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State Efforts To Expand Transition Supports for Young Adults Receiving Adult Public Mental Health Services


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State Efforts To Expand Transition Supports for Young Adults Receiving Adult Public Mental Health Services

March 2005

**Report on a Survey of Members of
the National Association of
State Mental Health Program Directors**

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State Efforts to Expand Transition Supports for Young Adults Receiving Public Mental Health Services

EXECUTIVE SUMMARY

BACKGROUND

Psychiatric disorders present during the transition to adulthood (ages 16-30) impede the development of adult role functioning. Most adolescents with serious mental health conditions continue to have those conditions into adulthood, and many adults with psychiatric disorders developed those conditions at the threshold of adulthood (ages 18-21). Taken together, these findings from various studies confirm that, whether psychiatric disorders develop before or during the transition to adulthood, their presence seriously hinders the successful assumption of adult roles. These findings underline the importance of mental health (MH) services throughout this stage of life, and the need for interventions that facilitate the development of adult functioning. Adolescents and young adults with serious mental health conditions may receive services from a variety of service systems, including special education, child welfare, vocational rehabilitation and the like. However, the target populations for all but state MH systems are much more broadly defined than those with serious mental health conditions. Thus, it is important to know what is being done within state MH systems to address the transition needs of their adolescents and young adult clients. Further, transition support innovations from these systems could be a critical resource for the development and dissemination of programs, strategies, and technical assistance to improve transition support targeted at adolescents and young adults with serious MH conditions in all systems.

A previous study of all U.S. state child MH systems showed that almost all were at least talking about the need to provide and improve transition support services, and most provided some, although limited, transition support services (Davis, 2001; Davis & Sondheimer, 2005). One of the ultimate limitations though, was the upper age limit of their services; most ending at age 18, with a smaller number extending to age 21. Thus, the primary agency that can address the continued transition and MH needs of young adults with serious MH conditions after ages 18-21 is the state adult MH system. There is no current literature on transition services or services for young adults within state adult MH systems. The present study was designed to parallel the earlier study of the child MH system, and describe efforts that state adult MH systems were making to address the needs of their young adult population transitioning into adulthood.

STUDY METHODOLOGY

This report summarizes findings from semi-structured interviews of the Adult Services Members of the National Association of State Mental Health Program Directors. They are referred to in this report as administrators. Transition supports refer to services that focus on preparing young adults to function as adults. Since many adult MH services focus on functioning, administrators were asked about adult MH services that were tailored to the unique needs of *young* adults, or only served young adults. Administrators were asked about specific efforts made to address the needs of young adults, including services, policies, work groups, and efforts to coordinate with other agencies. Administrators were also asked their opinions about system characteristics that facilitated or hindered the system's abilities to progress in this area.

FINDINGS

- Almost half of the states reported having at least one program that specifically focused on young adults, and two states were systematically focusing on developing services for young adults statewide.
- Half of the states did not offer a single program specifically tailored to young adults. Those that did offer young adult programs, most commonly did so in only one part of the state. Most types of transition supports were offered more often, in child rather than in adult MH systems.
- The array of innovative approaches that were spread across the country were impressive and have much to offer in terms of expertise and technical assistance to others interested in making similar efforts.
- All states had differences in eligibility criteria or priority population definition for child and adult MH services, with the adult definitions more commonly being narrower.
- A small number of states “grandfathered” the eligibility of some or all adolescents as they reached the upper age limit for children’s services.
- Many states were not using the federal definition of serious mental illness to determine service eligibility or priority population. Most of these states were using a more narrow definition.
- Adult MH administrators cited leadership, prioritization, and lack of funding as the key characteristics impacting the development of transition for young adults.
- In response to extremely limited funding and severe budget cuts experienced at the time of the survey (summer, fall, 2003), many states have had to restrict eligibility to the most disabled population and/or limit services to only the most basic ones. This was cited as the rationale for not providing specialized services to young adults.
- Despite the general absence of services tailored for young adults, most adult administrators did not cite this as a major weakness in the adult MH system. In fact, there was considerable disagreement among adult MH administrators regarding the need for specialized transition support services focused on young adults within the adult system. This is in sharp contrast with the frustration expressed by child MH administrators regarding their inability to adequately address adolescents’ needs within the child MH system, even though more progress has been made towards that end.

IMPLICATIONS

Despite converging evidence that young adults with serious mental health conditions struggle to attain adult functioning, the needs of young adults with serious MH conditions are largely unmet in the adult MH system. First, many are barred from entry into the system because of arbitrary distinctions between the nature of serious mental health conditions in minors versus adults. For those who do qualify for adult MH services, there are few specialized services available to them, and administrators are in disagreement as to whether any specialized services are even needed.

There is scant academic literature on the young adult age group or services for them, and no federal leadership on the issue. The few states that have made a concerted effort to address their needs have the goal of making all adult MH services developmentally appropriate, and view the needs of this age group as being quite distinct from those of more mature adults. Thus, there is developing expertise and leadership available to states that choose to address this system gap.

These results strongly suggest that a developmental perspective is generally absent in the adult MH system, although greatly needed. The one exception is that the unique needs of elders with serious mental health conditions have been recognized in federal legislation and programs, and in state mental health authorities. Perhaps insight into the parallels with the developmental issues at either end of the adult life span can provide the rationale for adult MH systems to develop specific services and policies regarding the young adult age group.

Young adulthood is a critical stage of development. Certain skills and abilities should develop during this stage, which set the foundation for later development. Helping young adults to develop skills and abilities to function as adults should occur while they are young adults because it is unlikely to happen at a later stage of life. In the absence of developing these skills and abilities, their capacity to function as adults will be greatly impaired rendering them more disabled and dependent on supportive systems.

Lack of sufficient fiscal resources was one of the most common issues identified that impede service development for young adults. Even though it is important to keep in mind that this study was conducted at a time of extreme economic hardship for states, it is also clear that prior to the economic hardship, little effort had been made to address the needs of this age group. Thus, while it might be unreasonable to expect much progress in developing new services during economic hardship, it is not the cause for the general lack of young adult services. It is more likely that the other factors administrators cited, namely leadership and prioritization, are the root cause or solution to this issue.

RECOMMENDATIONS

These recommendations are based on the assumption that developmentally appropriate supports are needed for transition aged youth and young adults, and that continuity of services are needed throughout this developmental stage. These recommendations are focused on the adult MH system, but also include other agencies, including the child MH system, since providing continuous and appropriate services for this age group cannot be achieved by any single agency. These recommendations also focus on the federal agencies and organizations whose missions put them in strong positions to affect practice in state MH systems, namely CMHS, the National Institutes of Mental Health (NIMH), and NASMHPD.

Leadership

At the Federal Level

- ✦ National and federal leadership is needed to raise the prominence of this issue for state systems. There is little consensus among MH administrators, that young adults have different service needs than mature adults, and that adult MH systems have a responsibility to address the developmental needs of young adults. CMHS and NASMHPD are in an ideal position to provide leadership by developing statements and activities that are consistent with the following positions:
 - Transition to mature adulthood is acknowledged as encompassing ages 16-30.
 - State adult and child MH systems are encouraged to take responsibility for ensuring that the specific developmental needs of 16-30 year olds in their systems are addressed.

- Development of young-adult specific services in the MH system are enhanced by a combination of providing guidance on how such development can occur, and incentives to do so.
- ✦ CMHS could provide important leadership by adjusting their official definitions of SED and SMI so that they do not pose an arbitrary age-related barrier to the continuation of services.
- ✦ Requiring states to include the following information in their annual application for federal block grant funding would also increase awareness of the issue:
 - Number of 16-30 year olds served; services received by this population; and total service-related expenditures
 - Descriptions of services for this age group and plans for service improvement
- ✦ NASMHPD is well placed to assume a greater role in advocating for the needs of young adults enrolled in the adult MH system. A possible first step in this process, would be for NSMHPD to conduct a comprehensive review of state-level MH system data to identify characteristics of the target population currently served, as well as details concerning service utilization in both the child and adult MH systems.
- ✦ CMHS, NIMH, NASMHPD would also demonstrate tremendous leadership by modeling for states, a self-reflective process that could guide states in their self-evaluation to improve transition supports. This process could include examination and debate about the value of separating branches, divisions, and programs into child and adult units, and the consequences of these separations for the transitioning population, with publication of the findings and recommendations for change. CMHS could also work with partners to encourage review of federal funding of MH services and the impact of funding regulations on the continuity of care from adolescence to young adulthood.

At Any Level

- ✦ Embrace the transitioning population by acknowledging their specific needs and commit to serving them throughout the transition stage.
- ✦ Partner with advocating organizations and individuals to expand appropriate service delivery.
- ✦ Look for opportunities to make a difference.
- ✦ Increase awareness about the population and their needs in the field.
- ✦ Keep the issue in the forefront of the public debate.

Resources and Funding

At the Federal Level

- ✦ CMHS is well-placed to provide fiscal incentives for serving young adults, ages 16-30, to ensure service continuity, to address the developmental needs of this age group, and to encourage innovative approaches.
- ✦ The majority of state MH services are financed by Medicaid. Medicaid funding for many categories of eligibility ends at ages 18-21, and varies across states. It is important for these eligibility categories to be reviewed for their impact on the transitioning MH population, with recommendations or guidelines about how to remove arbitrary age-related barriers until the end of the transition stage.
- ✦ Social Security definitions of disability differ for “children” and “adults”. Bringing these differences into alignment would reduce the likelihood that those deemed disabled as children would be deemed not disabled due to age restrictions.
- ✦ A GAO assessment of the size of the population that continues requiring transition support after adolescence, the costs of failure to serve these young adults adequately, and the costs of providing federal funding via various federal agencies to ensure adequate availability of continued funding throughout the transition stage, would greatly inform the decision processes of federal legislators, programs and agencies that are in a position to change the current systems.

At Any Level

- ✦ Take advantage of opportunity such as new or unexpected influxes of funds to increase adult MH transition support.
- ✦ Be ready to start small; any funding dedicated to this issue lays the foundation for further funding.
- ✦ Blend or combine funding with other relevant agencies, such as vocational rehabilitation or substance abuse funds for younger adults, or child and adult mental health targeted at adolescents who will enter adult services.
- ✦ Conduct joint discussions among adult and child MH administrators to develop a common understanding and appreciation of the special needs of young adults and youth in transition. Further, adult and child MH administrators, and other MH advocacy organizations should combine forces to seek greater state and federal funding.
- ✦ Analyze any untapped resources for transition support; several states have used Early Prevention, Screening, Diagnosis, and Treatment (EPSDT) funds to extend services from ages 18-21.

Prioritization

- ✦ Make transition a national, state, and local priority.
- ✦ Increase awareness of the issue by holding conferences or trainings with key stakeholders to clarify its importance and invite input into the next steps.
- ✦ Invite advocacy organizations and young people to partner in developing a plan to prioritize this issue.
- ✦ Develop a task force comprised of transition advocates and potential change agents within child and adult mental health and within other related systems.

