

ASPE TECHNICAL EXPERT PANEL ON EARLIER INTERVENTION FOR SERIOUS MENTAL ILLNESS: SUMMARY OF MAJOR THEMES

I. Purpose

On May 13, 2009, the Office of Disability, Aging and Long-Term Care Policy in the Office of the Assistant Secretary for Planning and Evaluation at the U.S. Department of Health and Human Services convened a Technical Expert Panel (TEP) to advise on the development of a research and policy agenda to prevent individuals with serious mental illness from long-term dependence on Social Security disability and related health care programs. The TEP discussed the intersection of policies relating to health care coverage and delivery, income support, disability benefits, employment supports and rehabilitation services and strategies for better aligning these policies; and evidence-based interventions to better support individuals at risk of losing jobs due to mental illness, or to increase the likelihood that they return to work and do not become permanently dependent on disability benefits and other public programs following a spell of mental illness. The goals of the TEP were to understand the policy issues relating to earlier intervention, discuss the current evidence-base, outline a series of policy responses, and develop a potential research agenda for ASPE. A list of TEP participants is provided in *Appendix 1*.

II. Building a Rationale for Earlier Intervention

A central issue discussed by the TEP was that of the need for earlier interventions to preserve or promote connections to the labor force. Dr. Howard Goldman prepared and presented a commissioned paper that provided a foundation for the discussion by summarizing some of the seminal research related to mental health, employment, and the disability trajectory. The evidence-based of research, domestic and international, regarding successful interventions continues to grow. For example, evidence-base interventions such as “individual placement and support” (IPS) demonstrated effectiveness for returning people to work and at least one study demonstrates the potential for preventing them from joining the disability rolls altogether. IPS models have been shown to be effective for older and younger working-age



clients, for those with different diagnoses and levels of severity, for those with substance abuse comorbidities, for those with different disability statuses, and for those with different work histories.¹

The commissioned paper also underscored the growing recognition in the mental health field that employment is a fundamental concern for people with serious mental illness because loss of employment results in loss of income, social supports, health insurance, and a way to participate in mainstream society. In fact, the American Psychiatric Association and other prominent groups regard the threatened loss of a job due to onset of a mental illness as a psychiatric emergency because so much is at stake in their recovery. Maintenance of employment may be a protective factor and prevent the long chain of negative consequences and disability associated with mental illness, as well as preventing dependency on public disability benefits such as Supplemental Security Income/Social Security Disability Insurance (SSI/SSDI).

However, as Dr. Goldman notes, a recent *Health Affairs* article by Drake and colleagues² identifies four key policy barriers that deter persons with serious mental illness from seeking or staying connected to employment:

- The link between eligibility for public health care programs and disability status.
- Limited integration of employment supports (including evidence-based supported employment) with mental health services.
- Disincentives for people who qualify for SSI or SSDI benefits to work.
- Lack of access to supported employment and mental health services early in the course of mental illness to avoid disconnection from the workplace.

Current Research Efforts

Several current research efforts cited in the commissioned paper served as a reference point for the TEP discussion throughout the day, including: (1) Mental Health Treatment Study (MHTS); (2) Demonstration to Maintain Independence and Employment (DMIE); and (3) psychopharmacology treatment recommendations and other related research. The focus of these studies ranges from targeting persons with serious mental illness already on disability to those “at risk” of going onto disability.

1. Mental Health Treatment Study

The Social Security Administration’s (SSA’s) MHTS is an experimental trial testing the effectiveness of integrating evidence-based supported employment with behavioral health services for individuals currently receiving SSDI. Participants are assessed during and after the intervention for changes in

¹ G.R. Bond and R.E. Drake, “Predictors of Competitive Employment among Patients with Schizophrenia,” *Current Opinion in Psychiatry* 21, no. 4 (2008): 362-369. G.R. Bond, H. Xie, and R.E. Drake, “Can SSDI and SSI Beneficiaries with Mental Illness Benefit from Evidence-Based Supported Employment?” *Psychiatric Services* 58, no. 11 (2007): 1412-1420. K. Campbell et al., “Who Benefits from Supported Employment? A Meta-Analysis” (Unpublished paper, Indiana University--Purdue University, Indianapolis, January 2009.)

