment).

Several approaches to address employment or career development in young adults with psychiatric disabilities are in the early stages of research. These approaches share an emphasis on career exploration, assessment and planning, support of concurrent employment and education or training, and support of young adults leading and improving their capacities for career planning and implementation. Several also actively include family members as potential supports.

CONCLUSIONS

Young adults with psychiatric disabilities need better supports for their current employment as well as for developing strong careers. Similar conclusions have been made regarding adult, in general, with psychiatric disabilities. Adult mental health and vocational rehabilitation systems can provide interventions to achieve these goals. However, the evidence is now

clear that effective vocational supports should be customized for this population. No current model has evidence that it achieves both strong employment and longer term career outcomes. The Individualized Placement and Support model has good evidence that it supports immediate employment goals for young adults in both its standard and versions for young adults with early psychosis. Further enhancements of this model may prove to support greater career strengthening. It is unlikely that any single model will improve employment and career outcomes of all young adults with psychiatric disabilities, and the array of developing interventions will likely further add to improved employment and career outcomes in this population. Eventually, comparative effectiveness studies that examine which models are best for whom at which points in their career trajectories will help refine the matching of effective interventions to individuals' needs, and provide the best supports for all young adults with psychiatric disabilities to achieve satisfying adult work lives that provide financial independence. It is time to shift from a focus purely on relatively short-term employment, to a focus on helping young adults gain the tools necessary for employment and the progression of employment into successful careers. In order to achieve this shift, we believe the following types of research are necessary:

1. **Identifying factors unique to young adult career paths.** It is difficult to develop interventions when the target[s] of the intervention is not well understood. Research to date does not reveal what the factors are in young adults with psychiatric disabilities that impede competitive employment, employment that supports fiscal independence, or strong longer term careers (i.e. satisfying employment that involves better jobs and better income over time). Many factors that have been found to relate to successful competitive employment in mature adults, such as job placement, likely apply to young adults as well, but should be confirmed. The factors associated with strong careers in typical young adults should be examined in young adults with psychiatric disabilities. Factors that may be unique to young adults or immature careers may hold the keys to more effectively helping them launch successful careers. Research should focus on factors that interventions could impact.

2. **Applying research findings to improve interventions.** Research from #1 should be used to develop or adapt interventions to target those factors. These interventions should undergo rigorous testing.

3. **Research to improve young adult career outcomes with IPS.** Since IPS has the strongest evidence of employment efficacy in young adults, several lines of research examining IPS could help elucidate alterations to it that could strengthen outcomes.

    a. The longitudinal impact of each IPS version on young adults' careers should be

examined, including the quality of employment and the capacity for employment to improve over time.

b. The research that can fully establish their efficacy should be completed for the young adult IPS versions.

c. Research in young adults in IPS is needed to identify subgroups that experience better or worse outcomes, or conditions associated with better or worse outcomes. Findings could inform IPS modifications, or the development of alternative or complimentary approaches.

d. Research is needed to illuminate the specific mechanisms of IPS that produce better employment outcomes in young adults. Findings would also help inform improvements in IPS or other approaches.

4. Continue research with developing models to test their career development efficacy. Current developing models that show promise need to establish their efficacy for improving current employment and developing careers. Those that establish efficacy or effectiveness should be furth

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SUMMARY OF RESPONSES TO PAPER:
"EMPLOYMENT AND CAREERS IN YOUNG ADULTS WITH PSYCHIATRIC DISABILITIES"

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7/31/13

Youth with psychiatric disabilities have the same vocational needs as those without psychiatric disabilities but are compounded by the symptoms of their illness and the associated stigma and potential discrimination. The Davis, Delman, & Duperoy paper does an excellent job of highlighting a plethora of significant vocational issues confronting young adults with psychiatric disabilities. Some additional ones, not otherwise noted, that might be considered, include:

a. Often limited access to SPED services, except for "behavioral" problems
b. The need for supports in additional areas like housing and transportation, etc. Many of the youth in the target group are coming from foster care or the juvenile justice system and might not have many natural supports with which to connect.
c. Young adults with and without mental health problems often need to explore many short term jobs before deciding on a career path, which may lead to what some may see as "job hopping". They may also be more attracted to the sorts of jobs we think of as lower status (e.g., working in restaurants) but that may involve more "action" which youth crave.
d. Distinguishing psychiatric impairment requiring intervention from age related dysfunctional behaviors that youth age out of.
e.

The paper seeks to identify key elements of career development as juxtaposed to employment or job acquisition. The authors see this enhanced emphasis as a counterweight to the multitude of barriers that young adults, ages 18-30, face in the vocational and career arenas. In the course of the review, the authors highlight significant reasons why career development should be a concern for researchers and practitioners through an extensive literature review contained in Sections II and III. They then go on to discuss issues in systems and programs specific to youth and young adults with psychiatric impairments.

1. Many of the respondents commented favorably on the:
   • Career development focus of the paper
   • Literature review contained in the earlier sections
   • Emphasis on environmental and social factors impeding employment and career progression for the group in addition to the clinical issues they must confront
   • Inclusion of quotes from young adults
   • Attempt to delineate types of research needed
   • Description of some existing innovative programs that target these young adults.

Some additional considerations were:
2. It is hard to make clear delineation between "career development and employment" or of "career counseling" per se, and difficult to create specific, concrete measures of career development.

3. It is difficult to clarify how the various interventions noted can all be classified as service models per se. "General VR Services" as an example is not a specific model of discrete interventions though, as noted in the paper when referencing the Plotner citation, there are some broadly accepted competencies that VR staff should bring to bear when dealing with youth and young adults with psychiatric disabilities.

The authors do show an understanding that use of the terminology "pre vocational services" is one that has been used for many years to throw obstacles and faulty mandatory sequencing of services into the path of all people with significant psychiatric disabilities, rather than merely describing helpful activities that can occur prior to, or concomitant with, employment. The emphasis of much recent employment research has been debunking the need for people to get engaged in precursors to employment (e.g., vocational evaluation, volunteer, staging a "readiness" continuum, sheltered work, etc) as a requirement before getting help to acquire a competitive job. The authors do cite reporting that young adults in vocational programs express a desire for "prevocational" supports. Because this paper is unpublished and the term is somewhat hazy, it is difficult to assess its relevance.

The primary author of this response, though not all responders, would support the notion that young adults do benefit from multiple avenues to employment experience including temporary jobs, volunteer options, work tryouts, etc. Nonetheless, it is perhaps a misnomer to characterize them as "prevocational," or align oneself with the notion that before engaging in employment, young adults must be assessed or evaluated as to appropriate career paths. One commenter, in particular, felt strongly that the existing research did not demonstrate any support for career counseling as a useful component in the employment trajectories of young adults. However, the primary author of this response paper does endorse the potential utility of career counseling seen not as passive 1-1 clinical activity. Rather, career counseling can be conceptualized as a set of processes that could and should include rapid focus on job acquisition as a method of investigating interests and aptitudes and providing career momentum, as well as the practical benefit of gathering references and developing a practical resume of a work history.

The distinction the authors make between "career development" and "employment" is somewhat ambiguous and not explicitly laid out. One generally cannot have a career without a job or employment. It appears that the point trying to be made is not the separation of career development from employment, but rather the notion that *initial* job acquisition is not an adequate measure of a career development track. It is hard to argue that exposure to employment experiences for young adults is not an important point of career development (in fact the authors do just that) so the concern they posit needs to be stated differently.

While some commenters lauded the attempt to analyze various existing service models, many felt that it was not deep or accurate enough to provide useful context. Furthermore, it appears that the authors would better serve the purposes of the paper to identify specific types of services, components, or engagement styles from a clinical or system or policy perspective more broadly, rather than use a necessarily shallow overview of existing services to drive the discussion. These recommendations could then be used to assess how best to revise or use existing service streams to better enhance career development. That person stated that there is some evidence for the effectiveness for IPS in this age group, but there is no strong set of data supporting any other employment model within this paper the responders reviewed. This same responder was of the opinion that "Instead of speculating about career development or job tryouts, etc., would it not be better to start from what we know?"

The inclusion of general VR services as a model misstates the content and context of a VR program. Once a young adult is determined eligible there is a plethora of services that potentially could be brought to bear to address the young person's barriers to his/her desired vocational goal. Any of the other services noted in the paper can and are, in some areas, used in developing a program of services and supports, including career counseling, for a client. These do encompass, but are not limited to evidence based alternatives, such as IPS. Nonetheless, there are key areas that have been identified in the rehabilitation literature as key competencies for VR staff to possess as they engage youth in the transition process that intersects with public vocational rehabilitation. These areas are in fact cited by the authors. VR services represent a public agency attempt to provide services leading to employment; they are not a discrete set of interventions or program "model."

Finally, it would be worth clarifying some terminology further as the discussion develops. The overall term "young adult with mental illness" might apply to a wide variety of groups and should be defined more directly. Another item in the paper mentioned "compromised" families without explaining what exactly the authors meant.

There are some themes that emerged or noted by one or more responders regarding further research or policy questions that might need to be answered as a complement to this paper, or of added benefit to the field overall

- Developing an analysis of the "active ingredients" of the current models that effectively address employment and career development
- Identifying how young adults might best be included in further research or in evaluating program efficacy
- Separating out more fully the evidence of efficacy and effectiveness for certain practices

and interventions from considered opinion. Many examples exist where developed data has shown the fallacies inherent in various strains of "common wisdom" in the field. One of the most egregious of these errors in the employment field had been the long held notion of the need for developing continuums of employment preparatory services to enhance "readiness" before engaging in direct employment and job development on behalf of the person.

- Exploring how families might be engaged more both as recipients of support, as well as providing greater support to young adults
- Assessing how being part of a disadvantaged socio-cultural or vulnerable group (race, ethnicity, language, teen single parenthood, poverty, etc.) in addition to mental illness affects career development and access to effective pre-career pathways
- Discussing how various disincentives or barriers to employment, other than SSA policies, can be countered to affect career development
- Understanding the skill sets that staff from various support systems need to better serve youth and young adults
- Examining the role of secondary school influences, including but not limited to IEPs and 504 plans, in career development pathways
- Researching various types of work options that may jumpstart not impede career development and long term work force participation
- Understanding how the extension of "adolescence" in our society in general with a later entry into solid career paths, as well as longer term structural unemployment (both exacerbated by the recent recession) may hinder career development
- Analyzing governmental social/financial assistance policies that could better assist and encourage young adults with psychiatric disabilities to enter employment and initiate the journey to fulfilling careers.

ADDENDUM TO THE EMPLOYMENT DOMAIN

This addendum provides a summary of the salient points discussed during the State of the Science conference presentation on the employment domain. We review the discussion by the audience and break-out groups, break-out group balloting results, and present final conclusions for future research directions.