- ✦ Gather locally relevant data and stories that can highlight the poignancy and importance of the issue in ways that appeal to each relevant audience.
- ✦ Combine data with an assessment of current resources and needs to help focus where work is needed.
- ✦ Have conversations with all involved parties, at all levels, to determine their concerns and desires (e.g. focus groups of youth in transition, their families, direct care providers, and state agency administrators, etc.)

State Efforts to Expand Transition Supports for Young Adults Receiving Public Adult Mental Health Services

FULL REPORT

BACKGROUND

Evidence of a Problem

How well do state mental health systems serve young adults with serious mental health conditions? There are several reasons for intense interest in the answer to this question. First, young adulthood is a critical stage of development. Certain skills and abilities develop during this stage, which set the foundation for later development, and often cannot develop at a later stage. In the absence of these skills and abilities, the capacity to function as adults is greatly impaired, rendering young adults with serious mental health conditions more disabled and dependent on support systems.

Arnett (2000) has coined the term “emerging adulthood” to capture the developmental stage post adolescence but before stable adulthood has been established; roughly ages 18-30. It is a period of rapid changes and closely spaced life events; it is the peak period of entering and exiting multiple social roles (Rindfuss, 1991). It is the period in life that can determine whether or not a juvenile delinquent desists from criminal behavior, or continues a longstanding criminal career (Sampson & Laub, 1993). It is the time of life when young people are held accountable for their actions as adults, and when their choices can affect the rest of their lives, or even take their lives. The period of late adolescence through emerging adulthood is referred to as the transition period (ages 16-30). Since adult MH systems serve those over age 18, it is important to know what is being done in those system to help young people enter adulthood.

Second, most youth with serious MH conditions in adolescence continue to have serious MH conditions in adulthood, and most adults with serious MH conditions, had those conditions by mid-adolescence. For example, adolescents who have attention-deficit/hyperactivity disorder (Ingram, Hachtman & Morgenstern, 1999), schizophrenia (Hollis, 2000), major depressive disorder (Lewinshon et al. 1999; Rao et al., 1995; Bardone et al., 1996), simple phobia (Pine et al., 1998) or conduct disorder (Bardone et al., 1996), are likely to have the same disorder in young adulthood. Studies have also found that adolescent disorders, including anxiety disorders, affective disorders, and conduct disorders, are strongly predictive of other adult disorders (e.g. Kasen et al., 2001; Peterson et al., 2001; Pine et al., 1998; Biederman, Faraone, & Kiely, 1996; Bardone et al., 1996; Rao et al., 1995; Pollack et al., 1990, 1992).

Although some young adults develop mental illness in adulthood, rather than during childhood or adolescence, a recent study has found that this is an uncommon etiology (Kim-Cohen et al., 2003). In this study of a community-based cohort followed prospectively from birth, only about a quarter of adults who had a psychiatric disorder at age 26 did not have a psychiatric diagnosis by age 18, and half had a diagnosis by age 15 (Kim-Cohen et al., 2003). Those with schizophreniform disorders at age 26 (schizophrenia or schizophreniform disorder) were just as likely as those with other disorders to have had a psychiatric diagnosis by age 15 (53%). Development of a psychiatric

disorder by mid-adolescence was even more pronounced among adult intensive MH treatment users, such as those typically served in state MH agencies. These studies reinforce the importance of quality and continuity in treatment throughout the transition stage.

Third, those with serious MH conditions generally fail in the tasks of young adulthood. In general, studies of adolescents with serious MH conditions who received child MH or special education services, uniformly demonstrate extremely poor functioning during young adulthood (reviewed in Davis & Vander Stoep, 1997, Vander Stoep, Davis & Collins, 2000). The literature on the functioning of young adults in adult MH services also indicates poor levels of functioning (Sheets, Prevost & Reihman, 1982; Pepper & Ryglewicz, 1982; Holcombe & Ahr, 1986; 1988; Test et al., 1985; Test, Burke, & Wallisch, 1990). It also appears that the provision of good MH services for young adults of transition age are important for **preventing** the development of new or deterioration of existing MH conditions. In his nationally representative household survey from the early 90's, Kessler and colleagues found that the presence of psychiatric disorders exerts a disruptive influence on the transition to adulthood (Kessler, Foster, Saunders et al., 1995; Kessler, Walters, & Forthofer, 1998). The changes during transition can both be interfered with by mental illness as well as contribute to the development of mental illness (Meich et al., 1999). These studies again reinforce the importance of good services for young adults with serious MH conditions.

Service System for Young Adults

Young Adults in the Adult MH System

Little has been published since the 1980's on how well adult MH systems serve young adults or on how well young adults in public MH systems are faring. There was a flurry of publications in the 1980's on the "young adult chronic" patient, an unfortunate label that reflected the times (e.g. Pepper et al., 1981; Bachrach, 1982; Snyder, 1985; Harper & Pepper, 1987). The young adult chronic patient was a new phenomenon because of the deinstitutionalization that occurred in the 1960's. In the 1980's this younger group of clients with mental illness had not experienced long years of institutionalization as previous cohorts had, rather they cycled in and out of MH programs, on and off the streets, and in and out of jails. They came to represent the problems with the poorly conceptualized policy of deinstitutionalization and consequentially homeless, mentally ill adults (Cournos & LeMelle, 2000). This group was also viewed as a problem for clinicians; and was characterized as hard to engage, non-compliant, chronically in crisis, dually diagnosed with substance use disorders, and seen as aggressive (Bachrach, 1984; Holcomb & Ahr, 1986; Sheets et al., 1982).

The overall benefit of this series of articles and the use of the young adult chronic label was to establish, within the adult MH system, the notion that the young adult population was different from the older adult population. However, in much of the subsequent work, the "young" factor became decoupled from the deinstitutionalization factor. Most of the young adult chronic literature and service development addressed service issues of all deinstitutionalized adults, not of **young** adults per se (i.e. Reifler, 2000; Cournos & Le Melle, 2000). Notable exceptions include; Mowbray, Herman, & Hazel, 1992; Mercer-McFadden et al., 1997; Collins, 2000; McLaughlin & Pepper, 1990.

There has been little attention paid to services for young adult patients or clients in MH systems in more recent years. Most of what is known, comes from following adolescents with serious MH

conditions into adulthood. Studies of service utilization after youth age out of children's systems indicate that few of these youth access any services even when they want them (Silver, 1995; Evans, Huz, McNulty, & Banks, 1996; Greenbaum, 2000). Parents' ratings of the degree to which various child and adult service systems have helped their child during the transition to adulthood have uniformly been worse for adult systems than child systems, and generally quite low (Davis & Butler, 2002). Aside from this and the young adult chronic literature, there is little other literature focused on the young adult population receiving care in the adult MH system. The few studies and articles on this topic support the notion that young adults are not served well in the adult MH system (Ialongo et al., 2002; Giugliano, 2004; Lincoln & McGorry, 1995), and are least likely to have behavioral health coverage of any adult age group (Wu & Schlenger, 2004). Generally, there is little developmental framework in the adult MH services or treatment literature, except in consideration of the geriatric population (e.g. Kohn et al., 2003; Bartels et al., 2003; Charney et al, 2003).

Transition Support Services in Child MH Systems

Since the transition period encompasses ages 16-30, it is clear that there is a need to understand efforts within state MH systems that are underway in the adolescent *and* adult system. Currently, all states except one (AR), have separate administration of their child and adult service systems. Recently, Davis (Davis & Sondheimer, 2005; Davis, 2001) reported on efforts that state child MH systems were making to address the needs of the transitioning population. State child MH systems here refers specifically to the part of the state MH authority that has administrative oversight of child MH services or to the part of the consolidated state child agency (typically including at least child welfare and child MH systems) that has administrative oversight of child MH services. Results of this study demonstrated that transition services within state child MH systems are sparse, nationally. Twelve states reported offering no specialized transition support services within the child MH system, while only 9 states had some transition supports available statewide. Only one state provided comprehensive transition supports statewide, though the size of the population served in this way was small because the MH services of all individuals with Medicaid coverage were managed by another state agency. Despite the general absence of transition support services, with rare exception, in every state's child MH system, discussions were underway about the needs to improve transition support services.

The current study was undertaken to complete the picture of transition support efforts within state MH systems.

STUDY METHODOLOGY

Participants

Adult Services Members of NASMHPD, or their designees, for all states and the District of Columbia, except Michigan, agreed to participate in the interviews. These participants are referred to as administrators throughout the report.

Procedures

Interviews were conducted between July and October 2003. Interviews lasted 15-60 minutes. The authors worked with NASMHPD's National Technical Assistance Center in contacting members. Administrators were sent a cover letter introducing the issue and the purpose of the study, including a supportive statement from NASMHPD, guidelines concerning the interview, and the interview instrument (see Appendix A). In the materials, transition services were defined as services that focus on assisting young people to complete the tasks of adolescence and take on the mantle of adulthood. These services were further defined as specialized for this age group; for example, the presence of a psychosocial rehabilitation program that served all adults was not recorded as a special transition effort, but one that had either modified its approach for young adults, or only served young adults was considered a transition effort. Typical transition programs were described as offering supports in the following areas: (1) Completing high school or earning a Graduate Equivalent Diploma (GED); (2) Entering and completing post-secondary education or training; (3) Obtaining and maintaining rewarding employment; (4) Preparing for and achieving independent living; (5) Developing and maintaining adult social support networks; (6) Obtaining age-appropriate MH services and supports; (7) Participating in transition planning and coordination of transition services and supports.

Answers were recorded in writing and responses to open-ended questions were paraphrased. Unclear responses were verified during the interview to ensure accuracy.

A coding scheme was developed for open-ended responses to identify themes. All of the interviews were independently coded by two individuals to test the adequacy of the coding scheme as well as the consistency between coders. (See Appendix B). Variations in the coding were resolved through discussion.

All responses were summarized in aggregate form using descriptive statistics.

Interview Instrument

Administrators were interviewed using a semi-structured questionnaire (Appendix A). Questions for the interview were developed from topics that the literature suggests are important for youth in transition to adulthood. These included the evaluation of critical elements from the current guidelines for transition support systems (Clark, Deschenes, & Jones, 2000): 1) Do young adults have access to supports for all domains of transition functioning, including (but not limited to) independent living, school, and vocational/career supports? 2) Was transition planning done? and 3) Are these supports developmentally appropriate? Efforts that would facilitate progress toward these goals were also assessed, such as the presence of work groups focused on this issue, and policies, contract language, or legislation consistent with these guidelines. Interview questions were the same as those asked of child and family division members in the spring of 2001.

