

CHAPTER 4

Implications for Policy

There is currently ample evidence that current policies and practices are generally inappropriate and foreshortened at the critical juncture when youth with serious mental health (MH) conditions are on the threshold of becoming functioning adults in our society. (Davis & Koyanagi, 2005)

PURPOSE

This chapter focuses on systems and policy issues at the national, state, and program levels. Information for program administrators and policymakers is provided on

- policy challenges and solutions for youth with MHN,
- components of effective transition systems for youth with MHN,
- the beginning road map to establish a systemic foundation,
- critical design elements,
- universal access,
- competitive employment,
- the importance of youth leadership in developing services and policy,

- family involvement and support,
- caring adults,
- critical process design features,
- interagency coordination and collaboration,,
- resource management,
- cultural and linguistic competence to address institutional bias, and
- professional preparation and development of youth service practitioners.

THE POLICY CHALLENGE

In the past few years, significant attention has been given to improving the nation's mental health services for both youth and adults with mental health needs. In April 2002, President George W. Bush signed Executive Order 13263 establishing the New Freedom Commission on Mental Health and charged the group with conducting a comprehensive study of the problems and gaps in the mental health service system and to making concrete recommendations for immediate improvements that the federal government, state governments, local agencies, as well as public and private health care providers, could implement. In July,

2003, the Commission issued its final report to the President, which called for nothing short of *fundamental transformation* of the mental health care delivery system in the United States.

In response to the Commission's report, the Federal Partners Senior Workgroup for Mental Health Transformation was created, made up of senior-level staff representing six federal departments, including 11 agencies/offices and the Social Security Administration. As an extension of the ongoing work of the Senior Workgroup, the Federal/National Partnership (FNP) for the Transformation of Children's Mental Health Care in America was formed. In July 2005, the Department of Health and Human Services released the "Federal Mental Health Agenda" which articulates objectives for a long term strategy to transform the nation's child, adult, and older adult public and private mental health service delivery toward community-based care.

Included in the Agenda are several beginning steps that call upon multiple federal departments to become a part of the solution. As part of a strategy to meet this challenge, the Agenda charges the Department of Education's Office of Special Education and Rehabilitative Services to work with other federal agencies on researching, demonstrating, and disseminating promising practices on transitioning youth with MHN into employment. Underscoring the particular employment challenges facing youth with mental health needs in the juvenile justice system, DOL, DOJ and SAMHSA are to work together to identify such youth and help them find employment, specifically through DOL's One-Stop Career Centers.

Additional challenges faced by this population include transitioning to independent living, and negotiating the shift from child to adult service systems. Through SAMHSA's Partnerships for Youth Transition Grants Program, states develop and implement comprehensive program models to support youth throughout the transition process. To support this effort, the Agenda calls for the expansion of the Program to additional states and communities by enlisting the financial support of other federal agencies.

According to the Commission, the challenge of improving service delivery can be tackled, in part, by

more effective use of research findings. For example, through Policy Academies, SAMHSA will share findings from its Juvenile Justice and Mental Health project with states and localities, and discuss strategies for implementing effective youth program models.

Increasing state infrastructure to support mental health services for transition-age youth is yet another significant policy challenge. Grants such as SAMHSA's Child and Adolescent State Infrastructure Grants enable states to improve their service delivery systems through increased access to services, workforce development, and implementation of evidence-based interventions, among other strategies.

The Commission's recommendations reflect a belief that federal agencies must play a significant role in promoting shared responsibility for change across all levels of government and the private sector. However, the Commission acknowledges that states will ultimately be the "center of gravity" for transformation of the mental health system.

Shortly after the New Freedom Commission's report was issued, the final report of the White House Task Force for Disadvantaged Youth was released. It began with the following statement: "The complexity of the problems faced by disadvantaged youth is matched only by the complexity of the traditional federal response to those problems. Both are confusing, complicated, and costly." The report outlined a vision for all youth that would have them grow up

- healthy and safe;
- ready for work, college, and military service;
- ready for marriage, family, and parenting; and
- ready for civic engagement and service.

The resulting work of the Task Force concluded that federal programs should focus on four goals:

- better management,
- better accountability,
- better connections, and
- priority to the neediest youth.

The need for long term, systemic change was evident. Several federal funding streams already required coordination and collaboration, accountability systems, and a service focus on the most in need. In response to the Task Force’s report, federal departments and agencies took action. The U.S. Department of Labor’s Employment and Training Administration, for example, issued a Training and Employment Guidance Letter in May, 2006, that expanded its strategic vision for serving youth under the Workforce Investment Act to include youth with disabilities among our nation’s neediest youth.

Legislative mandates also are fueling the need to address youth with mental health needs, particularly as they transition out of school. Transition services have been identified as critical parts of the educational process for all students in the No Child Left Behind Act of 2001, and for students with disabilities in the 2004 Amendments to the Individuals with Disabilities Education Act. These legislative mandates call for the creation of a universally available, high-quality school-to-work transition system that prepares all students, including those with MHN, for work and further education and increases their opportunities to enter first jobs in high skill, high wage careers. Specifically, the transition outcomes of all students, including those with MHN, will be improved by encouraging students to stay in school and attain high standards of academic and occupational achievement, and by building effective partnerships among secondary schools, postsecondary educational institutions, community members, and parents. Transition services for youth with MHN should be based on these fundamental service delivery pillars.

COMPONENTS OF EFFECTIVE TRANSITION SYSTEMS FOR YOUTH WITH MENTAL HEALTH NEEDS

Research on effective transition programs for youth with mental health needs is limited, but a review of school-based transition programs for youth with disabilities, employment programs, mental health and social service programs, and supported work programs for adults with severe mental health needs finds several components that appear to be instrumental in their success:

- a systemic foundation,
- family involvement and support,
- transition staff (discussed in Chapter 3) and other caring adults, and
- competitive employment.

THE BEGINNING ROAD MAP TO ESTABLISH A SYSTEMIC FOUNDATION

A well-marked road map has not yet been established for what should be included in a systemic foundation to upgrade the support systems for youth with MHN; however, components are beginning to emerge. As a part of the development of the Federal Mental Health Agenda, a national panel of experts was convened by SAMHSA’s Center for Mental Health Services. This group provided a range of policy suggestions to address the barriers (e.g., broaden eligibility for services, enhance interagency focus on the youth population, broaden existing grant programs, and require outcome-driven approaches and accountability), which build on the following characteristics, identified by Dryfoos in the 1990s, of a comprehensive system for supporting the needs of youth with MHN:

- system level change involving federal, state, and local agencies in education, mental health, vocational rehabilitation, Workforce Investment Act programs, Ticket to Work, Medicaid, Social Security, juvenile justice, foster care, transportation, and other areas;
- continuity of effort that provides for long-term programs, reduces interruptions in services, spans the transition cliff, and includes outreach and recovery options for youth who fall through the cracks;
- multiple service options for addressing work skills, emotional problems, educational issues, interpersonal skills, and independent living that reflect the fact that there is no one solution that works for all youth with MHN;
- multiple opportunities for success that emphasize small triumphs and multiple chances;
- community specific services geared to specific needs and resources;

- programs that are grounded in a stable, flexible educational context that include wrap-around services such as social services, vocational experiences, and focused academic instruction; and
- administrative and service flexibility that includes community settings such as competitive job placements, community service, etc.

The systemic policy changes recommended by the panel, which focused on enhancing services and outcomes for youth with MHN include

- eliminating disincentives for youth employment such as SSDI, organizational cultures, and the “creaming” of easy-to-serve youth in order to improve outcome data;
- encouraging the funding of Peer Support Specialists to help youth navigate service tunnels; and
- increasing the age for mental health and related services for children and youth to as high as 30 years of age.