State of the Science conference audience and breakout discussions. The audience and break-out group discussions generated several key themes. There was widespread affirmation of the central importance of employment success for this age group. There was extensive discussion of the meaning and value of the term "career." The greatest concern was that the term had certain economic class-based values attached that would be a disservice to many young adults. There was consensus that desirable employment outcomes include the capacity to be financially self-sufficient over time, but there was no consensus about the universally desired nature of long term employment otherwise. It was clear that, for many, being economically self-sufficient without necessarily being "upwardly mobile" could constitute a "career" and should be valued as an outcome. It was also clear that for those who desired opportunities for increasing expertise, income, or status from their work lives over time (a more traditional view of careers) should foster these kinds of outcomes as well. Research implications of any view of career as a desirable outcome include examining a longer term picture of the impact of career-related services; tracking an intervention's ability support continuous employment, and to minimize long breaks that aren't for other productive purposes (e.g. getting more education or training, parenting young children). Other research implications include understanding factors that underlie different types or aspects of careers that would have implications for the design of effective interventions.

Many in the audience reported on significant obstacles to vocational success, and the lack of appropriate services and supports to overcome them. The audience was concerned that many vocational support program staff did not fully believe that employment is an early step toward recovery, which would impede offering career development services. Additionally, audience members did not believe that there was sufficient evidence to support any existing vocational support for young adults. They instead believed that research was required on a number of specific vocational interventions, such as vocational skills development, one-stop career centers, Individual Placement and Support (IPS), the combination of supported employment and supported education. They were particularly interested in models supporting career paths, including career mapping and interventions designed to turn an entry-level job into a personally fulfilling career, such as work modeling/internships. They recognized that early work experience has a direct effect on

employment success and that the child/adolescent systems don't typically offer services that address this need.

Audience members also recognized the presence of stigma as a significant deterrent to employment success for any age group. However, young adults experience more self-stigma because of the nature of identity formation that occurs at this stage of life. Self-stigma can interfere in various ways with their efforts to work. In addition, stigma occurs in the workplace when employers, supervisors and staff believe that people with mental illness are less capable of work than others, which also have broad ramifications for young adults' success in the work place. Young adults in particular may benefit from job accommodations that introduce them to workplace culture and skills. Research implications that are specific to this age group include understanding what contributes to self-stigma in this developmental stage and its impact on career activities, and understanding any specific stigma associated with being young or less experienced that could mediate the general effects of stigma in the workplace. Research that helps identify effective approaches to reducing the impact of stigma in the workplace will also benefit this younger group of adults.

Balloting results. The authors of the review of research on employment and career development identified several priority areas for future research based on their review. The area of research with the highest number of participant endorsements was the need to continue research that can establish or test the efficacy and career effectiveness of the new models under development. The second most endorsed area of research was IPS-focused research to identify subgroups that experience better or worse outcomes (which could inform IPS modifications, or the development of alternative or complimentary approaches), followed by endorsement of the need for longitudinal research in relation to young adult careers (eg., quality of employment and capacity over time). Two other research needs were also rated highly: a) to identify similarities and differences between young adults with psychiatric disabilities and young adults with other disabilities, and b) research to illuminate the specific mechanisms of IPS that produce better employment outcomes in young adults.

Conclusions for future research directions. Taken together, the conference participants and the authors and reviewers of the research review recognized the need for much greater research efforts in the employment domain at all points in the employment trajectory for young adults (e.g. post-secondary school education and training programs, career preparation, job development, job supports). No existing intervention produces the types of employment outcomes that young adults, family members, or society would see as strong. The best evidence is for an intervention that typically helps people

obtain part time, short term, low wage jobs. Stronger interventions and supports are needed. In order to design stronger interventions and supports, more research is needed to understand what their targets should be and how those targets might vary across subgroups, community context, or as young adults mature. Research is also needed to guide the diminution of system or societal barriers to the success of these young adults.

EMPLOYMENT TOTALS TALLY

	Orange Mark Salzer	Green Nancy Koroloff	Blue Chuck Lidz	Red Krista Kutash	Yellow Kathryn Sabella	Total
1. Identify malleable factors that interventions can target that impeded or facilitate career paths and are unique to young adults:						
1a. Identify similarities and differences between young and mature adults with psychiatric disabilities	1				1	**2**
1b. Identify similarities and differences between young adults with psychiatric disabilities and young adults with other disabilities	1	3	2	2		**8**
2. Apply research findings to improve interventions:						
2a. Research from #1 should be used to develop or adapt interventions to target those factors	2			1	2	**5**
2b. These interventions should undergo rigorous testing	1	2			1	**4**
3. Research to improve young adult career outcomes with IPS:						
3a. The longitudinal impact of each IPS version on young adults' careers should be examined, including the quality of employment and the capacity for employment to improve over time.	2	2	2	2	2	**10**
3b. The research that can fully establish their efficacy should be completed for the young adult IPS versions.	1	1		1	1	**4**
3c. Research in young adults in IPS is needed to identify subgroups that experience better or worse outcomes, and/or conditions associated with better or worse outcomes. Findings could inform IPS modifications, or the development of alternative or complimentary approaches	1	2		6	2	**11**
3d. Research is needed to illuminate the specific mechanisms of IPS that produce better employment outcomes in young adults. Findings would also help inform improvements in IPS or other Approaches	1	2	1	2	1	**7**
4. Continue the research that can establish or test the efficacy and career effectiveness of the new models under development for their impact on career development.	3		2	4	4	**13**

Orange	Write In's:
	• To what extent are children's mental health services focused on employment? What are the barriers?
	• Develop new (st and std) model to better serve this (or older) populations
	• To what extent do children's mental health services work on employment services?
	Question Edits:
	• 1b. focus on young adults with psychiatric disorders not without
	• 1d. Identify young adults with psychiatric disorders or between young adults with PD and without
	Flipchart and Notes:
	• Children's mental health system is not equipped to think/act/integrate anything to do with employment is _____
	• Better preparation of children's MH system to promote employment
	• Disconnection re: CMH: Level of integration of SE: services
	• Extent of CMH focused on employment- what are the barriers?
	• What are the developmentally appropriate vocational tasks (exposure to world of work early in life)
	• Real concern about IPS present
	• Is there a real difference between young adults without disabilities than with disabilities? (Factors may be the same, reactions may be different)
	• Use legal obligations/Threaten with ADA
	• Community and employer engagement
	• Matching strengths of employers and employers reactions as a community to maintain young employees
	• Social forms: collective perspective
	• Impact of mental health system on youth (self stigma)
	• Discussion needed about how to change the system (financial incentives, what are adequate incentives to promote changes)
	• Operationalize the use of legal implications for NOT hiring people with disabilities
	• Are there better employment outcomes in individualistic vs. collectivist communities/cultures?
	• What is effective in preventing self-stigma and career prospect disillusionment
	• What kind of work modeling/internship experiences might be effective for children with SMHC
	• What is the effectiveness of community and employer engagement?
Green	Write In's:
	• None
	Question Edits:

	• 2b. Follow consumer 10-15 years out **Flipchart and Notes:** • Does focus on career path make a difference in outcomes and for whom • What are the factors for diverse cultural groups • What is impact of early work experience • What's the impact of stigma on young adults? Does it affect work life? • Impact of young adult impact in research? • Look at VR services for consumers from public mental health vs. private mental health • Impact of side effects of medication on employment • Role of physician on employment • Medicaid buy-in, has it made a difference in employment rates? • Living situation may be a malleable factor—maybe could do with ssi/ssdi data but family support is important • Career paths and career mapping—this presents an opportunity that can be done with young people. Figuring out what they want to do. • What are the factors that shape perspectives toward work in diverse cultures and families--families shape attitudes toward work? • Cultural perspectives shape the perspectives of work—work attitudes, models. We should be mindful of that. • Also early work experiences shape later attitudes—early experiences shape us. Need to foster early work experiences that are positive. • Which interventions should undergo rigorous testing? E.g., Project Search, New Guideposts, IPS?
Blue	**Write In:** • Research on effectiveness of accommodations in the workplace • Identify similarities and differences between young adults with psychiatric disabilities and young adults without psychiatric disabilities **Question Edits:** • NONE **Flipchart ant notes:** • What is the young adult vision for a "working life" • Quantitative/Qualitative Comparison research of typical non-disabled young adults vs. young adults with PD in terms of trajectories and needs, and what are the factors that support that • What is the relationship in employment and education for young adults achieving goals • How do we maximize opportunities to turn jobs into careers for young adults (what is the effect of combining supp. Employment and supp. Education • Test a model that turns entry level jobs into personally fulfilling careers • How do we effect organizational change for employers to de-stigmatize mental illness • How will Obama Care affect guaranteed benefits/what affect will it have on YA job selection
	• Research needed on accommodations in employment settings (effectiveness for employers and employees)
Red	**Write In's:** • Look at values belief skills, knowledge of providers as gatekeepers to work and recovery • Attitudes of employers • Roles of workforce development and its' effectiveness/models being used • Attitudes of providers and employers i.e. IPS- needs to be explained • Role/involvement of workforce system • One stops- need to be explored **Question Edits:** • NONE **Flipchart and Notes:** • Attitudes, values, beliefs and skills of providers toward employment of youth with PD (case managers, therapists AND employers) • Work-force system one-stop needs to be explored • Youth differences between job versus career • Provider attitudes towards recovery and employment • Providers needs to be able to connect "work" and "career"
Yellow	**Write In's:** • Barriers/difficulties $ splen-lead and presented level? • Trauma, substance abuse, juvenile justice/intervention and education **Question Edits:** • 1. Effect IM trauma, St and Std base in Juvenile Justice (noted x2) **Flipchart and Notes:** • Need to reframe the low wage/time limited sort of jobs as a step in career trajectory • Frame with the research questions within the context of the community services- BUT don't let this limit ideas • What makes It easier or more difficult to implement supported employment components (systems and organization level factors) • Socialization/education about ramifications of behaviors (criminal activity = no jobs) using peer education • Individualization within fidelity (individualize to culture, race, etc.) • Long term outcomes are a problem because the follow-up window – HARD to retain and impossible to fund! • Comprehensive nature of services- but right now communities doing the best they can with the funding=pull the child services agencies together to be comprehensive • Career vs. job = artificial • IPS = jobs • Expand research to validate adaptation, but more important, argument IPS to promote long term career development
	• Artifact of funding mechanisms = interventions are restrained by funding, funding not always unlimited • Not a lot of thought put into housing and employment in recovery and treatment, not a lot peer to peer youth • Make research culturally competent and unique to individual

SYSTEM AND POLICY CONSIDERATIONS FOR STRONG CAREER LAUNCHES IN YOUNG ADULTS WITH PSYCHIATRIC DISABILITIES

TRANSITIONS RTC STATE OF THE SCIENCE PAPER
September 2013

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This paper is part of a compilation of papers summarizing the state of the science in career development among young adults (ages 18-30) with psychiatric disabilities, entitled Tools for System Transformation for Young Adults with Psychiatric Disabilities. The purpose of these papers is to provide a summary of research-based knowledge about supports to help this population pursue postsecondary education and training and successfully move into adult working careers. These papers focus on knowledge that can inform the services these young adults can access in adult mental health and vocational rehabilitation systems, or other systems that provide them educational, training, or career supports at this age. These papers also propose future research agendas to strengthen this knowledge base.