Two reporting limitations were found in the earlier study. In some states, administration of the MH system was decentralized, and administrators reported that local transition support services and efforts could exist that they were unaware of. In addition, some administrators reported that their states had a Medicaid-funded MH system operating through a private managed behavioral healthcare organization (BHO) that served many adults, for which the MH agency had little

administrative responsibility and little information. As a result, the current instrument specifically asked about the decentralization of services, the basic organization of services, and the relationship between the state MH agency and Medicaid funded MH services. Administrators from 8 states indicated that their state's MH system was so decentralized that they could not describe the services or effort for the young adult population with confidence. These administrators agreed to circulate a brief questionnaire to those in the counties or catchment areas that could answer the questions, but only one state circulated this and returned the responses. Thus, this report will summarize what was learned from the more centralized states (43 states).

Second, several states report a significant carve-out of MH services for Medicaid recipients that were not part of the state's MH authority (*CA, FL, IL, IA, MA, NH, NM, NY, OK, TN, UT, VA*). Division members were not asked about transition support services offered within those carve-outs. Thus, division members answered to the best of their knowledge, but the information summarized here should be viewed as a conservative description of all of the efforts being made within state adult MH.

FINDINGS

Innovations in the Field

Several states have made concerted efforts to address the transition support needs of the young adults they serve. Some are only in the planning stages, having mounted significant efforts to assess what transition supports are available, and what else is needed, bringing together important stakeholders, and raising awareness about the characteristics of the young adult population and their needs. Some have made concerted efforts to work with the child MH system to provide better coordination for those exiting that system, or to exchange expertise to improve child and adult practices around transition needs. Most commonly, states have funded at least one categorical program or service coordination approach to address transition needs. This section summarizes some notable innovations in all of these stages of transition support improvement. In order for an effort to be considered "made by state adult MH systems", they either provided/funded the effort or was one of multiple agencies providing/funding the effort.

Work Groups

Adult MH in many states participated in or led specialized work groups focused on the needs of young people with serious mental health conditions as they transitioned into adulthood. For example, *New Mexico* has numerous Adolescent Transition Groups (ATGs). The first group started in Albuquerque in 1994 and has since spread to four other regions. ATG is a systems management approach utilizing the experiences of transition-aged youth and those advocating or providing services for them to identify systemic barriers to successful transition to adult services. ATGs can

range in size from 5-50 and typically consist of representatives from agencies involved in the child and adult services systems (any interested parties can attend). The groups have 3 goals: to attempt to transition young people into the services they will need as adults; to identify systemic issues, barriers, and gaps; to develop strategies to address these issues; and to offer professional support to those persons involved in the adult and child services systems. Anyone can present a client (e.g. provider, case manager, parent). The group then brainstorms suggestions. Most of the referred youth are dually or multiply diagnosed as having a mental health condition with either a substance abuse or developmental disorder. The groups meet monthly for a half-day and work as a think tank to help find appropriate supports. Reports regarding findings are regularly presented to agency personnel. The reports of the ATGs form an annual report that is provided to the lead administrator for the state's mental health/substance abuse agency. This is currently an unfunded initiative that provides informal problem solving.

In *Georgia*, a work group was formed in response to the disruption produced by last minute "transfers" from the child to the adult system. Their first action was to develop a protocol to begin transfer work at a person's 17th birthday. This protocol included identifying staff in each regional office who were responsible for adult MH eligibility determination and the logistical work associated with informing pertinent adult MH system staff about the transfer. This group also determined that there was a need for specialized services for this age group; in particular, there was a need for specialized housing services. At the time of the interview, *Georgia* was in the process of developing a demonstration project for 17-25 year olds, which would be a joint effort of both adult and child MH, working collaboratively with Housing and Urban Development (HUD) staff, to provide supported housing, with vouchers, and build supports around the housing component.

A work group began in *Arizona* in February 2003 that included 6 parents of transition age youth, representatives of local child and adult regional behavioral health agencies, a benefit specialist, a housing specialist, and the heads of the state level child and adult MH divisions. This group drafted a policy change requiring that transition planning begin at age 16 (rather than 17.5) and provides more specifics about what transition planning should entail. This group was also developing training for physicians and psychiatrists regarding medical record documentation to facilitate adult eligibility determination. They were also examining the applicability of the state's standard assessment tool for young adults.

Missouri's adult MH administrator chaired a work group that included youth and family members, the State Department of Vocational Rehabilitation, researchers from Washington University, the State's Department of Education and Special Education, Child Protective Services/Child Welfare, and a representative from Income Maintenance. The group developed a white paper on best practices with the transition age group, and are working on a "field guide" that would provide concrete information concerning contacts and expectations. Similarly, the transition work group in *Delaware and Chester Counties, PA*, has developed a guide for service provision for transition aged young people, for statewide distribution.

New York State has an internal work group within adult MH, that periodically includes representatives from vocational rehabilitation, education, and labor, and is focused on identifying services that would appeal to young adults. The group is in the process of getting organized and is fact-finding. *Massachusetts* has a similar work group that is a standing committee of the State's Mental Health Planning Council. The group includes state-level representatives of adult and child MH, experts in transition, consumer advocates, parents, a representative from the State's Vocational Rehabilitation Agency, and is moderated and organized by youth advocates with training and support from one of the adult consumer advocacy groups. The products of the group include a mentoring program for aging-out youth in residential treatment, a youth and young adult writing

collective, presentations to various groups about the transition stage from youth perspective, and a series of recommendations to the Commissioner of MH, which the group is working to enact.

North Dakota is in the process of revising its admission and continuity of care criteria for different levels of care for adult MH services. They are using a consensus-building process that includes case managers, family advocacy representatives, adult and child care coordinators, and youth. Part of the process is to determine how to bridge the child and adult MH systems.

Care Coordination and Transition Planning

Assertive Community Treatment (ACT)

Assertive Community Treatment (ACT; Stein & Test, 1980) is one of the evidence-based practices with adults with schizophrenia, highlighted in the Surgeon General's Report on Mental Health (1999), who are typically unwilling or unable to engage in treatment. A small number of states have used the ACT model to provide transition support (AR, DE, MN, OH, and WI). One ACT effort that has been repeatedly highlighted is the Transitional Community Treatment Team serving young adults, ages 16-22, in *Columbus, Ohio*. This program is focused on individuals with mental illnesses who are evaluated to be at highest risk for institutional placement, suicide, or homelessness (Bridgeo et al., 2000; Davis & Vander Stoep, 1996). The Team also operates a supervised and unsupervised housing program. The Team originated when the county in which it is located moved to the ACT model for the adult mental health system, and the head of mental health in the county asked that one team be reserved for this population.

The Village Integrated Service Agency (ISA)

Our Town Integrated Service Agency in *Indianapolis, IN* is a program that has adapted an award winning comprehensive approach (Village ISA from *Long Beach, CA*) for adults with severe and persistent mental illness to young adults (18-25 years old) with serious mental illness. This approach combines an ACT approach with psychosocial rehabilitation and links young adults to psychiatric and substance abuse treatment as well as housing supports using a consumer-lead planning team approach. Their approach emphasizes individual's strengths and abilities and de-emphasizes disabilities. "This empowers members to drive their own recovery as they work with staff to recognize and use their strengths and abilities to create and pursue personal service plans with quality-of-life goals that direct their participation in the Our Town ISA program." (<http://www.mcmha.org/our%20town.html>).

This program was launched in April 2003, partly funded by a grant from the National Mental Health Association, as an effort to encourage replication of model programs. The original model is described at <http://www.nmha.org/pbedu/schizophrenia/model/village.cfm>. Marion County MH association (who received the grant) chose to focus the model on the young adult population.

Person-Centered Planning

The *State of Mississippi* received a \$1.385 million in Real Choice Systems Change Grants for Community Living from the federal Centers for Medicare and Medicaid Services in FY 2002. The target population is individuals who are between ages 17 and 26 who have a serious mental illness or dual diagnosis (mental illness/substance abuse or mental illness/mental retardation). The goals of

the program are to demonstrate a model for systems change by training stakeholders in the Person Centered Planning (PCP) process and applying the PCP process in three selected mental health regions. A second goal is to document improvements in the quality of supports based on the PCP model by measuring satisfaction among individuals receiving services, support providers' acknowledgment of increased positive outcomes, and cost effectiveness of the PCP model. The final goal is to collaborate with the current support systems of Mental Illness Management (MIMS) and Intensive Case Management and future support models being considered in *Mississippi*. The ultimate goal of this project is to demonstrate that through PCP, young people with mental illness or dual diagnosis can, self-manage their illness and participate in their community with the support to allow them to achieve their goals and accomplish their highest level of independence. This effort highlights a federal grant mechanism that can help fund new efforts to address the specific needs of young adults.

Pennsylvania's Office of Mental Health and Substance Abuse Services funded pilot programs in 5 counties through block grants. In *Delaware/Chester County* the Transition Age Project serves 14-22 year olds. A core component of this project is PCP, for youth in the program. One of the side benefits of this program is that the program manager, who is an intensive case manager supervisor in these counties, meets weekly for group supervision with intensive case managers who are not involved in this project, and provides consultation to them on the transition aged young people they serve who are not in the project. *Westmoreland County, PA* also has a PCP program for transition age youth ages 16-24.

Recovery Planning

Florida's adult MH system is funding a pilot program in *Jacksonville* that emphasizes self-directed care. Adults with serious and persistent mental illness take part in a recovery plan that is paired with a housing voucher system in which 10 of the 100 "slots" in the program are targeted at the "transitioning population".

Age-Specialized Case Management

Montana's child MH program was recently moved from the state MH agency to a consolidated child agency, leaving a larger gap between the two systems. As part of an effort to ensure appropriate services to those aging-out of child MH who are in need of continued services, the adult MH system has two care coordinators in one region responsible for finding the adolescents exiting the child system, particularly hospitals, and linking them to a work group who manage adult services. This group focuses on the needs of young adults and youth exiting the child system.

Vermont developed youth in transition case management teams, based on their Community Rehabilitation and Treatment programs, that work in the boundary between child and adult services. It is an intensive case management approach with access to intensive mental health services, roommate services, vocational, and educational services. It is funded through Medicaid fees for case management services.

Transition and Transfer Protocols and Plans

Several states reported having developed protocols to either plan a youth's entry from the child MH to the adult MH system, or a transition to adulthood plan for young adults exiting the child system who were eligible for the adult system (*GA, ID*). *Iowa* has worked in cooperation with their

child welfare system to ensure that youth, who continue in foster care services to age 21 through funding from the federal Foster Care Independent Living Program funding, are aware of the array of adult services offered through local service coordination agencies. This is achieved through connecting youths' child welfare worker with the local agency office.

Age Specialization in Group Settings

One of the conditions that young people report the greatest discomfort or dissatisfaction with is being in a group therapeutic environment (e.g. day programs, supervised housing, residential treatment, or inpatient settings) surrounded mostly by much older adults (much older in this case being anyone over age 30). It is not uncommon for those who provide these kinds of programs to report that this age group has difficulty functioning in these settings as well. For example, more mature adults in supervised housing often object to the loud music that younger adults want to listen to, their messiness, energy level, or other aspects of young adult life. Several states reported efforts to group young adults or older adolescents and young adults together in these types of settings (*MA, NH, NJ, NV, NM, PA, UT, WI, and WV*). Some specific examples are listed below.