Much remains to be done. For example, a 2005 survey of members of the National Association of State Mental Health Program Directors revealed that states either did not have any programs focused on young adults or had programs in only a part of the state. Only two states (Maryland and Connecticut) were working on developing systematic services for youth with mental health needs statewide. Survey recommendations noted the need for leadership at the federal, state, and local levels, stating that “providing continuous and appropriate services for this age group cannot be achieved by any single agency,” and that continuity of services and developmentally appropriate supports are needed. Other thoughtful recommendations from the survey included (1) setting the transition period for youth with mental health needs at ages 16 to 30; (2) adjusting definitions of mental health needs so that they do not screen youth out of needed services; (3) developing partnerships to expand service delivery; and (4) collecting data and supporting research that will expand the limited research studies on youth with MHN. The good news from the survey is that there is “developing expertise and leadership available to states” (Davis & Hunt, 2005) that can help span the transition cliff and eliminate ineffective service tunnels.

THE CENTER OF GRAVITY – THE STATES

The states are being recognized as the place where the road maps will be developed to improve the needed services for youth with MHN. There are several critical program design elements as well as a set of process issues that need to be addressed by the states. In the list of key suggestions from the panel of experts discussed above, preparing for the world of work is a reoccurring theme that must be addressed. This will require deeper engagement of education and workforce development programs than has been the case in past.

As noted in Chapter 2, ensuring that a youth is healthy and ready for work, independent living, and civic engagement is easier said than done. There is no coordinated system that guides a youth through the process of becoming a productive and self-sufficient member of society and the labor market. Pieces of the system exist, such as Career and Technical Education, transition planning under the Individuals with Disabilities Education Act, and programs available through Vocational Rehabilitation and the Workforce Investment Act, but because these services are often incomplete and uncoordinated, they are frequently ineffective. Youth with educational and career challenges, such as those with MHN, too often fall off one of the many cliffs in the system or get shunted down an arbitrary or inappropriate service tunnel based on the point of entry into the system rather than the youth’s needs. Thus particular attention must be given to improving the processes and procedures used by all of the stakeholder agencies that have a role in contributing to the evolution of a new system.

Given the varied needs of youth with MHN, it will be necessary to include a number of different federal, state, and local agencies in the systems change effort to improve transition services and outcomes. Logically, the leadership on this task should begin at the state level, although the role of each specific agency will need to be established. Changes will be required in the service structure and procedures of workforce development organizations such as state Departments of Labor and Vocational Rehabilitation agencies, as well as the state and local mental health systems for children and youth. Prototypes will need to be tested

through local partnerships and collaboratives to assess a myriad of service strategies to identify those that most successfully improve outcomes; such testing will benefit all partners.

CRITICAL DESIGN ELEMENTS

What follows are a set of design elements that should be considered as these prototypes are developed.

Universal Access

An effective service delivery system should be based on a clear understanding of universal design, access, and service; however, there are no agreed upon definitions of these terms, which are often used interchangeably.

Therefore, for the purposes of attempting to create clarity throughout the system, NCWD/Youth proposes the following definition of universal access: *the design of environments, products, and communication as well as the delivery of programs, services, and activities to be usable by all youth and adults, to the greatest extent possible, without adaptation or specialized design.* In essence, this definition offers a common term that contains two parts, the physical and the abstract, the visible and the invisible. It is about both design and service delivery and captures the core concepts across the system.

Examples of universal access include ergonomic designs for tools and products in order to enable the maximum number of consumers to use them (e.g., “rocker” light switches; large, easy-to-grasp knobs on equipment; automatic doors; ramps instead of stairs) and Universal Design for Learning, in which teachers include all learners in their classes by presenting information in a number of different ways, provide different ways for students to demonstrate learning, and engage students by incorporating their interests into the class in order to motivate and challenge them. Table 4.1 outlines some basic principles of universal design.

Clearly, many complex concepts around “universal” and “access” converge in the workforce development system. This convergence results in enormous implications for policymakers and practitioners alike, beginning with a single definition of universal access that is commonly understood across the myriad of stakeholders in the system.

Achieving universal access under the above broader definition, however, will require substantially different approaches to the design of instruction, services, materials, products, communications, locations, and environments. Useful tools and instruments need to be developed to assist youth and adult workforce program practitioners to conduct self-assessments and to operationalize, implement, and measure their success in applying universal access. Staff competencies will need to be established and new forms of professional development for staff of service providers will be necessary.

Competitive Employment

Ensuring that new, young workers have access to high skill, high wage careers is critical. The labor market implications of the statistics for youth with mental health needs (see Table 1.1) are obvious and disturbing. The National Longitudinal Transition Study II, however, has some good news about youth with mental health needs. The study indicates that within a one-year period, youth with MHN were employed at a slightly higher rate than youth in the general

TABLE 4.1

Principles of Universal Design

1. The design does not stigmatize or disadvantage users.
2. A wide range of individual preferences and abilities are accommodated by the design.
3. How to use the design is easy to understand regardless of the experience, knowledge, language skills, or current concentration level of the user.
4. Information is effectively communicated to the user, regardless of the user’s sensory abilities, or surrounding conditions.
5. Adverse consequences of accidental or unintended actions are minimized by the design.
6. The design is used efficiently and comfortably with a minimum amount of fatigue.
7. Regardless of the user’s body size, posture, or mobility, appropriate size and space is provided for approach, reach, manipulation, and use.

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Center for Universal Design

population. High school students, however, are usually employed in low wage, entry-level positions with high turnover rates. Youth with mental health needs, who often have dropped out of or were suspended or expelled from school, were fired from a job, or have been arrested or incarcerated, are unlikely to have the knowledge or skills needed to qualify for or hold down a high skill, high wage career.

The most effective way for youth to learn work skills is in competitive employment and other work-based learning experiences. An effective transition system will ensure the involvement of employers at all appropriate levels, including advisory boards, cooperative arrangements with transition programs, job-shadowing, mentoring, and employing youth with MHN. The system will also need to provide assistance to employers on such issues as disclosure, accommodations, and job modifications.

Fortunately, the teenage years can be an effective time to intervene with youth with mental health needs because their impending entry into adulthood may generate a strong desire to learn positive work and “real world” academic skills. Effective transition strategies do exist and there is substantial reason to believe that many of these youth can succeed as adults in our society – if they receive appropriate services and support.

Many youth with MHN will need additional support and longer-term services to be successful in the transition process. There is no “magic cure” or simple solution, but there are emerging concepts and service models that indicate that coordinated educational, vocational, mental health, and social services can prepare young people with MHN to enter and succeed in the workplace, and – ultimately – to assume productive adult roles.

An example of a specific policy change, suggested by a national panel of experts convened by SAMHSA to consider transition issues for youth with MHN, is to increase the age for mental health services for youth from 16 to 30 years. By doing so, many of the discontinuities between adult and youth services would be ameliorated and the youth would have additional time in which to mature. This policy change is currently being considered by Pennsylvania and other states.

The Importance of Youth Leadership

Effective workforce development programs have youth development and leadership components at their core. Research shows that youth who participate in youth development and leadership experiences are more likely to do well in school, participate in their communities, and positively transition through adolescence to adulthood. Both the youth and the community benefit.

The mental health and the workforce development systems have both recognized the importance of youth leadership. Mental Health Systems of Care emphasize the active involvement of youth in making decisions and developing service plans. The Workforce Investment Act of 1998 fused youth development principles with traditional workforce development. The 10 required WIA program elements for youth include “youth leadership opportunities which may include community service and peer-centered activities encouraging responsibility and other positive social behaviors during non-school hours.”

Due to the growing recognition of the importance of youth development and leadership, the voice of youth is being heard in the development of programs, services, and policy for youth. Youth-directed organizations such as What Kids Can Do (“Voices and Work from the Next Generation” at <http://www.whatkidscando.org/index.asp>) and the National Youth Leadership Network (“the national voice for young leaders with disabilities” at <http://nyln.org>) conduct research, develop youth agendas, and communicate recommendations to policymakers and program administrators at a number of levels.

The framework for active youth involvement, found in Exhibit 3.2 (see page 3-28), describes youth leadership at the individual, community, and policy-making levels. Its continuum of power and choice leads to the progressive growth of youth leadership skills. The framework can guide youth to a decision-making role in developing and implementing the policies and procedures that have a direct impact on their lives.