² R.E. Drake, J.S. Skinner, G.R. Bond, H.H. Goldman, “Social Security and Mental Illness: Reducing Disability With Supported Employment.” *Health Affairs* 28, no. 3 (2009): 761-770.



workforce participation, mental health status and use of services. The program presently has 2200 enrollees with schizophrenia and mood disorders and early results are positive. Insurance premiums are paid for intervention group participants and they are reimbursed for all out-of-pocket behavioral health services and some work-related expenses. Assuming the study continues to show successful outcomes, there will be a policy challenge in terms of taking the program to scale due to financing issues. The majority of the expenses associated with the intervention are for supported employment, which is not covered by Medicare and has partial Medicaid coverage in some states.

2. Demonstration to Maintain Independence and Employment

Two states (Minnesota and Texas) are implementing DMIE programs, funded by the Centers for Medicare and Medicaid Services' (CMS's), that target employed individuals with severe mental disorders or people with a chronic physical health condition who also have a co-occurring mental health problem who are not currently eligible for Social Security benefits. The goal of the demonstration is to prevent or delay a person with mental illness from becoming disabled and losing their connection to the workforce.

Intervention participants receive an expanded Medicaid benefit set, which includes health and behavioral health services, as well as employment supports, including assignment to a navigator to assist in assessing needs and accessing services. Navigators, using motivational interviewing and goal setting strategies, provide a vital, yet relatively low-cost intervention component. Preliminary results demonstrate that participants have improved health and mental health outcomes and are less likely to apply for public benefits. These findings are especially promising because the programs are being implemented by Minnesota and Texas in the context of "real-world" public health systems rather than more tightly controlled experimental environments.

3. First episode psychosis Psychopharmacology Treatment Recommendations and Other Related Research

The group also discussed emerging evidence around psychopharmacological interventions for first episode schizophrenia. The current assessment of the evidence relating to first episode schizophrenia by the Schizophrenia Patient Outcomes Research Team is that existing evidence is not adequate to put forward a specific recommendation for intervention. Some psychosocial interventions, such as cognitive-behavior therapy, family psychoeducation and supported employment show promise. In addition, a participant mentioned several as-yet-unpublished research efforts on IPS by Patrick McGorry, Keith Nuechterlein, Eoin Killackey, and Miles Rinaldi with populations that have not already qualified for disability benefits. This area of research will be strengthened by the new National Institute of Mental Health research project, Recovery After Initial Schizophrenia Episode, which will test two different multi-faceted interventions for first episode psychosis, as well as by research being funded by the Robert Wood Johnson Foundation to implement the Portland Identification and Early Referral model in four additional states.



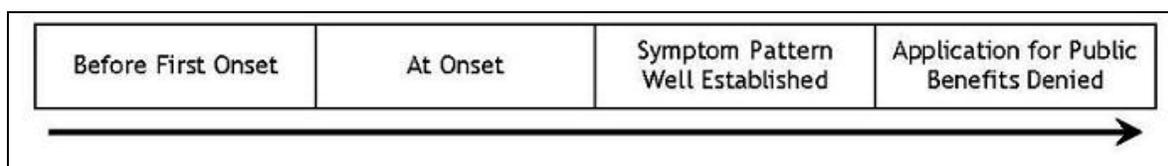
III. Defining Earlier Intervention

The TEP was asked to assist in the development of a definition of “earlier intervention” in terms of: (1) Target Population; (2) Timing; (3) Service Types; and (4) Settings.

1. Target Population

The panel acknowledged the complexity of identifying a target population for earlier intervention, including a concern about limiting the definition to a particular diagnosis. Although consensus was not reached regarding how best to target a population at risk for long-term disability, participants agreed that the definition needs to be functionally-related using a standard measure such as the International Classification of Function. The panel also agreed that the at risk population is likely to have a diagnosis of schizophrenia, bipolar disorder, or major depression. The group suggested a potential focus on consumers with psychosis because this is likely to be more predictive of long-term disability than depression. A focus on psychosis pushes the targeting of the intervention to young adults since this is typically the age of onset of schizophrenia.

A panel member developed a conceptual framework for understanding the population for earlier intervention that spans the continuum of illness from the prodromal phase prior to first onset of mental illness to the point at which a person might apply for public benefits, but is not yet disabled enough to qualify. Interventions at any point along the continuum below would still be considered “early” in the context of current practice.