Specifically, this paper is one of four papers: a framing paper that highlights issues shared across the subsequent papers, and three major papers, one each on education, employment, and system/policy issues. In order to provide multiple perspectives, a panel of various stakeholders reviewed each major paper. The reviewers' comments were then synthesized by one of the panel members into a response paper that is also included in this compilation. For your convenience, these papers are available for download as individual papers. However, you will likely find it most useful to refer to the framework paper as well as the other two major papers available on our website at http://labs.umassmed.edu/TransitionsRTC.

SYSTEM AND POLICY CONSIDERATIONS FOR STRONG CAREER LAUNCHES IN YOUNG ADULTS WITH PSYCHIATRIC DISABILITIES

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The written response to this paper can be found immediately after the reference section

This state of the science paper focuses on system and policy issues that facilitate or impede provision of age-appropriate and appealing services to support the education and career goals of young adults with psychiatric disabilities that adult systems currently serve. We examined the range of system and policy issues that may impact the services and supports received by young adults and the impact of these policies on the availability of services. After providing some definitions, this paper looks at the variety of trajectories that may lead a young adult to need or try to access adult services. The under representation of young adults in the adult mental health system and some possible explanations are discussed followed by an examination of the system and policy issues that impede the availability of age-appropriate services. Evidence that age-appropriate services are not broadly available is provided followed by an analysis of the barriers that seem most prominent. The paper goes on to describe several examples of creative policy approaches that support the availability of age-appropriate vocational or educational supports. Among other approaches, examples include two federal grant initiatives, the restructuring of a state system to establish a young adult service division, and extending the age for transition into adult services.

There are many areas that need research regarding system and policy barriers and facilitators. Prominent in this discussion are the need to carefully study the impact of offering age-appropriate services on outcomes related to the development of a career and the ability to work. A second set of research issues focuses on the implementation of age-appropriate services and the impact of current systemic barriers and facilitators on this implementation. The final set of research questions calls for greater understanding of the impact of involving young adults and their families in the process of system and policy change.

a. Research Regarding the Impact of Offering These Services:
- Does offering age-appropriate educational and career development supports increase sustained access to services for this population of young adults? Does provision of these types of services reduce service needs at later ages?
- What is the impact of providing age-appropriate services in terms of systems costs overall?

b. Research Regarding the Implementation of Offering These Services:
- What are the current systemic barriers and facilitators to offering age-appropriate educational and career development supports for young adults? What will it take to overcome these barriers?
- How do those barriers vary by system organization factors (e.g. local vs. state-level funding decisions), by funding mechanisms (e.g. implementation of ACA voluntary portions vs. not, use of Medicaid rehabilitation waivers), and other such system factors?

- Does increased contact and collaboration between child and adult mental health services result in greater implementation of effective educational and career development services for young adults?

c. Research Regarding the Impact of Involving Young Adults and their Families in System Change:
- Do national, state, and local level policies which reflect the input of young adults, and their families result in greater system change and more positive outcomes than those that do not?
- How is the process of policy change and implementation affected when young adults and their families are meaningfully involved?
- To what extent do policies that are designed to support young persons in both system planning and in planning their own services result in better outcomes for the young adult?

I INTRODUCTION

The previous papers describe the need for access to more effective services to help young adults with psychiatric disabilities succeed in the educational, training, and work experiences that build strong careers, and the evidence about the nature of such services. Service access is strongly shaped by the policies and systems that make services available. Therefore, this paper focuses on system and policy issues that facilitate or impede provision of services that support the development of strong careers among young adults, ages 18-30 years, with psychiatric disabilities. Specifically, this paper focuses on "adult" systems policies and the young adults with psychiatric disabilities that are currently served in these systems.

For our purposes, *adult* systems refer to publicly funded service systems that primarily serve adults. In all states, public adult mental health systems are defined as serving individuals ages 18 and older (Davis& Koroloff, 2007). State vocational rehabilitation systems largely serve adults with disabilities, but also work with high schools to address the vocational and school-to-work transition needs of special education students as young as age 16. Similarly, substance abuse or addictions systems typically focus on legal adults, but can also serve adolescents. Other adult public systems that young adults with psychiatric disabilities interact with are the criminal justice system, housing system, and higher education, each of which also focuses on adults above a specified age, often with some limited involvement of older adolescents. "Adult" health systems typically address the health needs of young people 18 and older and family practitioners have patients of all ages. Pediatricians can work with patients up to age 30. Because of the focus on education and careers, the adult systems of primary interest are adult mental health and vocational rehabilitation.

We focus on adult, rather than child or both systems for two main reasons. First, child systems have already launched many efforts to better prepare the youth they serve for adult functioning (see Davis et al., 2009). For example, 9 of the 11 sites that have been awarded SAMHSA grants to improve services for transition-age youth have been led by child systems. While child system efforts can be further enhanced, especially around career development, adult systems, particularly adult mental health systems, have been less attuned to the needs of the young adults with psychiatric disabilities in their systems (GAO report). Thus, this and the other papers focus on adult interventions and systems in an effort to stimulate discussion and movement on the adult system's side of young adulthood. Second, young adults are predominantly served in adult systems. Most young people "age out" of child systems upon their 18th and rarely later than their 21st birthday. For example, for 69% of state child mental health systems, the upper age limit is 18 years, while in 24% of states a child can continue to receive child mental health services until their 21st birthday (Davis & Koroloff, 2007). Foster care services can be extended to age 21, but many states do not do this, and

others do this only while individuals pursue educational goals. Thus, within the young adult age group, only 18-20 year-olds can be served in child systems. Only adult systems can serve the entire young adult age range (i.e. ages 18-30) and they are the only systems serving young people over age 20.

II YOUNG ADULTS WITH PSYCHIATRIC DISABILITIES IN ADULT SYSTEMS

Young adults with psychiatric disabilities in adult systems may enter these systems after having been served as children with emotional, behavioral, or mental health problems by the child mental health and/or special education systems. Individuals entering from these systems typically do so at ages 18 or 21. Young adults who were served in child mental health or special education services face unique issues caused by the typically abrupt move from the child to the adult system and the manifold differences in treatment philosophies and practices between child and adult systems (Davis, 2003). Some of the youngest adults in adult systems may still be involved in children's systems, though not as a result of their psychiatric disability. Young adults in most states may remain in the child welfare system until they are 21 if they are pursing education, working 80 hours or more per month, engaged in job training or have a medical condition that interferes with work or education.

Young people entering adult systems without prior involvement in child mental health or special education services may have first experienced mental illness after age 18, sometimes referred to as first episode psychosis. Others may not have been recognized as needing services or qualifying for available services previously. However, the majority of young adults with a psychiatric diagnosis by age 25 had a psychiatric diagnosis prior to age 18 (Kim-Cohen, et al., 2003). So, while some young adults in adult systems have only just recently begun to live with the consequences of mental illness, the formative years of the majority have been impacted by their mental health condition.

The need for developmentally-appropriate or age-tailored services has emerged from research that delineates the developmental stages of young adulthood and the impact of societal and environmental changes on the achievement of developmental markers (Settersten Jr., Furstenberg, & Rumbauth, 2005; Arnett, 2000). This understanding has led to mental health programs and interventions for transition age youth and young adults that are based in these developmental processes. For example, H. Clark and colleagues have published extensively on the Transition to Independence (TIP) model of intervention which is empirically supported and grounded in activities and principles that are developmentally appropriate for young adults (Clark, Deschenes, & Jones, 2000). Please see the companion Framework paper for additional details.

There is an additional set of service issues faced by young adults with psychiatric disabilities who received child system services because of their disability but do not meet eligibility or target population definitions for adult systems. This is a significant issue for many young adults, their families, and child system providers (see Davis, 2003; Davis & Koroloff, 2007; Davis, Green & Hoffman, 2009). Denial of access to adult mental health services to this population stems from differences in the definitions of serious mental health conditions for children and adults (Davis & Koroloff, 2007). *However, the focus of this paper is on system and policy issues that facilitate or impede provision of age-appropriate and appealing services to support the education and career goals of young adults with psychiatric disabilities that adult systems currently serve.* The thorny issue of access to adult systems for young adults who are transitioning out of the child mental health services but may not meet eligibility criteria for adult mental health services, *though of great importance*, is beyond the focus of this paper. It is our belief that stimulating improved educational and career supports for young adults with psychiatric disabilities in adult systems will eventually benefit all young adults with psychiatric disabilities who need those supports.

III UNDER-REPRESENTATION OF YOUNG ADULTS WITH PSYCHIATRIC DISABILITIES IN ADULT SYSTEMS

Young adults are generally under-represented in adult mental health systems yet an understanding of the prevalence of psychiatric disabilities among young adults ages 18-26 is beginning to emerge. The 2010-2011 National Survey on Drug Use and Health (NSDUH) estimates that 7.69% of young adults ages 18-25 have experienced a serious mental illness and that 30% of young adults have experienced any mental illness in the past year. These data also indicate that 6.74% of young adults had serious thoughts of suicide in the past year and 8.29% had at least one major depressive episode (NSDUH Model-Based Estimates, 2013). The GAO reported similar data from 2006. About 6.5% of non-institutionalized young adults have a serious mental illness and another 25% had a moderate or mild mental illness during the year. (GAO Report, 2008). One of the most precise prospective studies of the prevalence of psychiatric disorders, The Great Smokey Mountain Study, estimates that at any point in time, 13% of young adult's ages 18-26 are experiencing a psychiatric disorder (Copeland et al., 2011).

Epidemiological studies indicate that rates of mental illness are constant from young to mature adulthood (Copeland, 2013; Kim-Cohen et al., 2003). Although precise estimates of the number of young adults receiving services in the adult mental health system are rare, one study of the entire cohort of a state's adult mental health system reported that 6.7% of the service population was 18-25 years old while 21.3 % of the general adult population was in that age range (Fisher et al. 2011). The small number of young adults who are served as

adult mental health system clients likely reflects a combination of the lack of age-appropriate services that are appealing to young adults, stigma surrounding mental health services, and difficulty in accessing adult services. One of the consequences of under-representation in adult systems is that young adults are a minority population, and as such, it is easy for their unique needs to be overlooked.

IV. SYSTEM AND POLICY ISSUES THAT IMPEDE THE AVAILABILITY OF DEVELOPMENTALLY APPROPRIATE AND APPEALING EDUCATIONAL/ VOCATIONAL SERVICES FOR YOUNG ADULTS IN ADULT SYSTEMS.

a. Availability of Services

A survey of each state's adult mental health system (Davis, Geller & Hunt, 2006) found that only 49% of the adult mental health services in each state offered any service that had been tailored for young adults, only 10% offered age-appropriate vocational supports, and none offered age-appropriate educational supports. The GAO Report (2008) noted only three states (CT, MA, MD) that had made statewide efforts to improve services for young adults with psychiatric disabilities. Thus, it is clear that the major system that provides services for adults with psychiatric disabilities offers little in the way of age-appropriate services to support the critical tasks of educational completion and career establishment. Rather, there was a common theme that adult mental health system administrators expressed: we don't offer anything specifically FOR young adults, but young adults can access any of the services we offer (Davis & Hunt, 2005).