Program administrators and policymakers should ensure that the youth voice is incorporated into program organization, services, and activities, as well

as into decision-making on policies affecting youth, their families, and their communities. Examples of youth leaders in action are students who take charge of their IEP meetings and Peer Support Specialists who guide youth with MHN in navigating service systems.

Family Involvement and Support

As noted in the *Guideposts for Success* in Chapter 3, family involvement and support are critical to the success of youth with mental health needs. An effective transition system must actively involve and work effectively with families, which may include non-traditional arrangements such as tribal elders, court-appointed guardians, and grandparents who are raising a youth. Families will need information and support in locating appropriate services and navigating through service tunnels, as well as assistance in understanding their rights and other legal issues such as confidentiality, privacy laws (see Exhibits 4.2 and 4.3 on pages 4-19 and 4-20), and extending guardianship for a youth with MHN if that becomes necessary. Policies must sustain the family's supportive role, a role that changes over time as the youth matures and one that becomes increasingly important in preparing the youth for adulthood.

Caring Adults

As noted in Chapter 3, the role of youth service practitioners and other caring adults is important to the transition success of youth with mental health needs; it may, in fact, be the most critical piece of an effective program. These adults support youth in brokering services in multiple service tunnels, determining career goals, and placing and supporting youth in competitive employment and postsecondary education. An effective transition system encourages and supports the involvement of caring adults such as mentors.

A major role for youth service practitioners is to work closely with each youth with MHN and his or her family members in order to coordinate necessary and appropriate mental health and social services. To aid in this process, transition programs should develop connections with social service agencies at an administrative level through agreements outlining the ways in which agencies will work together to benefit

youth with MHN. These policies then can be implemented at the individual level.

This means that a strong system of brokers must be developed. The failed approach of the past, where the youth was referred from one agency to another agency for services without the two organizations sharing information on the progress of the youth or the youth not having a lead point of contact or case manager simply doesn't work. Having someone available to assist the youth and family in navigating the multiple systems needed for transition success is essential. In order to make this a reality, the next set of design features are of high importance.

CRITICAL PROCESS DESIGN FEATURES

Interagency Coordination and Collaboration

Collaborative, cross-agency cooperation (both statewide and in local communities) is becoming necessary to maximize available expertise and to leverage funding for youth service delivery. Agencies may wish to begin their cross-agency planning process by resource mapping, a type of environmental scanning that is a useful means of identifying, recording, and disseminating related resources and services that comprise the youth services delivery system. By detailing current capacities, needs, and expertise, an organization or group of organizations can begin to make strategic decisions about ways to broaden their collective capacity. The beginning point can be to identify providers of youth services and their funding resources. Resource mapping allows states and communities to identify service gaps and service overlaps. This information is essential for aligning assessment services and for strategic planning. A number of resource mapping resources are included in Appendix A.

Interagency strategic planning processes should address program evaluation and reporting requirements for outcome measures and continuous improvement data. The often elaborate reporting requirements of federally funded partners will need to be factored into data sharing and data management agreements. These agreements should also take into account confidentiality and privacy issues.

Data privacy practices of health, education, and human services organizations determine a portion of what must be addressed in any collaborative initiative among agencies and institutions. Two federal data privacy laws, the Family Educational Rights and Privacy Act (FERPA) and the Health Insurance Portability and Accountability Act (HIPAA), establish strict federal standards concerning the use of education, health, and human services information.

RENEW: **Sustaining a Grant-Funded Project**

RENEW is an evidence-based career and education project created by the Institute on Emotional Disabilities at Keene State College in 1996 from a grant by the U.S. Department of Education, Rehabilitation Services Administration. RENEW is designed to assist youth and young adults who are at risk of dropping out or who have serious emotional or behavioral challenges to finish high school, obtain employment, and successfully enter adulthood. To date, RENEW has worked with 467 young people who have been able to achieve significant success in schools, jobs, and further education.

After the successful completion of the grant, The Alliance for Community Supports (ACS), a private, non-profit corporation, was formed to continue the services provided by RENEW. RENEW is funded by private youth contracts and several state initiatives.

RENEW collaborates with the University of New Hampshire's Institute on Disability, Justice Works, the Office of Public Defender, and a steering committee comprised of community and public agencies and schools on a re-entry project for youth with disabilities involved in delinquency hearings or in out-of-district placements. RENEW and the University of New Hampshire's Institute on Disabilities are also part of the NH State Department of Education's statewide initiative to change the way schools deal with at-risk and ED students and to reduce dropout rates and academic failure.

RENEW uses community-based education practices such as "Real World Learning" and has a nationally recognized youth leadership program. A person-centered planning program called "Futures Planning" guides the process. Wrap-around, family supports, and a holistic approach are key RENEW tools. RENEW also teams with the Granite State Federation of Families and CARE NH to support RENEW families and their teens.

On March 6, 2006 RENEW celebrated its tenth anniversary of serving at-risk youth in the state of New Hampshire. For more information, refer to <http://www.allianceforcommunitysupports.com>.

FERPA is a federal law that protects the privacy of student education records. The law applies to all schools, colleges, and universities that receive funds under applicable programs of the U.S. Department of Education. Exhibit 4.2 provides an overview of FERPA.

HIPAA, which took effect in April of 2003, includes a set of federal privacy standards to protect patients' medical records and other health information provided to health plans, doctors, hospitals, and other health care providers. These new standards were developed by the Department of Health and Human Services to provide individuals with greater access to their medical records and more control over how their personal health information is used and disclosed. Exhibit 4.3 provides an overview of the HIPAA Privacy Rule.

In addition to FERPA and HIPAA, many states have enacted data privacy laws to protect individuals from misuse of confidential information by public and private entities. In general, private and confidential information about youth may not be shared or used in any form without the expressed and written consent of the affected individuals and those authorized to represent them.

Youth service organizations should have a working knowledge of the data privacy laws and regulations governing the operations of their respective organizations. These laws and regulations govern formal data management policies regarding (a) storage, protection, and security of confidential youth information; (b) receipt and sharing of youth information; (c) the intended uses of privileged information; (d) procedures for obtaining written authorization from youth (or family members) to authorize the receipt, sharing, and use of information; (e) prevention of potential misuses of confidential information; and (f) destruction of all electronic and written records after defined time intervals. Exhibit 4.4 is a sample interagency data-sharing agreement.

Once the organizations providing youth services are identified and a plan is made to align services, understandings or agreements between agencies must be developed in order to ensure that services are provided as planned. Formal interagency agreements such as Memoranda of Understanding (MOUs) are not

new, but to date there is little evidence that they have been used to build common infrastructures. Agencies that are party to these agreements will be breaking new ground in the alignment and provision of assessment services. Table 4.2 represents a composite of elements commonly found in MOUs.

Once interagency agreements are in place, some policy decisions necessarily will need to be made at the individual organizational level. Policies guiding the screening of youth for potential mental health challenges by youth service professionals, for example, may entail a description of the circumstances that trigger the screening process, permission policies and forms to be completed by parents or legal guardians, identification and training of staff who will administer the screens, a list of approved screening instruments, procedures for referring youth for full mental health evaluations, a list of approved professionals to whom to refer the youth for evaluation and therapy, and guidelines for reporting and implementing the service recommendations based on the evaluation results. Table 4.3 on the following page suggests roles and responsibilities for different stakeholders.

The Systems of Care (SOC) approach is one example of an effort on the part of youth, families, and the agencies that serve them to support children with mental health needs in an integrated manner. This approach has been used as a catalyst for changing the way public agencies organize, purchase, and provide services for children and families with multiple needs. The SOC approach is characterized by multi-agency sharing of resources and responsibilities and by the full participation of professionals, families, and youth as active partners in planning, funding, implementing, and evaluating services and system outcomes.