Adult Foster Home

In *Dakota County, MN*, a mother and daughter team who have contracts to provide “adult foster homes” have specialized their homes for 18-23/25 year olds. They provide clinical supervision (these are homes with a professional couple and professional staff) and specialized training for working with this age group. Each home typically has 4 young people in them.

Similarly, in *Charleston, South Carolina*, one of the Homeshare providers is set aside for youth in transition. Homeshare is an adult foster care type of program in that it is a living arrangement in a community household other than with natural family members. The home is owned or rented by the Homeshare provider. One consumer, for whom the provider receives reimbursement for expenses, lives as a member of the household. Providers are screened, trained, and participate in monthly Homeshare provider support meetings. Respite services are available for providers. The Homeshare Household for Youth in Transition receives special training in working with this age group. Homesharing is a concept that was developed primarily for maintaining elders in the community rather than in institutions, and is an international model that has been applied to those with disabilities, including mental illness (<http://www.homeshare.org/english/index.asp>).

Psychosocial Rehabilitation for Young Adults

Missouri's Truman Medical Center has a psychosocial rehabilitation program within their community mental health center that has recently developed a team to specialize in the young adult age group, and it is combined with intensive case management. *Nebraska* has psychosocial rehabilitation day programs in two regions that specialize in 17-26 year olds. *New York State* funded six proposals that were in response to RFPs for evidenced-based vocational support programs for 16-23 year olds.

Housing

Washington County, PA has a homeless program for 18-22 year olds with mental health and substance abuse problems, called “Can Do”. A case manager and support staff prepare young

adults for independent living through educational groups and individualized support in a “college dorm” atmosphere with 24-hour supervision.

Other Innovative Services

Homelessness

Pennsylvania used Projects for Assistance in Transition from Homelessness (PATH) grant funds to develop a request for proposals for county mental health/mental retardation offices for youth in transition use of PATH funds. A consortium of five counties in the northwest area was funded. The consortium used the funds for outreach workers for children aging out of child MH, often in foster homes, to locate affordable, safe housing, and get them established with Housing and Urban Development or public housing funding.

Texas has PATH-funded teams in 13 cities serving 4,000 individuals per year. Five of these cities have teams focused on youth (under age 18); three of these teams have specifically utilized child workers to do outreach to youth and are collocated in day shelter, the other two use standard PATH teams to address children’s needs.

Peer Support

The adult MH system in *GA* contracted with the *GA* Parent Support Network to provide peer support to young adults, ages 17-25, who are eligible for adult MH services, using federal MH block grant funds. The contracted peers receive supervision from a MH professional. *Hawaii* was developing a request for proposals for consumer peer support and psychoeducation, and planned to carve out one of each specifically for young adults.

Early Adult Intervention

The Pier Program in *Maine’s* Medical Center, targets those, aged 16-25, who are at risk of developing psychotic illnesses. Individuals with prodromal symptoms or precursor disorders are provided rapid therapies, and a rapid response team, as well as mentoring.

Comprehensive System-Building

Those in Maryland’s child mental health system have long recognized the need for better transition support services. A task force composed primarily of advocates for individuals with developmental disabilities launched a successful effort in 1996 to enact legislation requiring the Maryland Education Department and the Department of Health and Mental Hygiene to develop a statewide plan to improve services for children and youth in each system. The resulting state plan called for development of a comprehensive strategy to address the needs of transitioning youth and resulted in the appropriation of new funds to serve transition-age youth with mental illness. In 1999 the Maryland Department of Health and Mental Hygiene initiated funding for a range of programs for transition-age youth offered by a number of local mental health authorities. The goal was to create a diverse range of programs that would provide a statewide foundation of local expertise that other local mental health authorities could draw on to develop or expand their own transition

programs. These included a program for transition-age mothers, an Outward Bound program, a supported education initiative at a community college, and a specialized case management program that provided mentoring and supported employment.

Maryland is one of a relatively small number of states in which there is little demarcation between adult and child mental health services. In all but a few areas, such as residential services, eligibility requirements are the same for youth and adults. Thus, service coordination can continue uninterrupted for young adults during the transition period. This system building capability focuses directly on developing capacity for services that address transition needs into adulthood. Among the challenges Maryland has faced are the difficulties in identifying providers who are willing to work with transition-age youth and who also have the expertise, experience, and flexibility to do so effectively.

Connecticut, which has a consolidated child agency, developed a memorandum of understanding that describes the process of linking young people receiving services in the children's system to adult mental health services. *Connecticut's* memorandum of understanding defines the application process that young people must follow to request adult mental health services, designating financial responsibilities for services identified in the transition plan, requiring the children's system to designate a transition coordinator and identifying special populations of children who do not meet adult services criteria but who may still receive special transition services funded by the adult system.

Connecticut has developed specific programs for two groups of youth who are too old to receive services from the child system. One group encompasses youth designated as *special populations*, who have a history of perpetrating sexual crimes and youth who have pervasive developmental disorders. Both groups include some young people with serious emotional disturbances. The second group includes youth who do not meet the eligibility criteria for receiving adult mental health services when they age out of the child system, but whose conditions are expected to develop to the point that the youth will become eligible for adult services.

These youth are eligible to participate in the state's Transitioning Youth Programs (TYP), which provide supported housing and related services and were developed through a planning and consensus-building process initiated by Connecticut's North Central Regional Mental Health Board with funding from the Federal Center for Mental Health Services. The process included convening a one-day statewide conference on youth in transition. The TYP model grew out of a subsequent series of focus groups involving young people, families, providers and agency representatives. The state legislature provided funds to establish supported housing programs in connection with the four community mental health centers that provide both adolescent and adult services. The programs serve 18-23 year olds.

All four programs offer supported housing, yet each is different in the specific nature of the supported housing and related services provided. Differences include types of housing (e.g., living alone in scattered sites or with roommates in a shared building) and the degree to which case management, independent living skill preparation, and mental health services are integrated. Each program serves a small number of youth (4 to 13 at any given time). All program staff have received training in the Transition to Independence Process System (Clark et al., 2000), which proposes a developmentally appropriate system of care for youth in transition, and in the therapeutic stance described by Bruculerri and colleagues (2000), which emphasizes the importance of family systems and a developmentally-appropriate therapeutic approach.

One of the consequences of the relationship that formed between the consolidated child agency and the adult mental health agency was increased knowledge about mental health conditions in the

child agency (which was child welfare dominated), and increased awareness in the adult system about the nature of symptoms, functioning, and needed treatment for trauma survivors, which comprised much of the TYP population. In addition, as in the experience of Maryland, many adult providers learned how to work well with a young adult population, and their expertise began to be shared in non TYP adult MH services.

Initially, the programs that served these two populations were richly funded by the legislature, but in recent years the number of youth referred primarily from the child welfare system has exploded and the funding has been level or decreased. This has led to a strategy in which the funding has been decreased for the intensive supported housing programs and redistributed with the directive to make ALL adult MH services developmentally appropriate using the expertise that has been gained through these programs. Thus, Connecticut is the only state that has directed all of its adult MH programs to ensure that their services are developmentally appropriate for young adults, and has provided some expertise and training towards this end.

Helpful Policies

Several states now report policies that grandfather the eligibility of some or all of the child MH population into adult eligibility, simplify the application process for those in the child MH system, or allow for those who are found eligible by the adult criteria to receive adult services at an earlier age. The broadest grandfathering of eligibility is in *Oklahoma*. In *Oklahoma*, an individual who qualified for state mental health services as a child or youth is automatically eligible for adult mental health services as long as they are financially eligible. The financial eligibility can pose an arbitrary barrier since a young person can be determined “indigent” (a criteria for services) under the parents’ household income until age 21. At that point they must reestablish financial eligibility based on their own income.

New Jersey has a policy that any child in out-of-home treatment should be treated as a discharging inpatient adult. *Massachusetts* grandfathers the eligibility of adolescents aging-out of their most intensive residential treatment settings. *Minnesota* revised their definition of serious and persistent mental illness such that for adolescents who meet criteria for serious emotional disturbance by age 18 a simple statement from a mental health professional would serve to continue their eligibility as serious and persistent mental illness (rather than going through the lengthy eligibility process). *Missouri* rewrote their adult eligibility so that 16-21 year olds could qualify for adult targeted case management.

Other policies clarify services for the transitioning population. *Montana* has administrative rules that state that youth, aged 17, who are deemed unlikely to be eligible for the adult MH system, can remain in the child system until age 21. Those that are eligible for adult MH can be served in either system, according to personal preference. *New Mexico* has contract language that requires providers to develop mechanisms for the transition to adult behavioral services for 18-21 year olds. *North Carolina* has a policy mandating transition planning for entry to the adult system for the child MH priority populations (multi-agency involved or from TANIFF families)

Some states have developed policies to facilitate entry from other child systems into the adult MH system. *Maine* has a transition protocol with other human service agencies that serve children that provides a uniform format and ensures involvement at least 6 months before aging-out.

Status of the Field

The following summarizes some of the general patterns of progress toward improved transition services reported during the interviews. This section provides an aggregate picture of areas where progress has been made as well as those where barriers to effective transition services still exist.

Population Policy Differences

Administrators were asked if there were differences between the eligibility criteria for receiving children's mental health services and adult mental health services, and if they were different, whether there were any efforts to reconcile these differences. A corollary project to the current one, included obtaining a written copy of either the target population definition or eligibility criteria from each state for adult and child MH. The results of that project will be used to assess whether or not there are definitional differences between adult and child MH systems.

For the 44 states that responded to the request for written criteria, the view that eligibility or priority populations are quite different between the two systems was strongly born out. The results of that project will be published separately, but the highlights of the findings are presented in Table 1. In essence, no reporting state had parallel definitions for their adult and child population. Many states had different diagnostic criteria, generally with narrower criteria in the adult system, and those that had the same diagnostic criteria had different functional impairment criteria, while some states differed on both dimensions. It is important to note that administrators from 6 of these 44 states reported that eligibility differences were not an issue. Three said that there were no eligibility differences, and three said that it was not an issue. It is unclear why there is a discrepancy between administrator report and written policy, but it may partially result from states having sent copies of their target population definitions and administrators reporting on eligibility criteria. On the other hand, as one administrator put it, there is a lot of "gaming" the system to get youth needed services, so perhaps for the administrators who indicated that this was not an issue, eligibility processes work in a way that is not apparent from written criteria.