Vocational Rehabilitation agencies (VR) are also exploring ways to serve young adults with mental health challenges. Some VR services focus on adults with mental health challenges and some offer transition services. Few seem to target the specific needs of young adults with psychiatric disabilities (Marrone & Taylor, 2013). We are aware of one statewide effort by a state vocational rehabilitation agency to specifically target young adults with psychiatric disabilities. Vermont has attempted statewide implementation of the Jump on Board for Success (JOBS) program for young adults up to age 21 with emotional disturbances. In general, we have not identified any national studies of state vocational rehabilitation systems that assessed the availability of services that are age-tailored for young adults with psychiatric disabilities or for other disabilities.

While all state VR agencies provide some transition support services, as mandated by the Individuals with Disabilities Education Act (IDEA), there are wide disparities in the intensity, quality, and efficacy of various VR agencies' services to transition-aged youth. Moreover, the rationale for some recent federal programs that focus on this population is in part because of strong indicators that there is a shortage of effective services and approaches for them. A

recent report concluded that the U.S. has few national programs that target the employment needs of youth and young adults with disabilities. According to these authors

> "Vocational rehabilitation agencies are tasked with providing vocational services to help secondary school youth in the transition to work, but often do not begin providing services until after high school completion. Although some agencies have counselors who specialize in serving youth, many do not, though the vocational needs of transitioning youth with disabilities may be very different than those of experienced workers who seek vocational assistance because of a late-onset disability." (Moreno et al., 2013, pg 2).

It is important to note that the majority of adolescents with psychiatric disabilities do not receive special education services (Forness et al., 2012), so "transition" programs that primarily serve special education students will fail to serve many young adults with psychiatric disabilities.

Two federally funded demonstration programs were developed to help young people with disabilities better transition into successful work lives. The Rehabilitation Services Administration program's Special Demonstration Projects and the Social Security Administration program's Youth Transition Demonstration, each funded six sites that targeted transition-age youth and young adults somewhere in the age ranges of 14 and 25 years. The SSA evaluation included a random assignment design and concluded that both intervention and comparison groups showed improved outcomes (Fraker, 2013). Hopefully, lessons learned from these demonstration programs will help increase the availability of these services.

b. Barriers to Availability of Age-Appropriate Services

In a national study, when adult mental health system administrators were asked to describe factors that interfered with offering better or targeted supports for young adults, the most common issue described was that there was insufficient funding to do anything special for this small group (63%), or that there wasn't specific funding available targeted at this group (39%). The next most common barrier was the lack of leadership on the issue (56%), and that the issue was just not a priority in their system (51%). Interestingly, 44% of administrators indicated that they did not focus on this population because there were no "squeaky wheels", i.e. no individuals or groups external to the adult mental health system were clamoring for change (Davis & Hunt, 2005). Each of these factors suggest that barriers to improving services for young adults in adult mental health systems stems from a lack of leadership in a system in which there are many demands and too few resources. In essence,

the issue wasn't a priority because the "actors" that could make it a priority had not done so (i.e. targeted funding, leadership, squeaky wheels).

The authors of this paper recently conducted an informal focus group with state level administrators from six adult mental health agencies in states that had received grant funding from the Substance Abuse and Mental Health Services Administration to improve services for "emerging adults" with serious mental health conditions. When asked what the barriers in their states were to providing vocational and educational supports that were tailored to the needs of young adults they described similar barriers to those described above. Several suggested that it was generally difficult for providers to find funding for vocational support programs because it was difficult to obtain Medicaid reimbursement for it in their states, so there were few vocational supports for adults with psychiatric disabilities of any age. Others indicated that this age group simply wasn't a priority in their state. One individual noted that one stimulus for system change, consumer advocacy organizations, simply didn't have young adults in the organization and, consequently, issues that are important to the younger population are not advocated for by these groups. More youthful advocacy organizations, such as Youth Move, had influence with the child, but not the adult mental health system. One participant was of the opinion that general adult mental health services were available and accessible to any young adult who could qualify and that age-tailoring was not needed. Several others simply noted that the issue hadn't gotten any traction, and one individual was sufficiently frustrated to suggest that her state probably would do better by creating a separate system for "transition age youth" that served any 16-25 year-olds with a serious mental health condition. One state (Maryland) had embraced the need to address the unique needs of young adults in their adult system, and had taken numerous steps to foster innovative approaches to do so.

The learnings from this group discussion seem to corroborate the findings of the national study of state adult mental health administrators (Davis & Hunt, 2005). Thus, it seems the need for local, state, or federal leadership to prioritize age-appropriate educational and vocational supports for young adults in adult systems is still valid. Clearly new funding for these types of services would also be welcomed.

A recent analysis of federal programs that impact educational and vocational supports for youth and young adults with psychiatric disabilities (Koyanagi & Alfano, 2013) lists a "myriad" (pg. 16) of federal programs that can provide funds towards this end. However, as these authors point out, these programs may fund only a very limited set of services, may be targeted at a broad population providing services that are not well tailored for young people with psychiatric disabilities, or may have age limits (e.g. up to age 21) and other eligibility requirements which in turn may produce program funding that cannot be used for all clients

in this age group. Understanding the array of available funds, who can access them and what they support, requires time and energy. In the absence of strong motivation to find federal programs that can support the needed educational and vocational supports for young adults with psychiatric disabilities, it is easy for providers to choose not to. Vocational supports for young adults with psychiatric disabilities need to be sustained over a long period of time (see companion paper on career development supports), and allow for more extended vocational training than is currently available in many states. Current practices do not allow young adults the time needed to learn and consolidate career-related skills.

An additional system challenge to providing age-appropriate educational and vocational supports is that other services that young adult's need, such as clinical treatment or housing support, may also not be appealing or age-appropriate. When other needed supports don't effectively engage young adults they may not make progress on their educational or vocational goals. For example, if a young adult has a therapist who has not been trained to work with young people, the young adult may drop out of therapy and lose the support that could address symptoms impeding employment. Young adults drop out of mental health treatment faster than any other adult age group (Edlund et al., 2002). Thus, a corollary to the need to offer age-tailored educational and vocational supports is to offer all supports in an age-appropriate manner.

Finally, a significant challenge to providing age-appropriate educational and vocational supports for young adults with psychiatric disabilities stems from the disconnect between child and adult systems (see Davis, 2003; Davis et al., 2005, Koroloff et al., 2009). The youngest adults will still be involved with child welfare and child mental health systems. Adult providers need to be familiar with these systems and the services available (e.g. Chaffee Foster Care Independent Living Supports for young adults voluntarily receiving services while completing their educational goals, including college). Young adults entering the adult mental health system from the child mental health system who experience services changes that are less abrupt might be less likely to reject adult services (even when they need them). Because this is a small portion of the adult mental health population, it is easy for case managers and providers to fail to become familiar with their counterparts in the child system and work with them to make the young adult's transition to the adult system more coordinated and successful. Policies that would help young adults achieve a more successful transition include; providing time for a longer period of transition, allowing for both the child and adult case manager to be involved while the young adult becomes comfortable with the new (adult) case manager, requiring a young adult-guided transition plan that specifies which services are needed and appropriate in the adult system to help them achieve their goals.

V. SYSTEM FACILITATORS OF THE AVAILABILITY OF AGE–APPROPRIATE VOCATIONAL OR EDUCATIONAL SUPPORT PROGRAMMING

Over the past 8 years, there have been a number of efforts to address the needs of "youth in transition to adulthood" with serious mental health disorders and to increase the variety of age-appropriate services available to that population. Most of these efforts have focused on youth receiving services in the children's system. However, progress made in these efforts to facilitate access to adult services and increase leadership for improving services for young adults provide examples of system facilitators of age-appropriate vocational or educational supports in adult systems.

a. Partnership for Youth Transition (PYT)--SAMHSA
One of the early attempts to increase the number and types of services available for young adults was the Partnership for Youth Transition (grant initiative from SAMHSA.) This initiative focused on the development of program models but also required grantees to work with others in the community who were serving young adults. Research findings are available from one site in which social network analysis was conducted during year 1 and year 4 of the grant. The researchers found that the child system and adult system were connecting with each other more directly and more frequently by the end of the grant period (Koroloff, Davis, Johnsen, Starett, 2009). These changes were strongly associated with the leadership of the PYT project.

b. Emerging Adult Initiative (EAI) --SAMHSA
In 2009, SAMHSA announced a second initiative focused on improving mental health services and supports for young adults with psychiatric disabilities. The Emerging Adults Initiative (EAI), formerly The Healthy Transitions Initiative, contains specific language about increasing collaboration between child and adult mental health and grantees are expected to document steps they have taken toward this goal as well as steps to involve youth and young adult voice in planning and policy change. Grants were awarded to states (rather than communities) and involvement of both child and adult mental health entities at the state level is an expectation. Six of the grants were awarded to child mental health programs at the state level and one to an adult mental health division. Although still in process, this initiative holds promise for increasing the collaboration between child and adult mental health and revealing some of the strategies and interventions that have been successful.

c. Young Adult Services Division—Connecticut
Connecticut has a consolidated children's agency, the Department of Child and Families (DCF), that includes child mental health and a separate Department of Mental Health and Addiction Services which houses adult mental health services. This state has established a

Young Adult Services Division to help young adults transition successfully from DCF to adult mental health system (Davis, 2007). The process by which young adult transition from DCF to Young Adult Services is guided by specific policy that describes when the transition is initiated, what the procedures are, and which agency is responsible and pays for each aspect of the transition process. In order to receive Young Adult Services, an individual must be between the ages of 18 and 25 with a history of DCF involvement and have a history of major mental health problems. Services are available at community mental health agencies throughout Connecticut and include clinical services, case management, residential assistance and educational/employment services.

d. Young adult services—Maryland

The state of Maryland is taking steps to better serve young adults in the adult mental health system. Planning began in 1996 with a task force composed primarily of advocates for individuals with developmental disabilities. The state plan that emerged called for the development of a comprehensive strategy to meet the needs of transition age youth. In 1999 the Maryland Department of Health and Mental Hygiene, Mental Hygiene Administration began funding a range of locally-determined, age-specific programs for young adults based on a competitive selection of proposals from local mental health authorities. Conceptualized as an adult mental health system initiative, the overarching service goal was to provide young adults, who might have otherwise been ineligible for adult services, access to discrete, specially designed services and interventions that uniquely addressed their developmental needs. By extending the length of service involvement beyond the age of majority and by focusing more specifically on key transition domains, the intent was to serve as a bridge to adulthood, not necessarily to long-term adult mental health services, and as a result, wherever possible prevent the emergence of a serious mental health disorder. The services initially varied in scope, focus, service modality, and age range. By remaining flexible and responsive to the needs of local jurisdictions, a set of services were created for young adults that promoted innovations and allowed for testing of models and approaches which have been refined over time. Services are now being aligned around a single service delivery framework consistent with and informed by the Transition to Independence Process (TIP) (Clark & Unruh, 2009).