The SOC approach facilitates universal access because it enables cross-agency coordination of services regardless of where or how children and families enter the system. Agencies work strategically, in partnership with families, youth, and other formal and informal support systems, to address the unique needs of children and youth. To do so effectively, participants in SOC must

- agree on common goals, values, and principles that will guide their efforts;

TABLE 4.2

Memoranda of Understanding Components

The components of an MOU will vary according to its purpose, the needs of the signatory parties, and regulatory requirements. The following list was compiled from a wide variety of MOUs, none of which contained every item listed below.

Basic Information

- Parties to the MOU (Organization names, addresses, contact persons, phones, faxes, e-mails)
- Purpose of the MOU
- Duration of the MOU
- Authorized signatures, dates, titles

Setting the Stage

- Joint vision
- Key principles
- Commitments (e.g., specific screens and/or assessments, information exchange, cross referrals)
- Key practices (e.g., adherence to WIA Section 188 Disability Checklist service plan)

Description of Duties and Responsibilities

- Shared or coordinated service responsibilities
- Individual organizational service responsibilities
- Methods of referral
- Exchange of information
- Management structure

Measuring Progress

- Performance measurement standards
- Evaluation and review processes
- Reporting and recordkeeping requirements

Financial Options

- Budget and methods of payment
- Non-financial cooperative agreements
- Subcontracting arrangements

MOU Management Issues

- Modification, amendment, or assignment
- Renewal and termination
- Dispute process
- Assurances and certifications (often required or provided by funding sources)

Optional Attachments

- Confidentiality and information releases
- Cross referral forms
- Resource sharing agreement
- Governance agreement

For examples of memoranda of understanding and resource agreements, visit the New York Association of Training and Employment Professionals (NYATEP) website at <<http://www.nyatep.org/pubsresources/sample-mous.html>>.

- develop a shared infrastructure to coordinate efforts toward the common goals of safety, permanency, and well-being; and
- work within that infrastructure to ensure the availability of a high-quality array of home, school, and community-based services to support families and preserve children safely in their homes and communities.

The SOC approach is not a “program” or “model.” Rather, it is an approach for guiding processes and activities designed at the system, policy, and practice levels to meet the needs of children and families who are in need of supports. States and communities must have the flexibility to implement this approach in a way that works for each community. SOCs are not static; they evolve over time as community needs and conditions change.

Resource Management

Resources and funding are always problematic in developing cross agency collaborations. A number of potential funding streams for transition services for youth with mental health needs are available at the federal, state, and local levels. Federal funding streams that may support activities and services identified in the *Guideposts for Success for Youth with Mental Health Needs* (see Table 3.1 on page 3-3) include those of the Workforce Investment Act, the Rehabilitation Act, Medicaid, mental health systems, and several work incentives under the Social Security Administration such as the Medicaid Buy-in and Plan for Achieving Self-Support (PASS).

continued on page 4-12

TABLE 4.3

Roles and Responsibilities by Organizational Level

State

- Resource mapping and strategic planning across state agencies and stakeholders
- Development or amendment of Memoranda of Understanding (MOUs) between state agencies, including cost sharing for service centers throughout the state
- Coordination of state and federal program evaluation and reporting requirements, including selection of specific forms and procedures
- Development of policy guidelines for use by regions and localities
- Guidance for regions and localities regarding information dissemination
- Training to state and local personnel managers on global issues such as confidentiality, data-sharing, etc.

Region/Locality

- Resource mapping and strategic planning across regional/local agencies and stakeholders
- Development of MOUs between local agencies not covered by state MOUs, including locally determined services and coordination
- Implementation of state policy guidelines

- Coordination of services between partners, such as identification of qualified personnel to conduct specific screens, referral procedures for in-depth evaluations, and selection of administering organizations
- Information dissemination and guidance to organizations
- Training to local and organizational personnel on issues such as principles guiding appropriate screening and service delivery, etc.

Organization

- Internal resource mapping and strategic planning
- Development of agreements with agencies and organizations not covered by state or regional/local MOUs, including the provision of assessment services not provided by state service centers or regional/local providers
- Development of service schedules and administration policy internally and with partners
- Selection of unique screening instruments and development of policy guidance for screening and referrals to in-depth evaluations not covered by state or local policy
- Guidance and training of youth service practitioners as needed
- Provision of person-centered planning and direct services to customers

The Pennsylvania Community on Transition (PACT) Mental Health Practice Group

In 1998, the Governor of Pennsylvania issued an executive order titled “Interagency Committee to Coordinate Services Provided to Individuals with Disabilities.” The order resulted in a Memorandum of Understanding among the Pennsylvania Departments of Education, Public Welfare, Labor and Industry, and Health that described financial responsibilities, coordination of services, an interagency coordinating committee, and other parameters necessary for the provision of services to youth with disabilities. The intent of the MOU was to shift from isolated, single-agency activities to cross-systems efforts in the areas of Policy and Regulation Development, Strategic Planning, Service Delivery Systems, Data Collection, Program Initiatives, and Professional Development.

What began as a four-department/ten-office Training Team on the MOU has evolved into a cross-agency Community of Practice (CoP) on secondary transition. A Community of Practice is defined as “groups of people who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise in this area by interacting on an ongoing basis” (Wenger, McDermott, & Snyder, 2002, p.4). The foundation of this effort in Pennsylvania is built on shared work and knowledge to assist youth and young adults with disabilities to achieve their desired post-school outcomes.

The vision of the Pennsylvania Community on Transition (PACT) is that all Pennsylvania youth and young adults with disabilities will successfully transition to the role of productive, participating adult citizens; be empowered to recognize their talents, strengths, and voice; and have equal access to resources that will promote full participation in the communities of their choice.

The PACT mission is to build and support sustainable community partnerships that create opportunities for youth and young adults with disabilities to transition smoothly from secondary education to the postsecondary outcomes of competitive employment, education, training and lifelong learning, community participation, and healthy lifestyles. The foundation of its work depends on steadfast leadership, cross-system policy development, and fidelity to evidence-based, quality-driven practices.

In order to support the work of the PACT state leadership team, practice groups are being developed in the areas of community participation; competitive employment; healthy lifestyles; postsecondary education, training, and lifelong learning; juvenile justice and child welfare; mental health; transportation; and youth engagement. Each Practice Group

defines its own work and may focus on developing the meaning of the outcome or issue, cross-agency terminology, solutions to outcomes and issues, effective practices, and policy and program changes at the local, state, and national levels. Listservs, websites, conference calls, regional sessions, and state events are being created to connect and support practice group participants, who may be anyone interested in supporting youth and young adults in successfully achieving post-school outcomes.

The specific purpose of the Mental Health Practice Group is to promote the academic achievement and well-being of all Pennsylvania youth and young adults through the development of a comprehensive, cross-community, behavioral health support system. This effort will emphasize the utilization of evidence-based school mental health services in conjunction with existing school-wide and community mental health programs and services. Growing evidence shows that school mental health programs improve educational outcomes by decreasing absences, decreasing discipline referrals, and improving test scores, thus enabling youth and young adults to better achieve their desired post-school outcomes. This group will also explore and promote mechanisms to effectively assist youth and young adults in the smooth transition into needed adult services and supports.

The Mental Health Practice Group, which is also part of the national IDEA (Individuals with Disabilities Education Act) Partnership Transition Community of Practice, is currently developing goal statements and a plan of action for providing the key supports and services needed by youth with mental health needs in the state. Pennsylvania is also participating in the National Community of Practice on Collaborative School Behavioral Health. Information on these efforts can be found at the IDEA Partnership website in the Communities of Practice section at <<http://www.ideapartnership.org>>.

For additional information, please contact the following:

- Rick Boyle, Educational Consultant, PA Training and Technical Assistance Network office, Pittsburgh, rboyle@pattan.net, 412-826-2336, ext. 6863
- Ron Sudano, Educational Consultant, PA Training and Technical Assistance Network office, Pittsburgh, rsudano@pattan.net, 412-826-2336, ext. 6868
- Julie Barley, PA Dept. of Public Welfare, Office of Mental Health and Substance Abuse Services, jbarley@state.pa.us

The challenge of accessing funding from very large funding sources such as Medicaid and federal mental health programs is sorting through the funding streams and understanding both the complexities and opportunities they present. For example Jackson and Muller found that while Medicaid is now a significant source of funding for mental health services, many providers are not familiar with the needs of youth or adults with MHN and how to serve them. Other service providers may not be aware that Early Prevention, Screening, Diagnosis, and Treatment (EPSDT) may be used to provide services for the 18 to 21 year age group, according to Davis & Hunt.