The panel acknowledged that there are multiple opportunities for earlier intervention along the continuum across specific mental conditions and age ranges, each with different implications for the evidence-based practice that should be used and the site at which the intervention would be delivered. Discussion of population is closely related to timing and services in that way.

2. Timing and Strategies for Identification and Outreach

Participants agreed that the best time to intervene is at the initial onset of a person’s mental illness, or as early as possible. Because mental health conditions launch people on a declining trajectory, it is critical to identify and treat people during their first or second episode and to reduce the duration of untreated psychosis. The effectiveness of interventions diminishes over the illness course.

A subject of much conversation was how best to identify people in the early stage of mental illness. Participants suggested that early intervention should be targeted at illnesses that have observable markers. Clinical research is currently engaged in identifying prodromal signs that indicate a coming episode of mental illness, particularly schizophrenia.

Participants also noted that the Minnesota and Texas DMIE programs successfully identified participants with mental health conditions through pharmacy and health care claims data. The panel also discussed a variety of settings where individuals could be identified, including: the vocational rehabilitation system, prisoner re-entry, and youth transition programs. However, interventions targeted at people before they even meet the mental health system is a major departure from current practice and there is not currently a policy orientation that supports this concept.

3. Types of Services

The panel also discussed the types of services that are needed for early intervention and agreed that services offered should attend to employment and educational settings to keep people connected with their functional environment as much as possible. As previously discussed, IPS is one of the most promising models, though it can be difficult to fund because it crosses health and employment sectors. Benefit structures used in the MHTS and DMIE were designed specifically to fill the current gap in funded services, using flexible funding to pay for the additional benefits. There is less evidence for cognitive-behavioral therapy and peer support models at this time.

The participants recommended that services be customized, culturally competent, and person-centered. Interventions should consider potential modifications to address needs across age groups, populations, personal resource levels (i.e., insurance status), settings, and financing mechanisms. They also identified the need for a central case manager or navigator to coordinate services and maintain accountability for a person's treatment. Services should also account for co-occurring substance abuse or untreated ambulatory health conditions, which both tend to accelerate the trajectory of disability.

4. Systems for Outreach and Service Delivery

The TEP generally agreed that early interventions should take place in settings separate from services offered to long-term psychiatric patients, potentially in primary care clinics, self-help centers, or other community-based settings. In addition, the group discussed the possibility of working through employment related services, such as Employee Assistance Programs, as a strategy to identify and reach persons who do not self-identify as mental health consumers. There has been effort to involve the mental health system more closely in the Workforce Investment System, but it has not been very successful so far. A participant commented on the "iatrogenic effects of the mental health system" and urged that workplace and education settings be used wherever possible to counteract those effects.



State mental health systems currently focus on the most severe cases, leaving limited resources to serve people with less debilitating illnesses. Integrating and coordinating employment interventions through the public mental health system could be a viable strategy, but more resources would need to be invested in community mental health.

IV. Knowledge Gaps and Future Research

When asked if the current evidence is sufficient to inform policy in this area, the TEP called for more research, acknowledging that there are a number of efficacious interventions that restore and enhance independent functioning, but implementing them in the real world is an ongoing challenge. Moreover, many intervention models were devised in European countries that have the benefit of a national health system and have not yet been tested in the United States.

Translation of research to practice has been a major issue for SSA and their demonstrations; they continue to gather evidence from MHTS, Ticket to Work, and the employment network, but they need more impacts and practices to be translated broadly and sustained beyond the duration of demonstration funding.

The TEP discussed the need to plan research so that its outcomes are policy relevant. One participant recommended that careful consideration be paid to defining the outcome that is being tested and the need to incorporate evaluation and policy issues from the very beginning that will answer the questions: Who is at risk? Who is willing to pay for that risk? Who will need the intervention? Does the intervention directly link to the outcome?

An area of much discussion was the need for longitudinal research and long-term follow-up of study participants. TEP members asserted that research should include follow-up for as long as ten years in order to vary the length of the intervention, observe its full impact on disability, or to be able to model the decay of its effects. There is a need to understand the effectiveness of early intervention in changing the trajectory of participants' future experience. The economic benefits of continuing employment are especially apparent after many years elapse.

In particular, many participants commented that there is a need to continue the DMIE beyond its currently scheduled end date. They argued that it now has economy of scale and much remains to be found from replicating the model. However, the demonstration is currently scheduled to end in September and an extension would require Congressional action.