In 2009, two federally-funded initiatives converged in one local jurisdiction. The Maryland Seamless Transition Collaborative (MSTC), a five year Rehabilitation Services Administration (RSA)-funded model demonstration grant focused on seamless school to work transition model of practice. The Emerging Adult Initiative (EAI), referenced previously, supported local implementation with a link to state-level program and policy development in order to address broader system and financing issues, and to promote dissemination and replication statewide. These grants served as catalysts to the adoption of eligibility and medical

necessity criteria that span the child- and adult- mental health systems in order to provide continuous, uninterrupted access to age appropriate services and supports within designated programs for transition aged youth. In addition, building on the successful implementation of Evidence-Based Practice Supported Employment for adults with serious mental illness (Drake, Becker, & Bond, 2012), supported employment is now available to youth at age 16 prior to exit from high school.

Evidence of the effectiveness of Maryland's approach is found in the fact that 21% of the adults served in the Public Mental Health System were between ages 18 and 25, a percent very close to the percent of young adults in the general population. Further data from 2011 shows that 70% of youth and young adults, aged 16-25, enrolled in transition programs were engaged in competitive employment as compared with 46% of youth and young adults, age 16-25, enrolled in any service within the Public Mental Health System.

e. Adult peer-operated centers—Maryland
In addition to a series of transition programs funded out of the adult mental health system, Maryland has supported adult consumer groups and family advocacy groups to become more inclusive of the needs and preferences of young adults. One of the ways this has been achieved is through a grant from CMS to Moving Forward Maryland and the Family and Consumer Network Technical Assistance Center. The goal of this grant is to provide technical assistance (TA) to adult consumer groups about how to attract and work more effectively with young adult members. Peer-to-peer support is a critical component of services to young adults. Maryland has made an effort to provide young adults with peer-to-peer supports within adult peer support groups that are housed in peer-operated Wellness & Recovery Centers. Adult peer TA centers such as On Our Own of Maryland have begun to partner with family advocacy groups such as Maryland Coalition of Families to provide peer support, advocacy, and forums for young adults. These include: young adult recovery story panels presented to audiences both of providers and young adult peers; efforts to employ young adults in the peer workforce; and retreats for young adults focused on peer support, advocacy and strategic story telling.

f. International Efforts
In a recently published report by Mathematica that analyzed policies in the US and Europe that improve the transition of youth with disabilities to appropriate and gainful employment they identified several programs of interest in Europe (Moreno et al., 2013). Norway, Sweden, and the Netherlands have instituted disability benefit programs specifically for young adults that focus on rehabilitation and reintegration for this population thereby avoiding their long-term receipt of disability benefits. Receipt of benefits is contingent on participating in a vocational program unless the individual is assessed as unable to work (only

13% of the Netherlands benefits recipients), which can emphasize employment or schooling. Implementation of similar policies in the United States would provide funding for young adult specific vocational and educational supports.

VI. SYSTEM AND POLICY FACILITATORS FOR SMOOTHING THE HANDSHAKE BETWEEN CHILD AND ADULT SERVICES

Although the focus of this paper is on the development of age-appropriate education and employment supports for young adults, creating a smooth transition from child to adult services continues to be related to policies directed at the system or program being implemented. Following are two examples of system level policy changes that are intended to ease this transition.

a. Functional assessment-Missouri

Missouri received an Emerging Adult Initiative grant, and is implementing a new functional assessment process so that young adults with mental health disorders have a smooth transition from youth mental health services to adult mental health services. In the past, many young adults did not qualify for services in the adult system that required the individual to have a diagnosis of schizophrenia, bi-polar disorder, or major depression. A new policy was implemented requiring the use of "The Daily Living Activities Scale" (Scott & Presmanes, 2001) in both the youth and adult mental health systems to determine eligibility for services. This change bases eligibility on functioning, not on diagnostic criteria and has allowed more youth to access services in the adult system. It has also resulted in additional policy changes in rules and regulations. For example, some young adults may need a wraparound program, typically found in children's mental health systems, to meet their needs while others may need an Assertive Community Treatment team, typically found in an adult mental health system, to meet their needs. The policy makers are exploring how they can make the services meet the needs of the individuals versus making the individual meet the need of the service system.

b. Extended age for transition to adult services—Oklahoma

Oklahoma has changed the age at which a young person is eligible for services in the adult mental health system. Young people are now allowed to receive services in the youth system until the age of 21. Previously, young adults were not able to receive services in the youth system after the age of 18. Increasing the age that the individual may remain in child and youth mental health services delays the prospect of discontinuity of services to a time when the young person may have more skills to handle the challenges of changing service systems. Other states report they are exploring the possibility of moving the upper age for services in the child mental health system to the age of 26.

VII. OTHER SYSTEM AND POLICY INTERVENTIONS

Evidence is accumulating that suggests that a clear and positive requirement from system leaders and funders is an effective way to increase contact and collaboration between child providers and adult providers. Data to support this approach has been collected through social network analysis in one state (Koroloff, Davis & Sabella, 2013). A similar approach may hold true for increasing the range of age-appropriate services for young adults.

Involving young adults in articulating the challenges they face and the services and supports they prefer is an effective way to influence decision making in both child and adult systems. Encouraging young adults to plan and participate in advocacy forums, assume authentic roles in governing and planning bodies, participate in evaluation, certification and quality assurance reviews are some of the ways to influence system change.

VIII. FUTURE RESEARCH NEEDS

As the state of the science companion papers to this one highlight, research on age-appropriate career development and educational supports is growing but extensive future research is needed to establish an array of effective interventions for the diversity of young adults with psychiatric disabilities. This paper has begun to examine the need for focused and articulate voices to stimulate change in adult systems so that more age-appropriate services are provided to the young adults in adult systems. The leadership for this change could come from a variety of sources such as the current adult mental health or VR systems, children's programs focused on transition of youth who are aging out, family members who want to help their own youth make a successful transition, and young adult advocates who are organizing their own consumer networks or joining the networks already established by older adults. System research is needed to identify how that leadership is developed, and identify approaches that leader's use that effectively increases the availability of these services to young adults with psychiatric disabilities. Further, the broader implications of providing age-appropriate services to young adults are an area that has received little attention. For example, providing strong educational and career development supports may reduce the costs of expensive mental health services (e.g. hospitalization). Generally, little is known about what effect this change might have on either the overall outcomes in the adult mental health system or on the amount of financial support available for services.

a. <u>**Research Regarding the Impact of Offering These Services;**</u>
   - Does offering age-appropriate educational and career development supports increase sustained access to services for this population of young adults? Does provision of these types of services reduce service needs at later ages?

- What is the impact of providing age-appropriate services in terms of systems costs overall?

b. **Research Regarding the Implementation of Offering These Services**
- What are the current systemic barriers and facilitators to offering age-appropriate educational and career development supports for young adults? What will it take to overcome these barriers?
- How do those barriers vary by system organization factors (e.g. local vs. state-level funding decisions), by funding mechanisms (e.g. implementation of ACA voluntary portions vs. not, use of Medicaid rehabilitation waivers), and other such system factors?
- Does increased contact and collaboration between child and adult mental health services result in greater implementation of effective educational and career development services for young adults?

c. **Research Regarding the Impact of Involving Young Adults and their Families in System Change**
- Do national, state, and local level policies which reflect the input of young adults, and their families result in greater system change and more positive outcomes than those that do not?
- How is the process of policy change and implementation affected when young adults and their families are meaningfully involved?
- To what extent do policies that are designed to support young persons in both system planning and in planning their own services result in better outcomes for the young adult?

IX. CONCLUSIONS

1. Young adults are a minority group within adult service systems
2. Age-appropriate educational and career development services for young adults are rare within adult systems
3. Without a strong and deliberate focus on age-appropriate services for young adults, funding is not set aside or identified to fund these services
4. Efforts by state and federal leaders, as well as consumer advocates, has led to progress in several states, with accompanying policies, funding mechanisms, and practice guidelines developed
5. Research is needed to identify the impact of offering age-appropriate services on outcomes for young adults, as well as the impact on system processes that facilitate and impede service availability.

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SUMMARY OF RESPONSES TO PAPER: "SYSTEM AND POLICY CONSIDERATIONS FOR STRONG CAREER LAUNCHES IN YOUNG ADULTS WITH PSYCHIATRIC DISABILITIES"

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9/03/13

This paper, "System and Policy Considerations for Strong Career Launches in Young Adults with Psychiatric Disabilities", examines system and policy issues in adult systems that support or impede the completion of educational and training goals and therefore focuses mainly on the adult mental health and vocational rehabilitation systems. The paper defines the target population, its challenges, and offers the provocative view that young adults are underrepresented in adult systems, are therefore considered a minority group in the system, so their unique needs tend to be overlooked. The paper describes several initiatives designed to help integrate the child and adult systems, lists research that is needed, and finally concludes with a list of its six major conclusions.

The responding panel felt that while many core issues and important features of system and policy issues were addressed, several additions or revisions would strengthen the discussion:

1. Almost all responders had suggestions about the definition of the target population and its related implications for systems.

Suggestion : Defining "mental illness" would bring more clarity
The paper states that its focus is "young adults [ages 18 to 30] with mental illness." One responder suggested that the paper clarify the target group by identifying the diagnoses included in the analysis. The point was made that most jurisdictions shape their systems around some specific diagnoses. The lack of clarity in the definition was further underscored by another responder's comment that it appeared that youth with co-occurring disorders were not included in the paper. It was difficult to know if they were or were not included, because it may simply be that the population of young adults with co-occurring disorders have just been lumped under the more general definitions. The paper's authors themselves allude to the importance of diagnostic groups, later in the paper, when they discuss the fact that the focus of the paper does not include those young adults who "received services as children but were not eligible for the adult system' (page 3). A responder noted, however, that the statistics used to document the potentially low rate of involvement of young adults in the mental health system [page 4] does not make it clear whether or not all of the young people identified in the studies cited would, in fact, be eligible for adult mental health services, because generic statements such as "psychiatric disorders," "serious mental illness," etc., are used to describe the group.

Suggestion: Describing the breakdown of youth entering the adult system based on ethnicity and gender, would clarify the later conclusions.
A responder commented that the lack of discussion about specialized populations, or those populations who are over-represented due to health, makes it difficult to assess the extent to which the conclusions on page 16 are universally true.

<u>Suggestion: Describing more fully the rationale for the age range used, could serve to clarify the paper in general as well as the reasons that this group (versus other groups), is seen to require a developmental focus.</u>

Although the stated focus is on "young adults served within the mental health system," the underlying rationale for the paper relates to the issue of transition from one service entity to another and the ability of the latter to meet young individuals' needs. The word "transition" is also used to refer to changes in young people's lives as they move from societal roles of children and adolescents to assuming responsibilities of adults. As one responder pointed out, this latter use of the word transition is not primary to the definition of the population, nor to the thrust of efforts to improve services to these individuals. While most responders had little problem with the lower age limit of 18 as it conventionally defines societal boundaries for adult choices, there were several suggestions about the implications of the chosen upper limit of 30. It may be that the definition of the age range was a given limit that the authors had to work within; however several reviewers made the point that age limit seemed to be an arbitrary one:

First, most of the literature cited in the paper supported the upper age limit as around 25. Given that the purpose of defining the age range is presumably to describe or define what transition services would be developmentally appropriate, several responders felt that the upper age of 30 was relatively old for someone to be defined as still in transition from one system to another, or from one role to another. If 30 must be used, presenting a rationale to support it would make the paper stronger.