Resource mapping is especially useful in resolving funding issues, since it can be used to identify and organize information concerning organizations that provide youth services, funding sources and resources dedicated to youth services, and locations of service gaps and overlaps. Once the information is collected and organized, partnerships and collaborative arrangements may be made. Interagency agreements may be developed to specify which agencies will provide different types of services and how they will be funded.

Funding strategies may include “blending” and “braiding.” Blending combines funds into one funding stream by relaxing the regulations of the original funding sources to permit programmatic flexibility. Mechanisms are developed to pool dollars from multiple sources, making them in some ways indistinguishable.

Braiding taps into existing categorical funding streams and uses them to support unified initiatives in a flexible and integrated manner. Braided funds produce greater efficiency and effectiveness by reducing the reliance on any one funding source. Braided funds are not commingled since organizations maintain control of their funds while coordinating services with their partners. Braiding also provides seamless funding to families and youth while allowing dollars to be traced back to their source for accountability and reporting purposes.

For more information on funding strategies, see NCWD/Youth’s *Blending and braiding funds and resources: The intermediary as facilitator*, which is

available in Word and pdf versions at http://www.ncwd-youth.info/resources_&_Publications/information_Briefs/issue18.html.

A basic tenet of behavioral interventions is that to be effective, they should be administered consistently and continually over time. Unfortunately, most programs for youth with MHN run for a set period of time or are interrupted at various points because youth age out of the youth system and encounter a transition cliff. These service disruptions do little over the long term to promote vocational and career achievements. Therefore, it is important that strategies to provide continuing services without breaks are examined and implemented.

A critical issue for transition programs for youth with MHN is the development of creative funding and program options for services during and after high school and in the community setting. Transition programs for youth with MHN must often locate and connect with a number of service providers or agencies with different administrative and funding guidelines. Strategies such as resource mapping, partnership development, and blending and braiding of funds will be necessary to address this challenge.

Innovative strategies for funding mental health services at the state level are underway. California, for example, recently passed a funding initiative (Proposition 63) that places a 1% tax surcharge on individuals making more than one million dollars a year to support state and local mental health systems. This surcharge will create an \$800 million fund that will be used to support county mental health services, consumer participation, and innovative programs.

Information on potential federal funding sources is contained in *Moving on: Federal programs to assist transition-age youth with serious mental health conditions* at <http://www.bazelon.org/publications/movingon/index.htm>. This website provides fact sheets on 57 federal programs that offer services supporting youth with MHN as they transition to employment and adulthood. Information on individual, discretionary, and formula or block grants, as well as on program services and relevance, is also available.

Managing resources is one of the biggest challenges of any system, especially one where the demand for services exceeds the supply. The *Guideposts for Success* and the *Guideposts for Success for Youth with Mental Health Needs* can be used as frameworks for local resource mapping exercises to determine where existing resources are deployed, and where the service gaps and overlaps are. Policymakers and youth service providers can then decide how the gaps can be filled and the overlaps eliminated. This process will require some creative thinking about the routing of funds and the roles of staff. These steps can be taken while larger policy and regulatory change is underway.

Policymakers should exercise informed judgment in the budgeting and resource allocation process. This guide can help policymakers make the difficult decisions that will affect the transition to independence and employment for youth with mental health needs.

Cultural and Linguistic Competence to Address Institutional Bias

As noted in Chapter 3, part of the tunnel problem is the institutional bias encountered by many youth seeking services. Discrimination may occur based on a number of personal characteristics such as race, culture, language, age, gender, and disability. Discrimination against people with mental health needs has a number of sources including ignorance, myths, attitudinal barriers, and the stigma associated with these disorders.

Discrimination occurs despite the fact that access for people with disabilities is driven, in large part, by some very specific standards embedded in multiple laws and implementing regulations, such as the Americans with Disabilities Act, Sections 504 and 508 of the Rehabilitation Act, and Section 188 of Title I of the Workforce Investment Act. Section 188, which implements the WIA's non-discrimination and equal opportunity provisions, is applicable to programs, services, and activities receiving financial assistance under the title. Because of the stringency of Section 188 coupled with Sections 504 and 508 of Title IV, the WIA legislation is arguably one of the strongest civil rights laws on the books.

The consequences of services and policies that are not culturally and linguistically competent are serious and may result in inappropriate services or lack of any services — with potentially life-altering results. For example, in some cultures it is considered rude to disagree with a person in authority; therefore, a young person or a family member may answer “yes” to every question he or she is asked in order to be polite. Youth or family members who are English language learners may misunderstand spoken or printed questions or instructions in interviews, on career inventories, or in other situations that may ultimately result in decisions that send them down the wrong service tunnel or that deny them services altogether.

A number of guidelines and resources have been developed to ensure that programs and services are culturally competent, but change occurs slowly in most institutions and agencies. The National Mental Health Information Center suggests that culturally competent workforce development agencies and youth service providers

- appoint board members from the community so that voices from all groups of people within the community participate in decisions;
- actively recruit multiethnic and multiracial staff;
- provide ongoing staff training and support for developing cultural competence;
- develop, mandate, and promote standards for culturally competent services;
- insist on evidence of cultural competence when contracting for services;
- nurture and support new community-based multicultural programs and engage in or support research on cultural competence;
- support the inclusion of cultural competence on provider licensure and certification examinations; and
- support the development of culturally appropriate assessment instruments, psychological tests, and interview guides.

The Agency for Healthcare Research and Quality found that linguistically competent organizations provide readily available, culturally appropriate oral and written language services to English language learners through a number of practices such as bilingual staff, trained interpreters, and materials translated by qualified translators.

A number of resources that address cultural competence are available, such as the SAMHSA's Systems of Care website at <<http://www.systemsofcare.samhsa.gov>> and Georgetown University's National Center for Cultural Competency website at <<http://gucchd.georgetown.edu/nccc/index.html>>. These and additional resources are listed in the Policy and Systems Change section of Appendix A.

Professional Preparation and Development of Youth Service Professionals

The range of settings in which youth receive workforce development services is wide, and the responsibilities of the staff serving them call for both general and specialized knowledge. Youth service practitioners play an important role in connecting all youth to workforce preparation opportunities and support. Youth service practitioners must keep pace with constant changes in the labor market, economic shifts, new technologies, and the evolving needs and culture of today's youth. Yet, throughout the field of workforce development, there seems to be little professional training available for youth service practitioners and no formal system for accessing the training that is available.

The demands on youth service practitioners in the workforce development arena are great. They must be able to serve a diverse group of youth effectively, which requires a broad range of knowledge, skills and abilities. NCWD/Youth has synthesized 10 emerging competencies of effective youth service practitioners as the centerpiece of an effective workforce development system. The competencies are

1. knowledge of the field;
2. communication with youth;
3. assessment and individualized planning;

4. relationship to family and community;
5. workforce preparation;
6. career exploration;
7. relationships with employers and between employer and employee;
8. connections to resources;
9. program design and delivery; and
10. administrative skills.