There had been some efforts to remedy the problems caused by disparate definitions. Some states had begun to align these definitions for those who had received child services by "grandfathering" some or all adolescent clients into the adult system definition when they reach that age. Thus, if an adolescent had been a client of the child MH system (*OK, MN*), or in a specific service, such as residential treatment, in the child system (*MA, NJ, PA*) and met the child population definition by age 18, or did so with a minor qualifier, such as a professional stating that they continue to need services, they automatically met the adult population definition and could access whatever services were available to those adults. *Connecticut* has developed a committee process to determine eligibility of children exiting the child system (which is a consolidated child system and not part of the agency that houses adult MH).

TABLE 1
Frequency of Condition Requirements of Adult and Child Population Policies

| <i>Condition</i> | <i>Value</i> | # of State Policies | |
|--|--|----------------------------|--------------|
| | | <i>Child</i> | <i>Adult</i> |
| Age at which child services end and adult service begin (n=46) | Age 18 | 31 | 44 |
| | Age 19 | 1 | 1 |
| | Age 21 | 5 | 0 |
| | Ends at age 21 if entered <age 18 | 7 | NA |
| | Age 22 | 1 | |
| | Missing | 1 | 1 |
| Requires a diagnosis[†] (n=46) | Yes | 34 | 43 |
| | No | 9 | 1 |
| | This or other conditions qualify* | 3 | 2 |
| Included diagnoses when diagnoses were required or qualified (n=43 child systems, 45 adult systems) | Psychotic disorders | 43 | 44 |
| | Major affective disorders | 43 | 44 |
| | Borderline personality disorder | 43 | 34 |
| | Post traumatic stress disorder | 43 | 29 |
| | Attention deficit/disruptive behavior disorders | 40 | 18 |
| | Missing | 0 | 1 |
| Requirement of functional impairment** (n=46) | Yes | 29 | 36 |
| | No | 3 | 3 |
| | This or other conditions qualify* | 14 | 7 |
| Definition of functional impairment (n=46) | cutoff score on scale | 11 | 9 |
| | description of areas & impairment levels | 33 | 34 |
| | Missing | 2 | 3 |
| Impairment duration requirement (n =46) | none | 24 | 23 |
| | lasted 6 mo | 3 | 2 |
| | expected to last 6 mo | 1 | 1 |
| | last 1 year | 5 | 5 |
| | expected to last 1 year | 10 | 8 |
| | lasted 2 years | 0 | 4 |
| | this or other conditions qualify | 3 | 1 |
| | Missing | 0 | 2 |
| Other qualifying conditions; | Risk or history of out-of-home placement or Other intensive services | 13 | 17 |
| | Multiagency/interdisciplinary team involvement | 9 | 0 |
| | Presence/risk psychosis/dangerous to self/others | 7 | 6 |
| | Special Education Student | 4 | 0 |
| | Homeless and mentally ill | 2 | 5 |
| | Other | 16 | 13 |

[†] Must meet DSM-III-R/IV or ICD equivalent criteria.

* policy stipulates that this condition qualifies, but is not required if other conditions are met

** Summarizes whether or not a functional impairment is required, however it is defined.

The child system identifies any individual aging out of their system that is believed to be in need of adult MH services and refers them to the committee that is comprised of adult and child MH representatives who collaboratively determine their eligibility and make treatment

recommendations. The administrator reported that only a handful were deemed ineligible and that is because they could find no mental health condition at all. *Maryland* has extended child eligibility to age 24 in their 10 pilot sites (see Comprehensive System Building within Innovations in the Field, above). A slightly different approach to changing the eligibility demarcation at age 18 was to lower the *lower* age criteria to access specialized adult services to include 16 year olds (*MO*). Individuals who meet the adult criteria at age 16 for adult targeted case management could begin utilizing that service, rather than having to wait until age 18, and these case managers, then become more familiar with the child system with which youth are involved. A few states (*NH, SD*) could extend child service eligibility from ages 18-21 for any individual that met certain circumstances (e.g. they still needed services).

Distribution of Transition Support Services

This section summarizes the types of transition support services offered within adult MH systems and the number of states offering those services. Transition support services refer to services that support an individual during the transition age (ages 18-30 within the adult MH system), that are specifically focused on this age group. Administrators were asked about 13 different categories of services and whether adult MH offered any of these service types either to the younger adult age group or had tailored the approaches for younger adults (see Guidelines in Appendix A). “Offering” the service meant that adult MH at least partially funded the service. “Tailored” largely meant that there had been a recognition of the unique needs of young adults and that the approach offered to all adults had been modified for the young adults accessing the service.

If a service was formally limited to younger adult clients, it was counted (such as a day program for only younger adults). Not uncommonly, administrators described group homes that, because of some informal circumstance, had ended up with primarily younger adult clients, but was not a formal arrangement, and was not counted as a transition support service. Table 2 summarizes the reports of the 42 states in which administrators reported that they were able to report with confidence, the services that were offered on a formal basis in their state. Additional services might be offered to young adults on an informal and case by case basis, however, they are not reflected in the table.

As in child MH systems (Davis & Sondheimer, 2005), supervised housing was one of the most common services that had been tailored for the transitioning population. Administrators indicated that there was a need to separate younger and older age groups in supervised housing arrangements to accommodate lifestyle preferences that were relatively unique to each age group. Also similar to findings in the child system, comprehensive specialized programs are among the most common. In the child system it was the wraparound model, in the adult system it tended to be Assertive Community Treatment (ACT). What is overwhelmingly clear, however is that any single type of program was generally **not** available at all in the vast majority of states (81-100% of states), and that fully half of the states offered no specialized transition support programs at all.

TABLE 2
Availability of Transition Support Services Offered by State Adult MH Systems Specifically for Young Adults Ages 18-30

| TYPE OF SERVICE | DISTRIBUTION OF SERVICE number of states (n=42) | | | | |
|--|--|--------|----------------|-----------|----------------------|
| | None | 1 Area | Multiple Areas | Statewide | Distribution Unknown |
| Supervised Housing/Group Homes | 34 | 5 | 2 | 0 | 1 |
| Special Comprehensive (i.e. wraparound, PACT etc.) | 34 | 3 | 3 | 0 | 2 |
| Specialized Case Management (working only with youth/young adults) | 37 | 1 | 1 | 1 | 1 |
| Supported Housing | 37 | 3 | 1 | 0 | 1 |
| Vocational Support | 38 | 1 | 2 | 0 | 0 |
| Psychosocial Rehabilitation | 39 | 0 | 2 | 0 | 1 |
| Residential Treatment | 39 | 2 | 0 | 0 | 1 |
| Other | 39 | 1 | 1 | 0 | 0 |
| MH Treatment | 40 | 1 | 0 | 0 | 1 |
| Social Skills | 40 | 0 | 2 | 0 | 0 |
| Vocational Counseling/Preparation | 40 | 1 | 1 | 0 | 0 |
| Homeless Mentally Ill | 41 | 0 | 1 | 0 | 0 |
| Dual Diagnosis Treatment | 41 | 0 | 0 | 1 | 0 |
| Educational Support | 41 | 0 | 1 | 0 | 0 |
| Independent Living Preparation | 42 | 0 | 0 | 0 | 0 |
| Any Transition Services | 21 | -- | -- | -- | -- |

Distribution Disparity in Child and Adult MH Systems

Since a similar methodology was used to assess efforts that state child MH services were making in 2000, a direct comparison of services in Table 2 was made between child and adult MH systems in the 42 states, and is presented in Table 3.

It is important to note that the questions used to obtain information about specific transition support services were different in the two studies. Child administrators were asked an open-ended question about the presence of transition support programs, whereas their answers to that question resulted in a list of potential transition support service types that adult administrators were specifically asked about. Both groups were asked about any “other” efforts that were being made to serve this population. Another caveat to these findings is that the economy had worsened considerably between the first and second study, and it is possible that if child MH administrators were interviewed during the summer/fall of 2003, they would have reported fewer transition services as a result of budget cuts.

As can be seen in Table 3, most types of services were offered by more state child MH systems in 2001 than adult MH systems in 2004. Combining all types of services to determine whether each state offered some type of transition support service revealed that more child than adult MH systems offered some transition support services.

TABLE 3
Percent of States Reporting the Presence of Transition Support Services
Within Adult and Child MH Systems

| TYPE OF SERVICE | Percent of States With Service (n=43) | |
|--|---------------------------------------|----------|
| | Adult MH | Child MH |
| Housing (supervised, supported, or group home) | 23.3 | 32.6 |
| Special Comprehensive (i.e. wraparound, PACT etc.) | 20.9 | 30.2 |
| Vocational Support, Preparation, Counseling | 11.6 | 20.9 |
| Psychosocial Rehabilitation | 7.0 | 2.3 |
| Residential Treatment | 7.0 | 4.7 |
| Other | 4.7 | 9.3 |
| MH Treatment | 4.7 | 7.0 |
| Social Skills | 4.7 | 7.0 |
| Homeless Mentally Ill | 2.3 | 0.0 |
| Dual Diagnosis Treatment | 2.3 | 2.3 |
| Educational Support | 2.3 | 23.3 |
| Independent Living Preparation | 0 | 20.9 |
| Any Transition Services | 48.8 | 69.8 |

Catalysts and Impediments for System Change

This section summarizes the themes that administrators expressed regarding system factors facilitating and hindering the ability of adult MH systems to better address the needs of young adults. All interviewed administrators responded to this question. Administrators were specifically asked to focus on the characteristics of the systems, rather than characteristics of the population that might make it difficult to provide appealing services. For most themes that were described as hindering young adult system development, the flip side of the factor could be stated as supporting development. Rather than restate the obvious, this report presents just one side and leaves it to the reader to interpret the reverse.

Administrators raised more than 100 topics. Table 4 lists the themes they raised in at least five states. The ranking of the number of states raising the issue indicates how relatively common the view was expressed (i.e. the theme identified by the most states was ranked #1, and that identified by the second largest number of states was ranked #2, etc.). Complete definitions of these most common themes are described in Appendix B. Individual themes were coded as “other” when they were raised by only 1 administrator and could not be generalized to any of the other category definitions. Administrators from 28 states raised at least one theme that fell into the “other” category. Specific themes were grouped into one of four larger categories that were defined by the two authors and grouped by them using the same consensus process described for coding of administrators’ responses into specific themes.

These four larger categories are defined as follows:

- **Fundamental Change Factors** – Themes that described factors that are important for any system change, but not specific to the young adult issue. The components of fundamental

change address administrative functions, leadership, issue prioritization, and resource prospecting, including funding, to make the needed changes.

- ***System Fragmentation*** – Themes that reflected the difficulties generated by boundaries between service systems that can form barriers to efforts that require cooperation and coordination across systems.
- ***Helpful or Harmful Practices*** – Themes that described clinical or service practices that were viewed as being particularly beneficial or harmful for young adults.
- ***Direct Line Staff Issues*** - Themes that referred to issues about the direct staff, professional or not, that provided services or treatment.