Second, a group of responders felt that the reasoning behind addressing the issue of age-appropriate services linked to a chronologically defined target group, could have been more fully addressed. For example, these responders asked whether the question of age-appropriate, tailored services is a need unique to a specific adult population, or a need that appears over the course of the lifespan? While the paper itself cited research to support the notion that there are clear developmental stages of young adulthood [page 5], supporting the idea of the "age–appropriateness" of services unique to young adults, may well require clear research-based descriptions of how young adults differ from older adults in terms of their mental health needs and the types of services that can help young adults more successfully than older adults.

The stated definition and belief that developmental services are appropriate for transition-aged youth but not others on either side of the age limit, creates difficulties in a cross-cultural context. Age in many cultures is an arbitrary perspective rather than a chronologically-defined fact. Cultures vary in terms of how and when they determine that

someone is an "adult", what constitutes "coming of age", and how those culturally specific supports can be part of transition planning. In tribal communities, for example, expectations are related to stages of life rather than to specific age groups. Human development in any culture does not stop at an arbitrary age and therefore, rather than identifying a special group that needs a developmental focus, several responders felt that all treatment and rehabilitative services should be tailored to particular milestones, aspirations, and expectations rather than defined by chronological age.

Establishing this as a universal principle of effective services could help incorporate cross-cultural viewpoints. It would also take the question out of the realm of transitioning from one age-defined system to another and change it to a question of a common need for everyone receiving services that is not being adequately addressed at this time. Other responders also suggested broadening the focus of the effort either by including more related to the involvement of families, or by focusing on improving services along the developmental lifespan with implications for removing the distinction between children and adults at an arbitrary age.

<u>Suggestion: Adding systems beyond mental health and vocational rehabilitation, such as the juvenile justice system and the child welfare system, would strengthen the paper and its conclusions.</u>

The paper states that the analysis includes adult systems, primarily mental health and vocational rehabilitation systems, because of the focus on education and careers. Several responders pointed out that the focus on mental health and vocational rehabilitation systems could be expanded because other systems also deal with education and employment issues for youth. For example, the juvenile justice system is intensely involved in transition issues and does not appear to have been reviewed. Some states allow youth to remain in the juvenile justice system past age 18, where they may or may not receive mental health services as young adults.

Similarly, young adults are involved in the child welfare system because the age of majority in foster care has been extended to age 21. In some states, youth can remain in care if they are pursuing education, working 80 hours or more per month, engaged in job training or have a "medical condition" that serves as an obstacle to work and/or education.

While the responders understood that the focus of this paper was defined as only including the mental health and vocational rehabilitation systems, it was felt that the paper could be enriched by acknowledging more of the groups served by other systems equally focused on employment and education, and who were not included. Alternatively, the suggestion was

made to explain more fully why they were not included.

2. Several responders suggest ways to strengthen the paper by addressing the overall framework and/or assumptions upon which the paper's conclusions were based.

Suggestion: Tying the paper to "Pathways for Youth Draft Strategic Plan" working group goals would strengthen the paper's impact.

One responder pointed out that the ideas relative to collaboration, evidence-based practice, and partnership are consistent with those of this National Working Group. However, the responder felt that the paper could be strengthened by specifically pointing out how these ideas support or do not support the National Working Group's plan.

Suggestion: Discussing the assumptions upon which the paper rests would strengthen the paper.

Suggestions for improving the paper by addressing assumptions were listed or implied by several responders.

First, the assumption that there is a unified adult mental health system into which 18 year-olds can enter, could be further discussed. Beyond state mental health authorities, privately funded mental health care, for example, also serves a substantial number of young adults and should be included in discussions about this population.

Second, the assumption that there is a unified children's mental health system from which 18 year-olds exit, could be further discussed. A substantial number of young adults with mental health problems never were in the children's system, either because they did not have a diagnosed mental disorder as children, or because their care was privately funded. For example, individuals with first-episode psychosis typically do not have a history of treatment from youth mental health services. Discussions about young adults should include those who were never in the children's system.

Third, the assumption that services, such as employment and education supports offered in the adult mental health system, are not appropriate for young adults, could be further discussed. Several responders suggested that the paper include a definition, description, or research to clarify what is meant by "age-appropriate" services that are needed. There appears to be an indication in the paper that services not *limited* to people age 18 to 30, are not per se age appropriate. One responder noted that there is a difference between "age-

specific" services and "age-appropriate" services, commenting that the EIDP study showed better employment outcomes for young adults than for adults, even though the program was not specifically designed for them.

Lessons learned from the development of other programs' attempts to create sensitivity to varying perspectives (e.g. cultural sensitivity) should be applied. Those efforts found that central changes to the delivery of a service may not be required to increase responsiveness to a particular perspective, but rather that changes in aspects such as a service's engagement processes or the creation of different environments perceived to be more welcoming by a specific group, were what was needed. Making a service "age appropriate" may involve similar changes.

Some responders disagreed with this perspective however, arguing that there are cultural differences that do require greater changes—such as the kinds of goals considered important; the concept of a "goal" itself; expectations around family; the involvement of extended kinship networks in services or change processes; the concepts of time and the value of structured processes vs. non-structured processes, for example. In those cultures, the notion of "age appropriate" may in fact vary more greatly from "standard" service delivery.

While some research has been done on this topic, more research testing the elements that make a service seem appropriate for a particular group is needed.

Fourth, the assumption that adults over 30 are receiving better, more age-appropriate services than young adults age 18 to 30, could be further discussed. Employment and education support in the adult mental health system is very limited and not widely available for everyone. For example, the VR funding system does not allow for the provision of long-term employment support despite the fact that long-term supports are needed. Research shows that people with mental health problems referred to VR rarely receive the needed services, whether they are youth or older.

Fifth, several responders felt that the assumption that young adults aging out of the children's system would be better off if they could obtain those services, could be further discussed. Many adults who have experienced the adult mental health system have ultimately decided to opt out of it because they found that it impeded rather than aided their recovery. While the paper notes that the number of young people in the adult mental health system is lower than would be expected, one responder observed that the goal of increasing the percentage of young people receiving services from adult mental health providers is not an easy goal for which to rally public support. Although it may be true that many young individuals

will continue to need adult mental health services over the long term, it is also hoped that many will transition away from requiring mental health services altogether by successfully achieving adult roles they prefer. The value of transferring to the adult system is an open question ripe for research.

Sixth, the assumption that current services provided in the child mental-health system are in fact age-appropriate for young adults age 18 to 30 should be examined. Several examples were given in the paper of efforts to extend child mental-health services to age 21 or later. A responder noted that the developmental needs of a young adult in terms of living independently [e.g., maintaining a household, finding a job and transportation, dealing with benefits] are likely to be quite different from those of children. Another responder pointed out that some 21 year-olds may in fact be dealing with developmental tasks more often associated with much younger teens, again making the point that tying service designs to an age range may be less effective than tying it to specific developmental tasks.

<u>Suggestion: Thinking about changing the paradigm for services rather than worrying about how to integrate them, would improve the paper.</u>

Two suggestions were made to change how services are delivered rather than focusing on improving integration of current systems.

The first such suggestion was implied by some responders and stated by one—i.e. developing a MH system, organized around specific developmental tasks along the lifespan, might help to break down silos of care, as well as allow for a more flexible approach to delivering services independent of specific and fairly arbitrary age boundaries. In the adult spectrum, such an approach would help tailor services more at the "late life" end of the spectrum, so that not all those over 65 are expected to use or need the same kinds of MH services. In the youth spectrum, it could help youth struggling predominantly with issues of career and career identity receive tailored attractive services different from those who, at the same age, may still be focused predominantly on tasks related to separation from family and peer belonging. While this concept may well have its own inherent major challenges, research could be done to investigate various models of developmental tailoring and its system implications.

The second suggestion is closely tied to the issues already discussed in terms of how the population focus of the paper is defined. The underlying assumption that the best framework in which to address the needs of this population is to create a primary focus on "transition age youth", whether explicitly or implicitly defined as such, could be further explored.

One responder suggested three problems inherent in defining the target population as transition-age youth or young adults with mental health needs:

The first problem is that defining the population in terms of systems tends to invite system-level solutions rather than individual person-level solutions. It is possible to change systems without affecting individual problems and needs, especially if efforts are aimed primarily at the system itself. There is a need to define the primary target population in more individual and less systemic terms in order to maximize the chances that solutions will truly address these needs.

The second problem in defining the population in terms of transition from systems and system involvement, is that it greatly limits the number and range of stakeholders who may be invested in improving services and therefore their ability to advocate with policymakers. Individuals and their families who have received youth mental health services often have multiple life challenges that place practical limitations on their ability to serve as the primary advocates for better treatment. In the absence of strong public support to improve the effectiveness of the mental health system for a specific subgroup, the mental health system itself may be limited in its ability to do this job alone.

The third problem is that, while a broad goal is to improve the functioning of young adults with mental health problems with regard to education, career, and vocational outcomes, it is difficult to specify what the critical indicators for milestones are for this population, and hence, difficult to create a vision for people as to what a more effective system might look like and what it might achieve.

The responder suggests having an alternative focus, which is to establish the focus as improving mental health services for young individuals with a primary focus on the age range when psychiatric disorders are most likely to begin, i.e., adolescence and early adulthood. It is easier to articulate the goals of more effective mental health services in an unambiguous fashion with this change in primary focus. Mental health problems contribute to drop off from high school and college, limiting individual's career opportunities and vocational functioning, so improved functioning in those areas is a clear goal. Failure to effectively identify and treat youth mental illnesses that emerge in late adolescence or early adulthood, especially schizophrenia, contributes to significant disability over a lifetime and to high treatment costs. There are other less common but nevertheless devastating consequences of untreated severe mental illnesses in young people, including suicide and violence preventable by more effective treatment. By expanding the definition of the target population, a broader range of stakeholders could be marshaled to support significant attention to the problem and sustained funding to address it more effectively. The potential stakeholders include: all young

individuals with mental health problems and their families, whether in treatment systems or not, as well as teachers, criminal justice representatives, mental health policymakers, and others concerned with the welfare of young individuals.

3. Several responders suggested ways to strengthen the paper by identifying additional topics related to the employment future of young adults to explore.

Suggestions for topics to add included:
- Disincentives to work inherent in the receipt of Social Security (SS) benefits ; potential consequences of enrollment of young adults in SS Disability benefit programs on lifetime income and psychological health due to unemployment
- Implications of the Affordable Care Act (ACA) for young adults re: access to mental health care and employment supports i.e. Implications of increased access to mental health care and employment supports for young adults as a result of the ACA (e.g. fewer young people with serious mental illnesses will need to enroll in SSA benefit programs to obtain needed care and be encouraged instead to pursue career goals
- Potential role of the Department of Labor workforce investment system and other educational and training programs
- Systemic means for improving college opportunities;
- Acknowledging that beyond peer support, consumer-operated service programs provide employment supports (e.g. 39% of consumer operated in national survey reported helping people obtain jobs
- The role of disability-wide organizations as resources for young adults
- The role of private insurance in providing mental health care for young adults

Three additional comments were offered to strengthen the paper.

