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

TRANSITIONS RTC STATE OF THE SCIENCE PAPER
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By: Nancy Koroloff, Ph.D.,
Maryann Davis, Ph.D.,
Jim Wotring, M.S.W.,
Lacy Kendrick Burk, M.S., M.B.A.,
Lauren Grimes,
Theresa King, B.B.A.,
Steve Reeder

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.

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EXECUTIVE SUMMARY

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. <u>Research Regarding the Implementation of Offering These Services</u>

- 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. <u>Research Regarding the Impact of Involving Young Adults and their Families in System Change</u>

- 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"

Prepared by:
Marianne Farkas

Responding Panel:
Crystal Blyler
Shannon CrossBear
Mark Courtney
Marianne Farkas
Melanie Green
Mueser, Kim
Trina Osher

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.

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.

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.

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.

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.

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

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

Systems & Policy Questions:

	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

Write In's:

- 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)

Flipchart and notes:

- 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

Write In:

- 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

Question Edits:

- 1b. Do this to determine how to lower costs
- 2a. Do this while also doing 2b

Flipchart and Notes:

- 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.