Practitioners serving youth with mental health needs will need additional competencies in order to serve this population effectively. Specifically, in order to ensure that these youth receive comprehensive coordinated service delivery consistent with the *Guideposts for Success for Youth with Mental Health Needs*, these practitioners must develop knowledge and expertise with regard to

- behavioral action plans such as SAMHSA's Recovery Action Plans;
- health insurance options including Medicaid buy-in incentives;
- pediatric to adult health care issues such as the "medical home" concept, mental health screening for both youth and families, and youth choice in deciding medications and treatment;
- school-based mental health services including the role of the IEP team, training in mental health issues for IEP team members, the importance of parent involvement in transition planning, and mental health screens as part of the school health curriculum;
- funding sources and their eligibility requirements;
- strategies for combating workplace discrimination for youth with MHN and other issues under the Americans with Disabilities Act;
- accessing services for youth with mental health needs under the SSI disabled children's program, Ticket to Work and Medicaid Work Incentive Programs, and Vocational Rehabilitation;

- strategies for combating disincentives in systems serving youth with MHN such as organizational culture, red tape, and “creaming;”
- actively involving youth in the decisions affecting their lives including training Peer Support Specialists;
- locating and maintaining safe and affordable housing, developing transportation plans including acquiring driver’s licenses, and other post-placement supports in the community and the workplace; and
- a “team of teams” approach to coordinating services and supports from a large number of agencies and programs such as child welfare, parole and probation, juvenile justice, foster care, schools, GED and Adult Education, community colleges, health care providers, transition service providers, and more.

The success of all polices is ultimately dependent on the knowledge, skills, and abilities of the direct service providers. Professional organizations representing the various youth service practitioners therefore have a critical role to play in helping to establish the new roadmap. Many have developed codes of ethics to guide their behavior and ensure high standards. (For a sampling of ethics codes see Resources on page A-1). These organizations need to be involved in the development of new competency standards for their members, the promulgation of new training materials,

and the promotion of cross agency staff training. Pre-service preparation institutions must also be partners in the development of these competencies through cross disciplinary programs of study.

Professional development funding must be recognized as a high priority by policy makers at all levels of government. Its importance precludes it from being treated as an optional budget line item.

CONCLUSION

The road to independence and self-sufficiency for youth with MHN need not be a dead end. Obstacles such as the transition cliff and ineffective service tunnels can be eliminated through thoughtful systems change processes that incorporate sound policies and practices. Systems change initiatives have already begun in a growing number of states and communities across the country.

Practitioners and policymakers have key roles to play in ensuring that youth with mental health needs have a fair chance at achieving the American dream of independence and self-sufficiency. The road will not be easy, but the information in this guide should help ensure that it leads to successful transitions to productive and rewarding adult lives.

Please see Appendix B for the list of references.

Supporting Research

The following section contains research specifically related to effective transition *systems* for youth with mental health needs. Chapter 3 contains research related to direct *services* for youth with mental health needs.

Bureau of Labor Statistic projections for the period 2004-2014 show that total employment is expected to increase 13% during that decade. Two-thirds of the 18 million new jobs that will be created over the next 10 years will be in occupations that require a postsecondary education or training degree or certificate (Bureau of Labor Statistics, 2006).

Data from the National Longitudinal Transition Study 2 show that youth with mental health needs are employed in high school at a slightly higher rate than youth in the general population in a one-year period (Wagner & Cameto, 2004).

Research suggests that the teenage years can be an effective time to intervene with this population as their impending entry into adulthood may initiate a strong desire to learn positive work and academic skills (Albee, 1982; Hobbs & Robinson, 1982; Kazdin, 1993; Petersen & Leffert, 2002). There is substantial reason to believe that many of these youth can succeed as adults in our society if they receive appropriate services and support.

Emerging service models indicate that coordinated educational, vocational, mental health, and social services can prepare young people with MHN to enter and succeed in the workplace, and — ultimately — to assume adult roles (Bullis & Fredericks, 2002; Cheney, 2004; Clark & Davis, 2000).

Components of effective transition programs for youth with MHN can be drawn from (a) educationally based transition programs for youth with disabilities (Aspell, Bettis, Test, & Wood, 1998; Benz & Lindstrom, 1997; Izzo, Cartledge, Miller, Growick, & Rutowski, 2000; Kohler, 1993; Rusch, DeStefano, Chadsey-Rusch, Phelps, & Szymanski, 1992); (b) labor and employer oriented programs (Fabian, Luecking, & Tilson, 1994; Timmons, Podmostko, Bremer, Lavin, & Wills, 2004; Luecking, Fabian, & Tilson, 2004); (c) mental health and social service programs (Clark, 1998; Dryfoos, 1990, 1991, 1993; Kazdin, 1985, 1993); and (d) supported work programs for adults with severe and persistent mental illnesses (Bond, 1998).

Although elements of these programs have been integrated into school and community-based programs specifically for youth with MHN (Bullis & Cheney, 1999; Bullis & Fredericks,

2002; Cheney, Hagner, Malloy, Cormier, & Bernstein, 1998; Clark & Davis, 2000; Siegel, 1988), to date there have been few controlled studies of the long-term impact of transition programs for this population (Cheney & Bullis, 2004). The absence of such research is probably due to substantial procedural obstacles in evaluating multi-faceted service programs for youth with MHN (Kazdin, 1985, 1993) and the small number of transition programs for this specific population.

Dryfoos (1990, 1991, 1993) provides a clear and detailed discussion of the systemic foundation of comprehensive programs for youth with MHN. Reviews of effective programs for youth with MHN (Dryfoos, 1990, 1991, 1993; Kazdin, 1985, 1993) suggest that most effective programs are based in the schools. Specifically, high schools should provide social services, vocational experiences, and focused academic instruction (Dryfoos, 1991, 1993).

The American Youth Policy Forum conducted a national review of 50 evaluations of youth interventions and identified nine basic principles of effective youth programming and practice, including the participation of caring and knowledgeable adults, viewing youth as valuable resources and contributors to their communities, and high community involvement (James, 1999). Woyach (1996) identified 12 principles for effective youth leadership programs, including experiential learning and opportunities for genuine leadership and service to others in the community, country, and world.

NCWD/Youth conducted an extensive literature review on youth leadership and development and found a number of characteristics and outcomes of effective youth development and youth leadership programs. Outcomes included increased self-esteem, better life skills, fewer psychosocial problems, increased academic achievement, increased safety, better communications with their family, better problem-solving skills, positive engagement with their community, appreciation of cultural differences, and increased self-efficacy, self-advocacy, and self-determination. Program characteristics included experiential learning, service learning, mentoring, personal planning, collaborative teamwork, community projects, and opportunities to serve in leadership roles in the organization. At the administrative level, NCWD/Youth found that youth leadership organizations involved youth in every facet of the organization, including administration and program delivery, as a means practicing leadership skills (Edelman, Gill, Comerford, Larson, & Hare, 2004).

EXHIBIT 4.1: SUPPORTING RESEARCH

In response to the disenfranchisement of youth with MHN from the public educational system, there has been a dramatic increase in the number of alternative programs and schools (Lange & Sletten, 2002). Alternative educational placements typically include smaller student-to-staff ratios, allow for more personal relationships between students and staff, and provide flexible scheduling and personalized assistance. Many such programs require students to attend class for only part of a day, leaving open the possibility of using the rest of the day for community-based instruction, including structured competitive job placements (Tobin & Sprague, 2000). At the local level, for example, Cheney and his colleagues (Cheney, Hagner, Malloy, Cormier, & Bernstein, 1998), in a transition project for youth and young adults with MHN, established a cadre of social service partners from various agencies in Manchester, New Hampshire. At regular meetings of this group, project staff presented case studies of the difficulties each participant experienced in accessing services. These individual cases provided the impetus for policy changes that improved the service flow for individuals and created durable systemic changes in the social service system in that region.

Family involvement in the life of youth with MHN is critical to their transition success (Friesen & Stephens, 1998; et al., 2001a, 2001b; Osher, Van Kammen, & Zaro, 2001; Stroul & Friedman, 1994). Family members offer the most long-term and enduring support to youth with MHN, as well as the encouragement necessary for the young person to succeed in employment (e.g., assisting with transportation) and other transition outcomes (e.g., assisting the youth to enroll in postsecondary education). Families of youth with MHN must assist their youth in navigating a complex array of services in service systems that may be foreign to families who may not have worked with those programs earlier in their children's lives (Dunkle, 1995; Institute for Educational Leadership, 2001b; Richardson & House, 2000).