Fundamental Change Factors

These were the most commonly raised themes. It is not surprising that the single most common theme raised was the impact of insufficient resources. This interview was conducted in the summer and fall of 2003, in the midst of a national economic crisis that had resulted in severe state budget cuts in most states. Many administrators raised the issue during the interview process and spoke generally about how they were struggling to maintain even basic services for clients with the most disabling conditions. However, fiscal limitations were also one of the main themes raised by child MH administrators in the spring of 2001. This suggests that while fiscal limitations may have been particularly pronounced at the time that adult administrators were interviewed, it is a constant challenge for the task of changing the system.

Numerous models of organizational change list leadership as one key component (Burke & Litwin, 1992). Leadership is needed to develop a vision, to raise the issue to a high priority, to keep the issue in the forefront among many competing agendas, to constantly look for opportunities to make changes, to inspire those who need to change their ways of working, and to seek out and procure the resources and funding necessary to make the change. If there is leadership, prioritization and funding will follow. Leadership was viewed as necessary at the state and federal levels, and as needing to be complemented by persistent and intense advocacy from consumers, family members, and from providers (squeaky wheels). These were also the most common themes raised by child MH administrators in the previous study (Davis, 2001).

System Fragmentation

Within this category, administrators raised various issues about the fragmentation most commonly between child and adult MH systems, separate funding streams, separate administrations with separate regulations and policies, and separate practices. They also described the deleterious effects of territoriality, chiefly protecting funding or resources, on the system's capacity to provide good services for young adults. Some administrators raised these issues in reference to other agencies, such as substance abuse, vocational rehabilitation, or housing agencies.

Numerous administrators raised the specific issue that the separate eligibility or target population criteria used in the child and adult MH system was a barrier to continuity of care throughout the transition stage. Different child and adult eligibility issues were also related to Medicaid funded services. Administrators described that there were different eligibility criteria for Medicaid funded

services for those under age 18 or 21 than for those age 21 and over that had an impact on continuity of care. A few administrators raised this issue through the existence of multiple different ages of aging out of children's services (e.g. special education to age 22, child welfare to age 21, and child MH to age 18).

Helpful/Harmful Practices

These themes were defined as describing clinical or service practices that were viewed as being particularly beneficial or harmful for young adults. A long list of practices fell into this area, with the six most common described by administrators in 10 or more states. These included practices that were recovery oriented, flexible, individualized, and focused on functioning. This view stemmed from concepts about the kinds of services young adults particularly needed or were attracted to. Most of the helpful practices are part of the system of care values for children (Stroul & Friedman, 1984), with the addition of some of the more current adult models or values, including recovery, psychosocial rehabilitation, and ACT.

One intriguing point of contrast was that, as a group, administrators expressed opposite views about the value of separate or special services for young adults. Specifically, numerous administrators indicated that one of the characteristics of systems that facilitated improved services for young adults was to have more services that were specifically for this age group while a smaller, but still significant number of administrators expressed that specific services for young adults were not needed or were even deleterious. Those that expressed that it was not needed generally couched this theme in the caveat that if adult MH services were good, or progressive (i.e. individualized, recovery-based, etc.) that separate services would not be needed for young adults. One administrator expressed that it would be unethical to offer specialized services to young adults because it would be unfair to non-young adults who were unable to access those services. Several administrators expressed the view that specialty services in general, were detrimental to the system, that they produced a more fragmented and expensive system. The view that specialty services were not needed was also reflected in the manner in which administrators responded to the questions about specific transition support services that were available (summarized above). Numerous administrators listed a variety of programs, often vocationally oriented, or a psychosocial rehabilitation program, and when asked if it was tailored for young adults, or only served young adults, it was noted that such services were available to any adult in the system, but was seen as being particularly appropriate for young adults.

Professional/Staffing Issues

These themes were defined by their reference to the direct staff providing services or treatment, and generally reflected staffing needs when there is a new specialty population. Training is needed, resistance to change must be overcome, and staff with specific skills sets are required. One of the issues specific to the young adult population is the view that professional training reflects the same weakness as the system in general; individuals are trained either as child *or* adult MH professionals. This produces individuals who are not comfortable or trained to work with individuals whose developmental stage crosses this arbitrary child/adult distinction. Separate training can also foster some of the other issues implicit in the child/adult system fragmentation, including philosophical, cultural, and practice differences.

TABLE 4
Most Commonly Stated Themes From State Adult Mental Health Administrators (N=50)

| <i>Topic</i> | <i># States</i> | <i>Rank</i> | <i>Topic</i> | <i># States</i> | <i>Rank</i> |
|--|-----------------|-------------|--|-----------------|-------------|
| <i>Fundamental Change Prerequisites</i> | | | <i>Helpful Practices</i> | | |
| Insufficient Money or Resources | 26 | 1 | Recovery Model | 16 | 8 |
| Leadership | 23 | 2 | Programs Specifically for Young Adults | 16 | 8 |
| Priority | 21 | 3 | Flexible Services | 11 | 13 |
| Squeaky Wheels | 18 | 7 | Individualized Care | 11 | 13 |
| Fund YA Issue/ Services/ Population | 16 | 8 | Services that Focus on Functioning | 10 | 15 |
| Federal Initiatives/Leadership | 9 | 16 | No Need for Specialized YA Services | 10 | 15 |
| Increased Awareness | 8 | 23 | Normalized/Least Restrictive Environment | 9 | 16 |
| Requires Creativity | 8 | 23 | Person-Centered/Personal Futures Planning | 9 | 16 |
| Requires Service Guidelines Or Models | 8 | 23 | Appealing Services | 9 | 16 |
| Requires New Policies | 7 | 23 | Community-Based | 8 | 23 |
| <i>System Fragmentation</i> | | | <i>Professional/Staffing Issues</i> | | |
| Interagency/Child/Adult MH Relationships | 21 | 3 | Involving Families | 8 | 23 |
| Interactions Across Child &Adult MH | 19 | 5 | Coordinated Services | 7 | 31 |
| Eligibility Differences | 19 | 5 | Focus On Preparation For Independence | 7 | 31 |
| Territoriality | 12 | 12 | Strengths-Based | 6 | 37 |
| Separate Funding of Child/Adult MH | 10 | 15 | Use Child System Expertise | 6 | 37 |
| General Child/Adult Dichotomy | 9 | 16 | Assertive Community Treatment | 6 | 37 |
| Bureaucracy Bad/Small System Good | 9 | 16 | Small Caseloads | 5 | 42 |
| Poor Handshaking | 9 | 16 | | | |
| System Culture Differences | 8 | 23 | Training Needed | 15 | 11 |
| Ignorance of Other Systems | 8 | 23 | Dichotomous Training Bad | 8 | 23 |
| Multi-Stakeholder Buy-In Important | 7 | 31 | Resistance To Change | 7 | 31 |
| Different Funding Levels | 6 | 37 | Special Staff/Professionals Needed | 6 | 37 |
| Family vs. Individual Focus | 5 | 42 | | | |
| Connection To Substance Abuse System | 5 | 42 | | | |
| Child System Owns The Issue | 5 | 42 | | | |

IMPLICATIONS

A Nascent Problem

If the responses of adult MH administrators, and their reports about their systems is accurate, then addressing the service needs of young adults and the service implications is in its infancy (green) in adult MH systems. There was both an absence of recognition that young adults had needs that were different from older adults, and there was a belief that whatever those needs were they would be addressed by good, generic adult MH services that any adult in the system might access. It is also

clear that there is an important minority of administrators that did express that young adults were not well-served, and wanted to see the system improved along these lines.

As noted in Table 2, the sparsity of specialized services across the county for this population is clear, and likely reflects the embryonic state of this issue within adult MH systems. These findings corroborate the testimonials and reports by youth and parents that they find few appealing transition supports (Adams et al., 2000; Clark & Davis, 2000; Davis & Butler, 2002; Davis & Vander Stoep, 1996).

Nonetheless, numerous truly innovative efforts were described. Pooling the knowledge across states would provide a strong knowledge base that could be shared within adult MH, and with related child and adult systems.

The degree to which services were potentially continuous throughout the transition stage was addressed, in part, by the finding of misaligned child and adult MH population policies. These policies indicated that at least some older adolescents from the child MH system with continuing need for mental health and transition support services were likely denied access to services because of the arbitrary changes imposed on them due to the aging-out phenomenon. This conclusion is supported by child MH administrators' descriptions of eligibility issues (Davis & Sondheimer, 2005). Careful analysis of the federal definitions of serious emotional disturbance for children and serious mental illness for adults established by the Center for MH Services (Section 1911(c) and 1912(c) respectively of the Public Health Service Act; PL102-321) reveals extremely similar definitions of SED and SMI. Both use the same language to describe the diagnostic criteria, but different language to describe the functional criteria. The only implicit diagnostic difference would be age limitations in the applications of various diagnoses, such as with antisocial personality disorder requiring the age of 18. The functional definition for SED, though different, is not obviously broader than in the SMI definition. Many states do not use the exact federal definitions, and the definitions used are, indeed, generally more restrictive for adult MH. Thus, one critical area for child and adult MH systems to address together is how to bring their definitions of who is served into better alignment such that those who have been served in the child system, and deemed to have significant mental health and service needs, are not denied needed transition supports and related services because of a change in age.

Causes of Nascence

There appear to be several factors that contribute to administrators' lack of recognition of the unique needs of young adults in adult MH systems. Concern would have to generate from awareness and knowledge about this age group within the MH population, and their resulting service needs. It is therefore, essential that administrators are educated in the special needs of youth in transition to adulthood to provide a foundation for introducing system change. Some common characteristics of young adults with serious mental health needs include that they need habilitation, not rehabilitation, they prefer the company of same-age peers—peer approval is particularly powerful. The stigma of mental illness is also particularly painful at this age, they have not finished their schooling or they have quit prematurely, frequent job changes are common in all young adults, they are often still very imbedded in their families, they do not trust authority, they need to experiment in many areas of their lives to determine what they want (as opposed to what others told them they should want), they are sexually active but not socially skilled, drug and alcohol use may be considered by those of this age to be socially “normal”, many suffer the sequelae of emotional or physical trauma, and their parents struggle to find new ways of relating to their legally adult child.

All of these characteristics have important service implications that are difficult to accommodate with small modifications of approaches for more mature adults. Thus, *some* specialized services are needed to serve them well, and much education is needed to successfully tweak even progressive services for adults. Those familiar with adult MH services can compare them to appropriate transition support services described by Clark and colleagues (Clark, Deschenes & Jones, 2000; <http://www.fmhi.usf.edu/cfs/policy/tip/systemdesc.htm>). Comparative analysis can help identify areas of needed change.

RECOMMENDATIONS

Leadership

There is a long path on the road to embracing this population and providing them with appropriate services. This journey will need dogged and visionary leadership to create a developmentally appropriate framework and a culture of thinking developmentally within adult MH services. That leadership will keep the issue in the forefront, seek or create the necessary resources, and encourage the needed creativity to address this system disparity.