First, the adult mental health policy and financing systems strongly value rigorous empirical study of consumer outcomes. Unlike some other projects cited in the paper, the SSA youth transition demonstration project in Maryland did in fact conduct a rigorous study of employment outcomes. An example of why rigorous research is so important to improving the system is the fact that, while employment outcomes of the young people in the demonstration project were good, the findings also suggested that these outcomes did not differ significantly from those of the young people in the control group. Translating the implications of this study into policy development for adult mental health or VR systems requires both that rigorous research be done and that the nuances of the findings be examined.

Second, the adult mental health system has a variety of data regarding employment models.

States, communities and organizations, partnering with vocational components of the adult mental health system should familiarize themselves with the research literature and ensure that the programs with whom they are partnering have the best record of achieving desired outcomes (e.g. long term independent employment in the mainstream labor market). While limitations exist in all models, the most researched one at present is supported employment or the IPS model. Greater efforts to engage young adults in evidence-based supported employment models should be discussed.

Third, a suggestion was that the paper incorporate examples of international promising approaches from the OECD report (Moreno et. al., 2013) that might be useful in the U.S.

Lastly, suggestions were made to add the following research topics for the future, to the list:

- Rigorous research on the TIP model
- Research exploring the longer-term outcomes of young adults who do and do not gain or opt for access to adult mental-health and/or disability services
- Research exploring the impact of providing age-appropriate services in terms of system costs overall
- Research exploring how to overcome systemic barriers to offering age-appropriate educational and career-development supports for young adults
- Further research identifying the role/s with the responsibility for making changes in system organization and the incentives to motivate them to do so
- Research investigating whether national, state, and local level policies that reflect the input of young adults and their families result in greater system change and more positive outcomes than those that do not

ADDENDUM TO THE POLICY/SYSTEMS CONSIDERATIONS

This summary provides a concise description of the comments made and issues raised during the State of Science Conference. Topics described here come from the audience discussion after the presentation about policy and system change as well as from the break out group discussions and participant balloting. Although the discussion was wide ranging and represented a variety of perspectives, some common themes emerged.

State of the Science conference audience and breakout discussion

The presentation on Policy/Systems Considerations and the related Comment/Response panel provoked some controversy among the general audience. The discussion reflected the general tension between some individuals in the adult mental health service field and proponents of special services for young adults. In the face of little empirical evidence that usual adult services serve young adults particularly poorly, and the research investigating the efficacy or benefits of developmentally tailored interventions is too early to be definitive, combined with high financial stress on most service systems, there is an understandable rationale for providing young adults the same services as mature adults. The initial discussion from the general audience underscored the need for more research determining the efficacy of developmentally tailored approaches, and whether those are more effective that comparable non-developmentally tailored approaches. Another line of discussion suggested that all services (adult and child) need to be made developmentally appropriate across the life span. The general audience also had some discussion about the age range that should be considered as transition age or emerging adulthood. The lower age of 14 years was too low for some participants and the higher age of 30 considered too old, although there were a number of proponents for each end of the range. Generally an age of 16 or 17 was suggested for the lower point of the range (which dips into services from child systems). The higher end of the range most commonly discussed was 25 to 27. This discussion also underscored the need for research to help define at what ages, or with what developmental markers, the rapid developmental changes of young adulthood stabilize such that services for "non-young" adults would be appropriate.

The comments from the small group discussions reflected concern about policies related to opportunities to access and stay in higher education. There was considerable discussion about the need to study the expectations that service providers and families have for young adults with serious mental health challenges. Policies and system rules that reinforce lower expectation as well as the need for training for staff regarding their expectations were offered as examples.

Another strong theme was the need to consider the whole array of service needs, not just the young adult's need for mental health services. The need to test comprehensive interventions, ones that address housing, independent living, relationships as well as education and employment were suggested. Research question that look at the effect of good mental health services on the individual's utilization of other services such employment and education supports were requested by several participants. Policies that reinforce comprehensive services that support all of the young adults needs were singled out for research.

Another theme, which might be expected in a discussion of policy and system research needs, was a call for better outcome measures, more fidelity assessment and randomized clinical trials of young adult specific interventions. Of particular note was the call for rigorous testing of the TIP model which is used in many states and represents an approach that addresses the whole array of service needs.

Balloting results

Conference participants were provided with a ballot that listed 9 research areas that the authors of the research review developed based on that review. Each participants was asked to indicate the three most important from his or her perspective. Two items tied for receiving the most endorsements. Both were in the cluster of research questions related to implementation of age appropriate services. The first topic was, "Measure the current systems barriers and facilitators to offering age-appropriate educational and career development supports for young adults. Identify what it will take to overcome these barriers". The interest in this areas of research suggests that participants accepted the importance of age-appropriate services and need research that will help them understand how best to implement these kinds of services by elaborating on the system barriers and facilitators.

The second highly endorsed research topic was: "Test whether increased contact and collaboration between child and adult mental health services result in greater implementation of effective educational and career development services for young adults." Initial research in this area has been conducted by both the Transitions RTC and Pathways RTC in their respective research agendas. Although the value of increasing contact and collaboration between child and adult mental health systems and the best process for doing that has received some attention, the actual impact of such collaboration on the effectiveness of services has yet to be explored.

A third research topic endorsed by a large group of participants was "Examine whether offering age-appropriate educational and career development supports increase sustained access to services for this population of young adults." Concerns about outreach and engagement of young adults into services have emerged as critical issues over the past few years. Exploring whether providing age-appropriate educational and career development services to young adults makes them more likely to begin and stay with services would help providers understand the engagement dilemma more fully. Even a partial answer to this research question could greatly affect the shape of services for young adults in the future.

Conclusions for future research directions

Discussion of research needs related to policy and system change opens up a broad topic and allows for a wide diversity of ideas and discussion. This is reflected in the range of research topics summarized above from both the group discussions and the balloting. One frequently cited research need is the importance of establishing with some empirical certainty the impact of developmentally appropriate services on retention in services and on the long range functional outcomes for young adults as they move into adulthood. The policy and system issues related to this research need are multiple and range from the impact of certain fiscal policies that maintain service system silos to the impact of eligibility criteria, such as specific required diagnoses, on access. Another critical need is for continued theory development to help understand more exactly that the unique service needs of young adults are as opposed to older adults. Examples such as the importance of relationship to peers, strain toward independence from family, experience managing mental health symptoms and the side effects of psychotropic drugs and inclination toward risky behaviors need to be dissected in terms of focus in an age-appropriate intervention. Variations in these behaviors and capacities as a function of different experiences, cultural background, and other factors that are prevalent among subgroups of young adults with serious mental health conditions, that could contribute to variability would also benefit from theoretical attention. A future research agenda must include continued study of the critical elements that constitute developmentally appropriate services and the short term and long term outcomes of receiving such services.

POLICY TOTALS TALLY

<u>**Systems & Policy Questions:**</u>

	Orange Mark Salzer	Blue Chuck Lidz	Red Krista Kutash	Yellow & Green Kathryn Sabella	Total
1. Research regarding the impact of offering these services:					
1a. Examine whether offering age-appropriate educational and career development supports increase sustained access to services for this population of young adults.		2	3	3	**8**
1b. Determine whether provision of these types of services reduces service needs at later ages.		2	2	2	**6**
1c. Describe the impact of providing age-appropriate services in terms of systems costs overall.		1	2	4	**7**
2. Research regarding the implementation of offering these services:					
2a. Measure the current systems barriers and facilitators to offering age-appropriate educational and career development supports for young adults. Identify what it will take to overcome these barriers.		1	5	3	**9**
2b. Determine how barriers vary by system organization factors (e.g. local vs. state-level funding decisions), by finding mechanisms (e.g. implementation of ACA voluntary portions vs. not, use of Medicaid rehabilitation waivers), and other such system factors.				4	**4**
2c. Test whether increased contact and collaboration between child and adult mental health services result in greater implementation of effective educational and career development services for young adults	1	5	1	2	**9**
3. Research regarding the impact of involving young adults and their families in system change:					
3a. Test whether national, state, and local level policies which reflect the input of young adults and their families result in greater system change and more positive outcomes than those that do not.	1	1	2	2	**6**
3b. Examine how the process of policy change and implementation is affected when young adults and their families are meaningfully involved		1	2	4	**7**
3c. Measure the differences in young adult outcomes between implementation of policies that are designed to support young persons in both system planning and in planning their own services, and policies that do not explicitly include young adult voice.		4	1	2	**7**

Orange	**<u>Write In's:</u>** • Employment/Education/Juvenile Justice/Menu of services/Trap into • What do we know about the "outcomes" of those who are out of the children's mental health system and don't engage in the adult mental health system? • How does the adult mental health system work more effectively with non mental health systems support young adults? (workforce/housing/DOL/VA/Education) **<u>Flipchart and notes:</u>** • Not sure it's not better to leave a larger gap between children and adult systems • What are the other systems that should be involved, VR, DOL, workforce for better services? • What do we know about people who get children's services who do not go into adult systems? • Drop out is not necessarily a bad outcome • How does the adult MH system work more effectively with non-MH systems (e.g. workforce, vr, education) to support young adults? • To what extent are young adults with PD prepared in secondary education (skills/knowledge) for careers and employment? Is this a MH issue or a secondary education issue?
Blue	**<u>Write In:</u>** • Importance of employee assistance programming? Helping youth with mental health needs return to employment. Need to understand how individual learning/career development phases/planning(?) are _____ your mental health needs in meeting employment goals in high school, college, and out of school settings **<u>Question Edits:</u>** • 1b. Do this to determine how to lower costs • 2a. Do this while also doing 2b **<u>Flipchart and Notes:</u>** • Does service use lead to better outcomes/Does increased contact with child and adult systems lead to better integrated services? • What is the impact of consumer and family participation/Would teaching self-advocacy facilitate this input? • Do we need specifically targeted services for young adults? • How do we get the data to show better outcomes (cost reduction)? • Large importance of self-advocacy and self determination. Improving youth's ability at self-advocacy skills • Assumption: does more services lead to better outcomes? What happens to those who don't get services? • Policy Barriers: Gun Laws, 72 hour holds • Enforcement of ADA Policy- federal grants, how do we create long-term commitment to systems reform after the grand period ends • Why doesn't research impact policy more? In mental health, it saves $, reduces homelessness, less money in criminal justice system • Can we tie number of employed with federal money?