Family members also need to be prepared for their youth's attainment of the age of majority, which is usually 18 years of age although this varies from state to state. If the family does not extend their guardianship over their son or daughter past majority age, they may not have access to information on their youth's transition experiences. Since many youth with MHN have average to above average intelligence as well as the ability to control their MHN through various treatment approaches, effective strategies for continued family involvement or guardianship should be explored (Friesen & Stephens, 1998; Holden, et al., 2001a, 2001b; Osher, et al., 2001).

Studies of resilient adults with MHN (Cicchetti & Garnezy,

1993; Garnezy, 1991; Murray, 2002; Rutter, 1985, 1987, 1993b; Todis, Bullis, D'Ambrosio, Schultz, & Waintrup, 2001; Werner & Smith, 1989, 1992) point to the critical role of one or more responsible adults in changing their life trajectories during their teenage years. The critical role of a transition specialist or committed staff person in the execution of individualized transition services for youth with MHN has also been identified repeatedly in the literature (Benz, Yovanoff, & Doren, 1997; Bullis, Tehan, & Clark, 2000; Clark, 1998).

Clark (1998) suggested that effective transition specialists should be organized, be able to accommodate scheduling changes, have practical knowledge of local employment opportunities, establish personal connections with employers (Fabian, Luecking, & Tilson, 1994; Luecking, Fabian, Tilson, 2004), and focus on supporting youth with MHN to achieve major transition outcomes rather than providing individual therapy or counseling. Several model demonstration programs for youth with MHN have suggested that a reasonable caseload for a transition specialist is 12 to 15 youth at a time (Bullis & Fredericks, 2002; Cheney, Hagner, Malloy, Cormier, & Bernstein, 1998; Clark, 1998).

The most effective way for youth with MHN to practice and learn work skills is in a real competitive employment setting instead of the classroom or in a make work situation (Benz, Yovanoff, & Doren, 1997; Hazasi, Gordon, & Roe, 1985; Kohler, 1993). There are comprehensive and clear descriptions available to guide professionals in approaching and recruiting employers to hire youth with disabilities and to be involved in transition programs (Fabian, Luecking, & Tilson, 1994; Luecking, Fabian, Tilson, 2004) that are based largely on needs assessments, focus groups, service experience, and program evaluation data. There are also statements of employer perceptions of building school-to-work partnerships between the public schools and competitive employers (Center for Workforce Development, 1994, 1999a, 1999b). There has not, however, been systematic research on the characteristics of employers who are apt to hire people with disabilities (Gillbride, Stensrud, Vandergoot, & Golden, 2003) or become involved in transition programs for youth with MHN, or on the structure of the cooperative arrangements between transition programs and employers that offer the most effective services (Bullis, 2004).

Surveys of employers who hired youth with MHN through community and school-based transition programs (Bullis, Fredericks, Lehman, Paris, Corbitt, & Johnson, 1994; Bullis, Moran, Todis, Benz, & Johnson, 2002) indicate that employers who agreed to hire youth with MHN typically did

EXHIBIT 4.1: SUPPORTING RESEARCH

so because of three reasons: (a) past positive experiences with supported work or transition programs, (b) an altruistic commitment to help young people in their community, and (c) a history of personal or family experiences reflective of the problems experienced by the youth with whom they work (e.g., the employer had problems as a youth, or had a son or daughter with problems, so the employer wanted to help other youth with similar problems). Interestingly, no employers who responded to those surveys indicated that they hired a youth because of fiscal incentives, such as the Targeted Job Tax Credits, saying that such programs were too cumbersome and time-consuming to use.

From these results, as well as guidelines for working with competitive businesses in school-to-work programs (Institute for Educational Leadership, Center for Workforce Development, 1994, 1999a, 1999b; Fabian, Luecking, & Tilson, 1994; Luecking, Fabian, Tilson, 2004), it appears

likely that transition specialists will need to interact with the business owners and managers in their locales and “sell” those employers on hiring a youth with MHN.

Resource mapping focuses on what states and communities have to offer by identifying assets and resources that can be used for building a system. It is not a “one-shot” drive to create a published list or directory, but rather a catalyst for joint planning and professional development, resource- and cost-sharing, and performance-based management of programs and services (Crane & Skinner, 2003).

Discrimination against people with mental health needs may be a result of stigma, myths, and attitudinal barriers (Dew & Alan, 2005).

Please see Appendix B for the list of references.

Family Educational Rights and Privacy Act (FERPA)

The Family Educational Rights and Privacy Act (FERPA) (20 U.S.C. §1232g; 34 CFR Part 99) is a federal law that protects the privacy of student education records. The law applies to all schools that receive funds under an applicable program of the U.S. Department of Education.

FERPA gives parents certain rights with respect to their children's education records. These rights transfer to the student when he or she reaches the age of 18 or attends a school beyond the high school level. Students to whom the rights have transferred are "eligible students."

- Parents or eligible students have the right to inspect and review the student's education records maintained by the school. Schools are not required to provide copies of records unless, for reasons such as great distance, it is impossible for parents or eligible students to review the records. Schools may charge a fee for copies.
- Parents or eligible students have the right to request that a school correct records that they believe to be inaccurate or misleading. If the school decides not to amend the record, the parent or eligible student then has the right to a formal hearing. After the hearing, if the school still decides not to amend the record, the parent or eligible student has the right to place a statement with the record setting forth his or her view about the contested information.
- Generally, schools must have written permission from the parent or eligible student in order to release any information from a student's education record. However, FERPA allows schools to disclose those records, without consent, to the following parties or under the following conditions (34 CFR § 99.31):
 - ~ school officials with legitimate educational interest;
 - ~ other schools to which a student is transferring;
 - ~ specified officials for audit or evaluation purposes;
 - ~ appropriate parties in connection with financial aid to a student;

- ~ organizations conducting certain studies for or on behalf of the school;
- ~ accrediting organizations;
- ~ to comply with a judicial order or lawfully issued subpoena;
- ~ appropriate officials in cases of health and safety emergencies; and
- ~ state and local authorities, within a juvenile justice system, pursuant to specific state law.

Schools may disclose, without consent, "directory" information such as a student's name, address, telephone number, date and place of birth, honors and awards, and dates of attendance.

However, schools must tell parents and eligible students about directory information and allow parents and eligible students a reasonable amount of time to request that the school not disclose directory information about them. Schools must notify parents and eligible students annually of their rights under FERPA. The actual means of notification (special letter, inclusion in a PTA bulletin, student handbook, or newspaper article) is left to the discretion of each school.

For additional information or technical assistance, you may call (202) 260-3887 (voice). Individuals who use TDD may call the Federal Information Relay Service at 1 (800) 877-8339 or at the following address:

Family Policy Compliance Office
U.S. Department of Education
400 Maryland Avenue, SW
Washington, DC 20202-4605

U.S. Department of Education
Policy Guidance
<<http://www.ed.gov/policy/gen/guid/fpco/ferpa/index.html>>

Health Insurance Portability and Accountability Act Privacy Rule

The *Standards for Privacy of Individually Identifiable Health Information* (Privacy Rule) establishes, for the first time, a set of national standards for the protection of certain health information. The U.S. Department of Health and Human Services (HHS) issued the Privacy Rule to implement the requirement of the Health Insurance Portability and Accountability Act of 1996 (HIPAA). The Privacy Rule standards address the use and disclosure of individuals' health information — called "protected health information" — by organizations subject to the Privacy Rule — called "covered entities" — as well as standards for individuals' privacy rights to understand and control how their health information is used. Within HHS, the Office for Civil Rights (OCR) has responsibility for implementing and enforcing the Privacy Rule with respect to voluntary compliance activities and civil money penalties.

A major goal of the Privacy Rule is to assure that individuals' health information is properly protected while allowing the flow of health information needed to provide and promote high quality health care and to protect the public's health and well being. The Rule strikes a balance that permits important uses of information, while protecting the privacy of people who seek care and healing. Given that the health care marketplace is diverse, the Rule is designed to be flexible and comprehensive to cover the variety of uses and disclosures that need to be addressed.

Protected Health Information. The Privacy Rule protects all "individually identifiable health information" held or transmitted by a covered entity or its business associate, in any form or media, whether electronic, paper, or oral. The Privacy Rule calls this information "protected health information (PHI)."