National and Federal Leadership

Given the missions of the Center for Mental Health Services (CMHS), the National Institutes of Mental Health (NIMH), and NASMHPD, they are ideally positioned to raise the prominence of this issue for state systems. These federal agencies and organizations play a critical role in shaping MH services through knowledge development, dissemination, and incentives. There is little consensus among state MH administrators that young adults have different service needs than mature adults, and that adult MH systems have a responsibility to address the developmental needs of young adults. CMHS and NASMHPD could provide leadership by developing statements and activities that are consistent with the following positions:

- Transition to mature adulthood is acknowledged as encompassing ages 16-30.
- State adult and child MH systems are encouraged to take responsibility for ensuring that the specific developmental needs of 16-30 year olds in their systems are addressed.
- Development of young-adult specific services in the MH system are enhanced by a combination of providing guidance on how such development can occur, and incentives to do so.

State practices could be greatly modified if CMHS reexamined their definitions of SED and SMI, and the structure of their grants, with an eye towards encouraging continuity and appropriateness of services across the transition age. Further leadership could be provided through these three agencies examining their rationale for and the consequences of organizing into child- and adult-defined subdivisions. Similarly, if the Social Security Administration reviewed and minimized the impact of their age-defined categories on the transitioning population, state MH services would likely alter because of the change in funding potential. NIMH is in an ideal position to help develop

knowledge, through research, about the developmental course into adulthood for youth and young adults with serious mental health conditions, and development and identification of appropriate treatments and services specifically for this age group.

Another specific area of leadership that is immediately needed is to estimate the number of young adults who are impacted by the current system. The number of young adults that are either in state adult MH services, or would be in those services were it better suited to their needs, is unclear. Reflecting the lack of recognition of the importance of this age group, federal reporting mechanisms for state adult MH systems do not request any further age breakdown than the number of those aged 21-64, and 21 and over, for the community mental health services block grant application uniform reporting system and for NASMHPD's Research Institute's state profiling system, respectively. It is difficult to develop services in the absence of knowing the size of the population for whom those services are developed. Thus, CMHS and NASMHPD would provide important leadership on this issue if they requested an age breakdown of 16&17 year olds, 18-20 year olds (that might be served in either child or adult MH) and 21-25 or 21-30 year olds. It is interesting that CMHS requires the reporting of those over age 64 – thus communicating the importance and separateness of the elder population (see Appendix C).

Efforts regarding the transitioning population within CMHS to date have largely generated from the Child, Adolescent, and Family Branch, reflecting the greater investment in this issue within the child MH system, and the separateness of child and adult services. These efforts have included this knowledge development project, and the previous parallel project, consensus building meetings, and other knowledge development projects. However, there was greater intra divisional coordination in the recent Partnerships for Youth Transition grant program, which funds five demonstration sites across the country. It is a cross-divisional effort with project officers from the Adult and Homeless Branches as well as the Child, Adolescent, and Family Branch. CMHS has provided an important model of cross divisional monitoring with this grant program. Further, in general, federal government Branches, Divisions and Offices that primarily serve adults or children can model appropriate recognition of the transitioning population by expanding the use of their funds to include youth in transition, starting at age 16 for adult programs and up to age 30 for child programs, and coordinate these programs to reduce redundancy. Moreover, any federal government program that is age defined and includes any portion of the 16-30 year age range, could provide needed central leadership by insuring that they include the full age spectrum of transition in their program.

State or Local Leadership

Leadership is needed at every level of the system, from local consumer, family, and mental health professional advocacy groups and local administrators, to state level administrators and policy makers, and strong national and federal leadership. Leaders need to embrace this age group, inclusively, and partner with other stakeholders and advocates. One of the most important avenues for system change is for leaders to maintain constant awareness of the issue so that as opportunities for system change are not only recognized as such, but are actively sought out. Leadership at the local level can also raise awareness of the issue, and keep it in forefront of the public debate.

Resources and Funding

Federal Level

CMHS is in an ideal position to provide fiscal incentives to states to provide continuous, appropriate and appealing services to any young people with serious mental health conditions in this age group. Medicaid is also in a powerful position to provide needed funding for young adult services. Many eligibility categories end at ages 18-21, and vary across states. Exceptions to the age-based termination of eligibility for youth with serious mental health conditions until they reach a more mature age might also provide more fiscal support for young adult services. For example, when a young person with a significant mental health condition, who has qualified for Medicaid because of living below poverty level, would no longer qualify as such under adult poverty guidelines, there should be a Medicaid eligibility category in which meeting either the child OR adult Social Security Administration's mental health disability category would qualify an individual for Medicaid coverage up to the age of 30, at which point the individual would need to meet the adult SSA disability criteria or another category to continue. Lastly the Government Accounting Office (GAO) should assess the size of the population that continues requiring transition support services after adolescence, the size of the young adult population with SMI, and identify the costs of not serving these young adults adequately against the cost of providing federal funding to support the development of adequate services in the adult MH system.

Any Level

Identify resources that could be used for this age and disability group, such as the federal MH block grant dollars, or Early Prevention, Screening, Diagnosis, and Treatment funds that could support services for 18-21 year olds, to begin funding efforts to improve services for them. Be willing to start small, and build upon any progress. Blend or combine funds with other agencies that might be motivated to serve this population, such as substance abuse, vocational rehabilitation, or corrections. Bring together various stakeholders, from the child and adult systems, to develop a common understanding and appreciation of the special needs of young adults and youth in transition. Combine forces to advocate for increased funding.

Prioritization

The task of leadership is to make support of the transition into adulthood for young adults a national, state, and local priority. As with funding issues, it is important to partner with relevant stakeholders, including young adult and family advocates, to raise the profile of this issue through inviting their input into the next steps, and holding joint conferences or trainings. Task forces can be developed that are comprised of transition advocates and potential change agents within child and adult mental health and within other related systems. Gather locally relevant data and stories that can highlight the poignancy and importance of the issue in ways that appeal to each relevant audience. Combine data with an assessment of current resources and needs to help focus where

work is needed. Have conversations with all involved parties, at all levels, to determine their concerns and desires (e.g. focus groups of youth in transition, their families, direct care providers, and State agency administrators, etc.)

STUDY LIMITATIONS

There were several important limitations to the methods of this study (detailed in Appendix D):

- Generally, information was obtained only from administrators, which includes the limitations and bias of their knowledge, or their efforts to obtain the knowledge.
- The lead investigator had a strong child/adolescent service system bias in which the recognition of the young adult “issue” by the adult system was assumed. This led to some inefficient questions, and some apparently defensive responses, that may have impeded more thorough information gathering.
- The timing of the interviews resulted in an overemphasis of the impact of severe budget restrictions.
- Availability of transition support services for young adults in highly decentralized state administrative structures are underreported by this methodology.

These findings, demonstrate that state adult MH systems are attempting to improve their transition support services, but they have a long way to go before young adult clients and their families can count on the availability of comprehensive, age-appropriate, appealing services throughout the transition stage.

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Appendix A
Study Guidelines

For purposes of this interview transition services are defined as those services that are focused on assisting young people complete the tasks of adolescence and take on the mantle of adulthood. Typical transition services offer the following supports:

1. *completing high school or Graduate Equivalent Diploma (GED)*
2. *entering and completing post secondary education or training*
3. *obtaining vocational support/training*
4. *independent living/housing preparation and support*
5. *assistance in developing and maintaining adult social support networks*
6. *continuation of mental health services through the transition (up to age 25)*
7. *transition planning and coordination of transition services and supports*

Items 1-6, below, are the focus of the telephone interview. At the end of the interview Dr. Davis will ask you about documentation that would address items 7-11.

We are interested in efforts that help to open the door to transition supports for all adolescents who need them in the child mental health system, who have aged beyond their upper age limits. We are also interested in all efforts that address the needs of any young adult in your system. In some states these are separate issues, so we will ask about them separately to insure that all bases are covered.

1. In order to have some context, would you describe who adult mental health serves (basic eligibility criteria), how adult mental health is configured in regards to the offering of direct services, the centralization of policy making and funding decisions, and the organizational relationship to child mental health services.
2. Are there differences between the eligibility criteria for receiving children's mental health services and the criteria for receiving adult mental services? If so, are there any special efforts to reconcile these differences?
3. This section asks about efforts by adult mental health to provide or improve transition support services.
 - A. *Are there case managers who specialize in the young adult population?*
 - B. *If so, at what age can they begin working with them, and what kind of training do they receive for this work?*
 - C. *Can case managers begin working with young adults while they are still receiving child mental health services?*
 - D. *Do you offer categorical programs that serve only a younger adult age group in the following areas*
 - a) Educational Support (High school, GED, or post secondary education)
 - b) Vocational Counseling
 - c) Vocational Preparation
 - d) Vocational Support
 - e) Independent Living Preparation
 - f) Supported Housing
 - g) Supervised Housing
 - h) Other housing supports

- i) Homeless Mentally Ill Programs
- j) Treatment for Comorbid Substance Abuse
- k) Mental Health Treatment
- l) Social Skills or Social Support
- m) Specialized Transition Planning and Service Coordination - (i.e. PACT or ACT teams, wraparound services)

E. Are there any special work groups within mental health, that adult mental health participates in or leads, that address the needs of youth exiting the child system? Of the young adult population?

F. If so, what have been the products of their efforts?

G. Are there any special efforts to coordinate with schools' transition planning mandates?

H. Has a system needs assessment been done for transition services or the young adult population? Statewide or locally?

I. Are there other efforts that adult mental health has made to address the transition needs of the population exiting child mental health or the young adult population?