Systems & Policy Questions:

	• Child welfare-wellbeing focus • Outcome measures must be relevant to the political/policy concerns (i.e. crime, costs, etc.) • Look at the impact of different college policies on students with mental health conditions • James bell-worked on 10 factors for sustainability • Mental illness not to become a permanent issue • Training issues around setting higher expectations • Colleges-policies that reinforce low expectations. Dept of Ed has program on expecting high expectations • Policy change- training for faculty and staff on mental health issues. • How does setting high expectations impact performance of students?
Red	**Write In's:** • How are ancillary systems supporting or not supporting career development and employment **Question Edits:** • 2a. Look at multiple systems (MH/Housing/Vocation/Work/etc.)
Yellow and Green	**Write In's:** • Describe and apply knowledge of unique service needs of this population • What are most effective services for young adults relative to Mental Health (EBP Specific to Young Adults) • Rigorous research on the TIP Model • Research long term outcomes young adults have when they do not apply/approve? for access to adult mental health or disability services • Describing and measuring accurately the elements of implementation practices so as to better identify what elements are having the best impact **Question Edits:** • 2. Increate in functional outcomes • 2b. Add "services and outcomes" **Flipchart and Notes:** • Need more description of describing and applying unique services needs • Relationship between effective mental health system and employment/education • What is "effective" or "quality" • Integrated system "framing" team, consultants, coordination • More specification: services research or clinical trial • Redirect Money • Measure fidelity outcomes and implementation • Research regarding the impact of offering services should include a focus on functional outcomes—living, learning, working—housing stability, working etc. • Do young adults have different service needs than mature adults? They may have unique needs. We should tailor our services to the
	unique needs of young adults. There is some knowledge that can assist us here including that about brain development, risk taking, the importance of peer relationships, the role of the family, social networks, etc. This research doesn't speak to services per se but should inform the discussion about services. • What is the relationship between having effective good mental health services and whether it affects access to use of supported employment services? • Access to good mental health services in general is an issue. Need to have access to good mental health services for the other services employment, housing, to be effective. • Motivational interviewing may be relevant to helping young adults make decisions. • Individuals who get service outside the public system do not show up in our research. We should be mindful of that. • Where do we house programs that can address all aspects of a young person's life? That cut across domains and are not in "siloes"? • Can we use other evidence based treatment for young adults? • Example of something innovative: Delaware DVR is now paying for applied behavior analysis to help job coach target and define behaviors needed for a job. • Integrated approaches and consultation are needed. • Gap in research so there isn't a lot of research to inform policy in this area of best or evidenced based employment approaches for young adults. • HTI-Healthy Transitions Initiatives. Some of these sites are using TIPS model. • There is research base for adult interventions—MI, but not enough specification of models. Maybe we can dissect elements to figure out what is promising. • We can't wait the 15 years to inform practice from research. • Implementation research is important but need to have well specified models to do this. • We need good measures of outcomes and implementation of new models. • One big deterrent to getting good services is having so many care providers. YA get overwhelmed. • Let's not forget a focus on employers; we need them for the jobs they provide but often we don't focus on them. • Self employment is worth examining.

SUMMARY OF EMERGING ADULT INVOLVEMENT AND PANEL

In order to infuse the youth voice and perspective throughout the Transitions RTC State of the Science Conference, young adults with lived experience of a serious mental health condition employed at the Transitions RTC were involved in the planning and implementation of all aspects of the State of the Science Conference. In addition, all three topic papers (employment, education and policy) featured a young adult co-author with lived experience, and each response panel had at least one young adult member.

The State of the Science conference also featured a panel of young adults from the Washington DC Metro area. The young adult panelists candidly shared their personal experiences with seeking services in the child and adult mental health systems, as well as their struggles in successfully completing their education, and maintaining employment while living with a mental health condition. The young adult panel was moderated by Lacy Kendrick-Burk, Executive Director of Youth MOVE National, and panel participants were recruited by Lauren Grimes, Trainer and Youth Coordinator for On Our Own Maryland.

Young Adult Panel Biosketches

Jennifer is 22 years old. She graduated from Montgomery College in Rockville, MD in May of this year with an Associate's degree. She currently attends the University of Maryland in College Park, where she is majoring in Family Science with a certificate in African American Studies. She is also a 2009 Horatio Alger National Scholar and a member of the youth mental health advocacy group, Montgomery County All Stars. Jennifer was diagnosed in October 2011 with a mood disorder after experiencing mental health challenges for five years. She has recently experienced a series of successes after struggling to maintain enrollment in college and facing many obstacles in her academic progress that is so important to her. Her struggles have motivated her to speak openly about the positive and negative experiences she has had with numerous services and supports while trying to pursue a postsecondary education while simultaneously dealing with mental health issues.

Chris is a 24 year old young adult mental health consumer. Chris currently works part-time for the Montgomery County Federation of Families for Children's Mental Health, where he helps with office work and organizing the activities of the youth peer group, The Montgomery County All Stars. Chris has been attending All Stars groups and Youth MOVE groups since 2008 and has continued to support the groups and their members as a peer, volunteer, and now a paid organizer and advocate. Chris has struggled with the symptoms and diagnosis of bipolar disorder for many years. He has received substance abuse and mental health services from programs in both the child and adult behavioral health systems. In order to help

himself and others move towards recovery, he has contributed to the fight against stigma and helped organize youth leaders to create advocacy opportunities for others.

Lucy first entered into the foster care system when she was 12, and had numerous placements in foster homes and independent living programs over the next 7 years. She struggled to find a sense of belonging as she moved through these placements and through multiple systems receiving services. Lucy now lives in her own apartment in Hagerstown, MD, and is involved in the Healthy Transitions Initiative Program and the Community Employment Program at Turning Point. She recently participated in her first Young Adult panel which presented at the National Pathways to Adulthood 2013 Conference in Baltimore, Maryland. She is excited to have another opportunity to practice her public speaking, and would love to become an Advocate for children and young adults in the foster care system in the future.

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AGENDA

Conference Host: Gwen White
Main Conference Room: 3301

Tuesday, September 24, 2013

8:00 am	Registration open, breakfast served in room 3302
8:30-9:15 am	Welcoming remarks
9:15-9:30 am	Overview of the population and goals of conference
9:30-10:00 am	Keynote
10:00-10:15 am	Audience discussion and Q&A
10:15-10:30 am	BREAK

10:30 am-12:45 pm   Topic #1: Education
   10:30-11:00 am   Presentation of the state-of-the-science
   11:00-11:45 am   Comments/Response and Audience Discussion
   12:00-12:45 am   Break-out group discussions
(Please refer to the group assignments in the conference program)

12:45-1:30pm: LUNCH PROVIDED
Please pick up your lunch in room 3302. Then join us back in 3301 for a video:
A View into Young Adults with Psychiatric Disabilities: The Mission and Work of the Transitions RTC.
Break-out rooms will be available for networking

1:30-2:15 pm	Young adult panel
2:15-2:30 pm	BREAK

2:30-5:00 pm   Topic #2: Employment
   2:30-3:00 pm   Presentation of the state-of-the-science
   3:00-4:00 pm   Comments/Response and Audience Discussion
   4:15-5:00 pm   Break-out group discussions
(Please refer to the group assignments in the conference program)

5:00 pm   Networking reception in Room 3301

Wednesday, September 25th

8:00 am   Registration open and breakfast served in Room 3302

8:30-10:00 am   Topic #3: Policy/System Integration
    8:30-9:00 am   Presentation of the state-of-the-science
    9:00-10:00 am   Comments/Response and Audience Discussion

10:00-10:15 am   BREAK
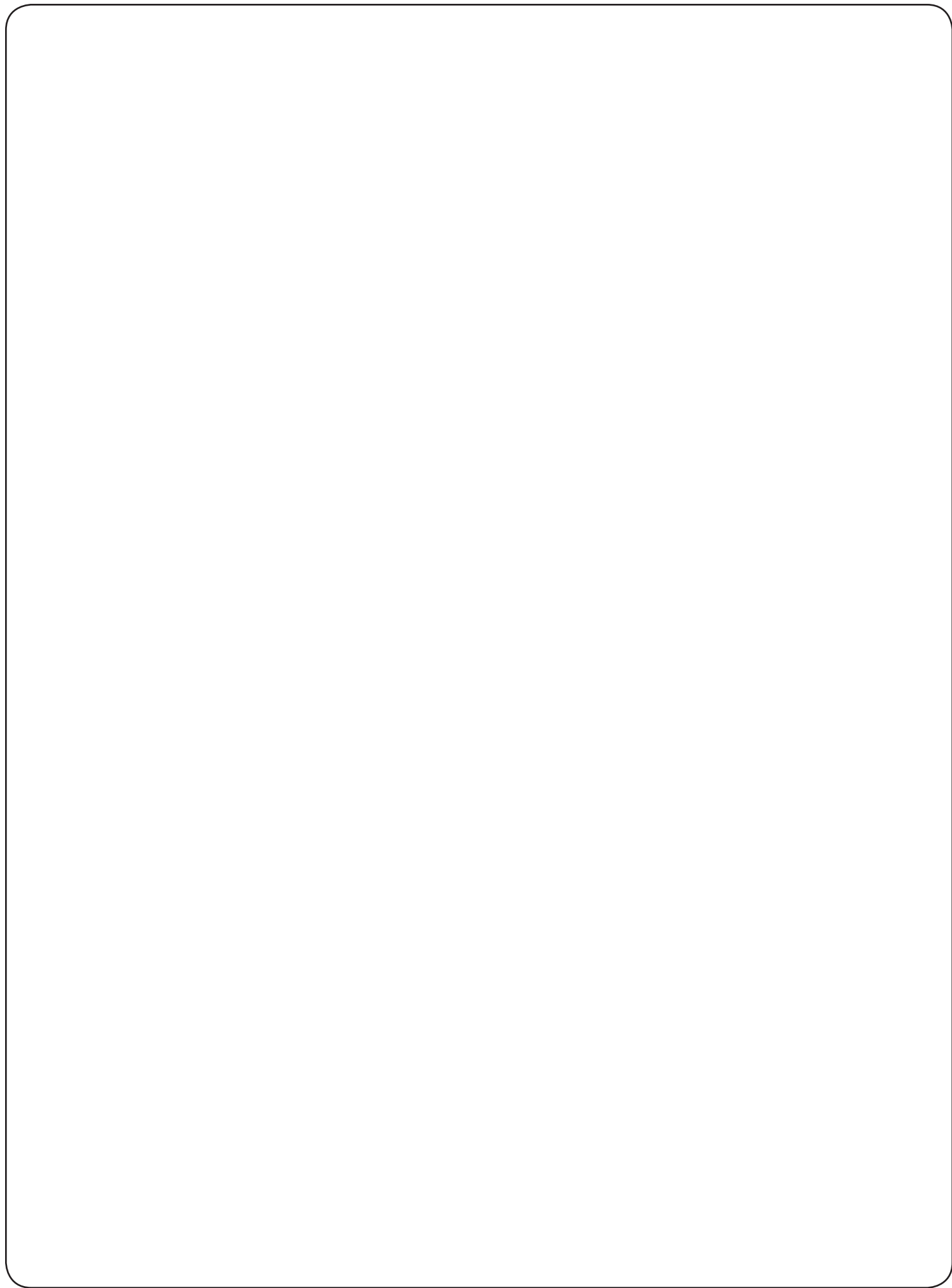

10:15-11:00 am   Topic #3: Policy/System Integration (Part II)
10:15-11:00 am   Break-out group discussions
(Please refer to the group assignments in the conference program)

11:20 am: Conference wrap-up and conclusions

Noon: Conference adjourns

The Learning & Working During the Transition to Adulthood
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