"Individually identifiable health information" is information, including demographic data, that relates to

- the individual's past, present, or future physical or mental health or condition;
- the provision of health care to the individual; or
- the past, present, or future payment for the provision of health care to the individual;

and that either identifies the individual or could reasonably be believed to lead to the identification of the individual. Individually identifiable health information includes many common identifiers (e.g., name, address, birth date, and Social Security Number).

The Privacy Rule excludes from protected health information employment records that a covered entity maintains in its capacity as an employer, and education and certain other records subject to, or defined in, the Family Educational Rights and Privacy Act, 20 U.S.C. §1232g.

De-Identified Health Information. There are no restrictions on the use or disclosure of de-identified health information. De-identified health information neither identifies nor provides a reasonable basis to identify an individual. There are two ways to de-identify information: 1) a formal determination may be made by a qualified statistician; or 2) the removal of specified identifiers of the individual and of the individual's relatives, household members, and employers is required, and is adequate only if the covered entity has no actual knowledge that the remaining information could be used to identify the individual.

Covered Entities. The Privacy Rule, as well as all the Administrative Simplification rules, apply to health plans, to health care clearinghouses, and to any health care provider that transmits health information in electronic form in connection with transactions for which the Secretary of HHS has adopted standards under HIPAA (the "covered entities"). For help in determining whether you are covered, use the decision tool available online at <http://www.cms.hhs.gov/hipaa/hipaa2/support/tools/decisionsupport/default.asp>.

To view the entire Rule, and for other additional helpful information about how it applies, see the OCR website: <http://www.hhs.gov/ocr/hipaa>. In the event of a conflict between this summary and the Rule, the Rule governs.

Excerpted from "OCR Privacy Brief: Summary of the HIPAA Privacy Rule" Office for Civil Rights
U.S. Department of Health and Human Services
<http://www.hhs.gov/ocr/privacysummary.rtf>

Sample Inter-Agency Data-Sharing Agreement

State of _____

REQUESTER

Agency Name _____

Data User _____

Title _____

Address _____

Phone _____

DATA PROVIDER

Agency Name _____

Custodian _____

Title _____

Address _____

Phone _____

I. PURPOSE

In this section, both parties must state in non-technical language the purpose(s) for which they are entering into the agreement, i.e., how the data will be used, what studies will be performed, or what the desired outcomes are perceived to be as a result of obtaining the data. The source of the data will come from any and all public health or claims databases. The data will only be used for research and/or analytical purposes and will not be used to determine eligibility or to make any other determinations affecting an individual. Furthermore, as the data will be shared within a State, it will be subjected to all applicable requirements regarding privacy and confidentiality that are described herein.

II. PERIOD OF AGREEMENT

The period of agreement shall extend from _____ to _____.

III. JUSTIFICATION FOR ACCESS

A. Federal requirements: Section 1902(a)(7) of the Social Security Act (as amended) provides for safeguards which restrict the use or disclosure of information concerning Medicaid applicants and recipients to purposes directly connected with the administration of the State plan. Regulations at 42 CFR 431.302 specify the purposes directly related to State plan administration. These include (a) establishing eligibility; (b) determining the amount of medical assistance; providing services for recipients; and (d) conducting or assisting an investigation, prosecution, or civil or criminal proceeding related to the administration of the plan.

If the State Medicaid agency is a party to this agreement, specifically as the provider of information being sought by the requestor, it must be demonstrated in this section how the disclosure of information meets the above requirements.

An example of permissible data matching/sharing arrangements is the matching of data with a registry of vaccines or diseases for the purposes of improving outreach or expanding Medicaid coverage of populations being served under Medicaid.

States should identify any additional requirements that are needed for the release of additional data in this section.

B. State requirements: Cite specific State statutes, regulations, or guidelines (See Appendices)

IV. DESCRIPTION OF DATA

In this section, the parties provide specific detailed information concerning the data to be shared or exchanged.

V. METHOD OF DATA ACCESS OR TRANSFER

A description of the method of data access or transfer will be provided in this section. The requestor and its agents will establish specific safeguards to assure the confidentiality and security of individually identifiable records or record information. If encrypted identifiable information is transferred electronically through means such as the Internet, then said transmissions will be consistent with the rules and standards promulgated by federal statutory requirements regarding the electronic transmission of identifiable information.

VI. LOCATION OF MATCHED DATA AND CUSTODIAL RESPONSIBILITY

The parties mutually agree that one State agency will be designated as “Custodian” of the file(s) and will be responsible for the observance of all conditions for use and for establishment and maintenance of security agreements as specified in this agreement to prevent unauthorized use. Where and how the data will be stored and maintained will also be specified in this section.

This agreement represents and warrants further that, except as specified in an attachment or except as authorized in writing, that such data shall not be disclosed, released, revealed, showed, sold, rented, leased, loaned, or otherwise have access granted to the data covered by this agreement to any person. Access to the data covered by this agreement shall be limited to the minimum number of individuals necessary to achieve the purpose stated in this section and to those individuals on a need-to-know basis only.

Note that, if all individually identifiable Medicaid data remains within the purview of the State Medicaid agency, matching with any other data is permissible. Any results of the data matching which contains individually identifiable data cannot be released outside the agency unless the release meets the conditions of Section III.

Any summary results, however, can be shared. Summary results are those items which cannot be used to identify any individual. It should be noted that the stripping of an individual’s name or individual identification number does not preclude the identification of that individual, and therefore is not sufficient to protect the confidentiality of individual data.

VII. CONFIDENTIALITY

The User agrees to establish appropriate administrative, technical, and physical safeguards to protect the confidentiality of the data and to prevent unauthorized use or access to it. The safeguards shall provide a level and scope of security that is not less than the level and scope of security established by the Office of Management and Budget (OMB) in OMB Circular No. A-130, Appendix III — Security of Federal Automated Information System, which sets forth guidelines for security plans for automated information systems in federal agencies.

Federal Privacy Act requirements will usually not apply if this agreement is entered into by state agencies and no federal agencies are involved. The same applies to the Computer Matching and Privacy Protection Act of 1988. However, State laws, regulations, and guidelines governing privacy and confidentiality will apply.

It is strongly suggested that the guidelines presented in the Model State Vital Statistics Act be applied. The guidelines are available from the U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control and Prevention, National Center for Health Statistics, Hyattsville, Maryland (DHHS) Publication No. (PHS) 95-1115.

Where States have enacted laws based on this model, the actual provisions of the statute take precedence.

VIII. DISPOSITION OF DATA

(Sample Language)

The requestor and its agents will destroy all confidential information associated with actual records as soon as the purposes of the project have been accomplished and notify the providing agency to this effect in writing. Once the project is complete, the requester will

- 1. destroy all hard copies containing confidential data (e.g., shredding or burning);
- 2. archive and store electronic data containing confidential information off line in a secure place, and delete all on line confidential data; and
- 3. erase all other data or maintain it in a secured area.

IX. DATA-SHARING PROJECT COSTS

In this section, it should be stated in detail how the costs associated with the sharing or matching of data are to be met. If these can be absorbed by the “salaries and expenses,” and the partner providing the requested data is agreeable to absorbing such costs, this should be noted here. If there are extra costs to be assumed, the parties need to specify here how they will be met. If the requesting party is to bear the burden of specific extra costs, or the party providing the data is unable or unwilling to bear such, these special requirements are to be formalized in this section.

X. RESOURCES

The types and number of personnel involved in the data sharing project, the level of effort required, as well as any other non-personnel resources and material, which are required, are to be listed here.

XI. SIGNATURES

In witness whereof, the Agencies’ authorized representatives as designated by the Medicaid Director and Health Commissioner attest to and execute this agreement effective with this signing for the period set forth in Article II.

(Name)

(Name)

(Title)

(Title)

(Date)

(Date)

Source: Centers for Medicaid and Medicare Services
<<http://www.cms.hhs.gov/states/letters/smd10228.asp>>