- 4. *If there is specialized transition planning (question 2.D.13 above), at what ages does it occur, who is involved, and is there any flexible funding available to this process?*
- 5. *What efforts are made to coordinate with child mental health's efforts to provide transition supports to the adolescents they serve?*
- 6. *What efforts, such as interagency agreements, interagency committees, or system of care approaches, is adult mental health making to coordinate transition services across other child-serving systems (schools, child welfare, juvenile justice, etc.)?*
- 7. *What efforts is adult mental health making to coordinate transition services across other adult systems (vocational rehabilitation, substance abuse services, housing services, etc.)?*
- 8. *What are the budgetary and fiscal considerations that aid or limit transition support services and efforts?*

Appendix B
Theme Definitions

Theme Definitions

| THEME NAME | DEFINITION |
|--|--|
| Fundamental Change Prerequisites | |
| Insufficient Money or Resources | Insufficient funding or resources to do what is needed for YA*, either for something specific, like outreach extension; or in general, general under funding that reduces ability to specialize. |
| Leadership | Requires leadership to push the issue forward |
| Priority | Transition is not a priority issue/ transition needs to be a priority issue. This can be regarding the population, or the issue of their needs. |
| Squeaky Wheels | Does not get priority without advocates embracing/providers embracing the issue; increased voice of advocates helps transition issues |
| Fund YA Issue/ Services/ Population | Money has not been put towards/ Funding needs to be invested in the issue, the population, special services for them OR funding is prioritized for some other population. |
| Federal Initiatives/Leadership | No federal initiatives or leadership on this issue; leadership needed |
| Increased Awareness | Awareness of the needs of the population, lack of services for them is needed |
| Requires Creativity | Requires creativity to solve the system issues; requires a system that rewards creativity |
| Requires Service Guidelines Or Models | Hard to make changes in the absence of a model or guidelines |
| Requires New Policies | New policies are needed to change the system |
| System Fragmentation | |
| Interagency/Child/Adult MH Relationships | Helpful to have interagency relationships /contact/communication; helpful to have good relationship between CMH & AMH. |
| Interactions Across Child & Adult MH | Helpful to have interaction across CMH & AMH; strong presence of CMH within SMH council helpful. |
| Eligibility Differences | Eligibility differences interfere/removing differences facilitates |
| Territoriality | Detrimental to have people protecting funding/resources; territoriality inhibits coordination/lack of cooperation across agencies |
| Separate Funding of Child/Adult MH | Separate funding and administrations of funding of CMH & AMH interferes |
| General Child/Adult Dichotomy | General reference to the split between CMH & AMH |
| Bureaucracy Bad/Small System Good | Bureaucracy interferes with making changes, small systems can make things happen more quickly, or fix it more informally through relationships |
| Poor Handshaking | Poor coordination between other agencies or CMH with AMH at the time that adolescents age out, interferes. |
| System Culture Differences | Various cultural differences between CMH & AMH CMH more multi-agency than AMH habilitation vs. rehabilitation, AMH needs to recognize YA acquiring new skills |
| Ignorance of Other Systems | Being unfamiliar with other systems' details not helpful |
| Multi-Stakeholder Buy-In Important | Can't achieve system change without support/buy-in of other systems |

| THEME NAME | DEFINITION |
|---|---|
| Different Funding Levels | Unequal funding in CMH or child system vs. adult system interferes with AMH ability to provide the needed array of services |
| Family vs. Individual Focus | CMH more family focused & AMH more individual focused, makes continuity difficult |
| Connection To Substance Abuse System | Strong connection to SA services/system important |
| Child System Owns The Issue | Because CMH "owns" (pushes, raises etc.) the issue, AMH does not |
| Helpful Practices | |
| Recovery Model | Helpful to have <u>recovery</u> model (vs. palliative care); will shape services to be more appropriate for the young adult population |
| Programs Specifically for Young Adults | There are not many programs specifically for young adults in AMH/need customized services for YAs |
| Flexible Services | Helpful to have <u>flexible</u> model; will shape services to be more appropriate for the young adult population |
| Individualized Care | Helpful to have <u>individualized care</u> model, will shape services to be more appropriate for the young adult population |
| Services that Focus on Functioning | Functional focus helpful; a culture of focusing on what will benefit clients holistically or practically |
| No Need for Specialized YA Services | Do not need specialized YA services – if we provide good/progressive AMH services to all clients, then do not need specialized services for this age group |
| Normalized/Least Restrictive Environment | Providing services in the least restrictive, most normalizing environment |
| Person-Centered/Personal Futures Planning | Person-centered planning helpful |
| Appealing Services | Helpful to have services that appeal to YAs |
| Community-Based | Community-based services good |
| Involving Families | Services that involve YA's families helpful |
| Coordinated Services | Well-coordinated services helpful |
| Focus On Preparation For Independence | CMH or extensive out-of-home treatments not sufficiently preparing adolescents for independence; child system promotes dependence/doesn't teach independence. |
| Strengths-Based | A strengths-based approach is helpful |
| Use Child System Expertise | Learn about approaches that work with older adolescents from child system |
| Assertive Community Treatment | Assertive Community Treatment (or PACT) is helpful |
| Small Caseloads | caseloads in AMH too high to do good transition work/small caseloads-intensive/targeted case management helpful |
| Professional/Staffing Issues | |
| Training Needed | Need to provide training (helpful) |
| Dichotomous Training Bad | Professional training as either a child specialist or adult generalist not helpful |
| Resistance To Change | psychological resistance to change (from traditional approaches) interferes, has to be overcome |
| Special Staff/Professionals Needed | Requires knowledgeable staff/professionals; hard to find knowledgeable staff/professionals for this population. |

Appendix C
Age Reporting Requirement for
COMMUNITY MENTAL HEALTH SERVICES
BLOCK GRANT APPLICATIONS

**COMMUNITY MENTAL HEALTH SERVICES
BLOCK GRANT APPLICATION GUIDANCE AND INSTRUCTIONS
FY 2005 - 2007**

(see <http://mhbg.samhsa.gov/MHApplication041204.doc>)

Appendix I: URS Basic and Developmental Tables

Fiscal Year 2005 CMHS Uniform Reporting System: Guidelines for Basic Tables:

Table 2A. Profile of Persons Served, All Programs by Age, Gender and Race/Ethnicity
This table provides an aggregate profile of persons in the reporting year. The reporting year should be the latest state fiscal year for which data are available. This profile is based on a client receiving services in programs provided or funded by the state mental health agency. The client profile takes into account all institutional and community services for all such programs. Please provide unduplicated counts if possible.

Please enter the "total" in the appropriate row and column and report the data under the categories listed.

| Table 2A. | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
|-----------------------|-------|---|----|-------|----------------------------------|---|----|-------|---|----|---------------------------|---|----|---|---|----|-------|---|----|--|---|----|-----------------------------|---|----|------------|---|----|---------------|---|----|
| Report Year: | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| State Identifier: | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Persons Served by Age | Total | | | | American Indian or Alaska Native | | | Asian | | | Black or African American | | | Native Hawaiian or Other Pacific Islander | | | White | | | Hispanic * use only if data for Table 2B are not available. | | | More Than One Race Reported | | | Other Race | | | Not Available | | |
| | F | M | NA | Total | F | M | NA | F | M | NA | F | M | NA | F | M | NA | F | M | NA | F | M | NA | F | M | NA | F | M | NA | F | M | NA |
| 0-3 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 4-12 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 13-17 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 18-20 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 21-64 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 65-74 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 75 + | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Not Available | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Total | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |

Instructions for Tables 2A and 2B:

- 1 Include all persons served directly by the state mental health agency (including persons whose services are funded by Medicaid)
- 2 Include all persons in the system for whom the state mental health agency contracts for services (including persons whose served are funded by Medicaid).
- 3 Include any other persons who are counted as being served by the state mental health agency or come under the auspices of the state mental health system. This includes Medicaid waivers, if the waiver is run by the SMHA.
- 4 Count all identified persons who have received a mental health service, including screening, assessment, and crisis services.
- 5 For states where a separate state agency is responsible for children's mental health, unduplicated between the child and adult agencies when feasible. Otherwise, recognize and indicate that there is overlap between the 0-17 group and the 18 and over group but that there is unduplication within each group.
- 6 "Hispanic" category in Table 2A allows for states to report if they do not currently compile Hispanic Origin as a separate question. States that track Hispanic Origin as a separate category should report on Table 2B instead of Table 2A.

Appendix D

Study Limitations

Study Limitations

It is important keep in mind that this report is limited to the perspectives of the adult MH directors or their designees. Also, although respondents were provided the interview questions in advance, it is likely that they did not formally “prepare” for the interview by reviewing the materials thoroughly and preparing responses in advance. Their responses should be considered to reflect their working knowledge of efforts in their system, or the working knowledge of others they invited to join the interview. Overall, the lack of reporting a categorical service does not guarantee that it was, in fact, not offered.

Interviewee opinions about system factors that facilitate and hinder better services for young adults were likely to be less detailed than those that might have been expressed had they viewed this population as a priority and therefore, been actively concerned that their needs were not being addressed by the current system. Interviews were conducted in the summer and fall of 2003; a period during which there was tremendous economic difficulty and state budgets were extremely tight. Therefore, it may be reasonable to assume why lack of money/resources was the most commonly stated theme in the report. The effect of the economy on interviewee’s responses might have masked other system characteristics that were not mentioned.

Some interviewer bias in the design of the survey instrument may have been present as a result of the Principal Investigator’s prior experience in conducting similar interviews with child administrators two years previously, and having clinical training and research experience in the field of child/adolescent mental health. One bias was assuming that adult division members would be aware of or share concerns about the accessibility, appropriateness, or desirability of adult services for young adults with serious MH conditions. This assumption that was implicit in the question about the services offered only to young adults or tailored for their needs, perhaps prompted some of the responses that administrators volunteered about the availability of general adult services to young adults (they were not denied access to any services because they were young).

Investigator bias also resulted in somewhat incomplete reporting of MH services for young adults. The questions about types of transition support services were developed from the answers obtained from child administrators, and services in child/adolescent mental health systems are almost always offered within similar age groups (typically split at least as children under 13 and teenagers). The question about MH treatment in the section on services that were tailored for or only offered to young adults may not have been a sufficient prompt to obtain accurate information about age-grouped mental health treatment. In particular, one of the ways that MH treatment may differ between adult and child MH systems is that *any* group setting in the child system is likely to contain individuals who are relatively similar in age (pre-adolescent or adolescent groupings) whereas it is unclear how much age grouping goes on in group treatment settings in adult MH systems. Some administrators volunteered that there was a young adult hospital unit, or a young adult day program, but it would have been better if these questions were specifically posed (i.e., Do you have separate hospital units, day programs, partial hospitalization programs for young adults?). It would also be useful to assess how common a practice it is for treatment groups to be offered specifically to young adults, such as trauma survivor groups, dual diagnosis groups, psychoeducational groups and the like.

Another process that reflected the interviewer's biases was in asking about any efforts to reconcile differences between the child and adult eligibility or priority population definitions. This again prompted somewhat defensive (even if legitimate) responses, about how the adult system was overwhelmed with serving adults with what were characterized as "real" mental illnesses, that it was not well-designed for people with behavior problems, and how the child system needed to work harder to prepare those ineligible youth for adult life without services.

This analysis was based on the administrators from 42 states with either centralized administrations, or contracting or monitoring mechanisms that would inform administrators of existing services. The remaining 9 states had highly decentralized administrative structures. One of the advantages of decentralization is that it can lead to local innovation, thus it is likely that some transition support efforts in those locales were unreported. Administrators from both Pennsylvania and California requested information about transition support programs from local administrators and relayed numerous innovative programs, supporting the notion that there may be more in the way of specialized supports for young adults in some decentralized states. However, it was unlikely that transition supports were widely available in decentralized states without the lead adult MH administrator being aware of that. Thus, the general conclusion that state adult MH systems lack sufficient transition support services is reasonable.

Appendix E

NASMHPD Adult Services Members at the Time of the Interview

JUNE 25, 2003

Active Members Roster
of:

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ADULT SERVICES
DIVISION**

NOTE: Each member has been designated, by the State Mental Health Commissioner, to represent their respective state in NASMHPD'S Adult Services Division.

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