V. Potential Policy Levers and Suggested Next Steps

Community Mental Health System and Workforce Issues: TEP participants noted the scarce resources available to and the eroded condition of the public mental health system due to poor training, an overemphasis on medication, and a workforce in crisis. Regarding the workforce, panelists noted the lack of training and capacity to carry out evidence-based interventions with fidelity, as well as limited experience implementing early interventions or interventions designed to promote employment.

Medicaid Buy-In: Participants discussed the experience of Medicaid Buy-In programs and why they are and are not effective. One participant noted distrust of the Medicaid and Social Security programs among mental health consumers, and that the program's successes have not been well-communicated. Though all states' programs are different, they generally place too much emphasis on personal care attendant benefits rather than supported employment benefits, a mismatch of services for this population.

Framework for Early Intervention: Building on the conceptual framework put forward in the meeting, TEP members identified the need to develop a detailed framework to identify and assess opportunities for earlier intervention along the continuum of disability. This would help identify populations and service settings for intervention and support policy prioritization.

CMS Community-Based Services Waivers: Another major area of discussion was Medicaid and the role of waivers in providing community-based services to mental health consumers, including workplace supports. It was also proposed that people who have been rejected or otherwise delayed from receiving vocational rehabilitation might be offered the same types of services under a Medicaid benefit; this would require a change in statute or interpretation of statute.

Further CMS Guidance and Clarification Needed on Coverage for Employment Support Services: A participant from state government commented that states need clear guidance from CMS about how to build supported employment benefits in the Medicaid program. There is a need to translate the mental health "language" of supported employment to the CMS "language" of reimbursement, at the individual code level, in order to build common understanding.

Potential Role of the Private Sector: Participants considered the current and potential roles of schools and employers in identifying mental health needs, helping people to obtain good treatment and services, and maintaining connection to mainstream workplace or educational settings and associated insurance. Participants also discussed involving private sector health and disability insurers to learn about their experiences, models for coordinating benefits, and potential cost savings resulting from coordination. Participants suggested that ASPE might bring more insurers and large employers together to exchange information and inform a 2-3 year agenda.



Relevant Lessons from Welfare Reform: The TEP raised the issue of what might be learned from experiences with welfare reform. Vulnerability is very intense in both populations; one thing going wrong can cause a cascade of negative consequences. The welfare reform effort was largely a success and may offer relevant lessons, but mental health and disability policy changes would face a different set of obstacles because of the need to cooperate across agencies.

Proposed Research Questions Suggested by Participants

- Identify what characteristics the currently disabled population had before they became disabled.
- What volume of people might potentially be involved in a broad-based early intervention effort?
- What crises precipitate mental health conditions?
- Evaluate the differences in success rates for consumers who accept the label of “person with a mental illness” versus those who do not.
- Evaluate the role of parents’ insurance benefits on the treatment of mental health conditions in young adults and the potential for public/private coordination of benefits.
- How can we ensure that services are integrated and coordinated enough to be effective for individuals and also sustainable at a system level?
- What are the real and perceived barriers to states using Medicaid waivers, such as 1915c or 1115 waivers, to implement employment support services and programs for people with mental illness?
- How similar are the TANF population and the population of mental health consumers? Do they face similar issues related to child care, employment, transportation, etc.?
- What are the impacts of the two year wait for Medicare for SSDI beneficiaries on their mental health and functioning?

Appendix 1: Members of the Technical Expert Panel

Richard Balkus -- Social Security Administration

Crystal Blyler, PhD -- Substance Abuse and Mental Health Services Administration

Ron Brand -- Minnesota Association of Community Mental Health Programs

Randee Chafkin -- Department of Labor, Employment and Training Administration

Robert Drake, MD, PhD -- Dartmouth Medical School

Howard Goldman, MD, PhD -- University of Maryland School of Medicine

Robert Heinssen, PhD, ABPP -- National Institute of Mental Health

Chuck Ingoglia, MSW -- National Council for Community Behavioral Healthcare

Les Kertay, PhD, ABPP -- Unum

MaryAlice Mowry -- Minnesota Department of Health

Patricia M. Owens, MPA -- Government Accountability Office

David Stapleton, PhD -- Mathematica Policy Research

Dena Stoner -- Texas Mental Health and Substance Abuse Services Division

Shawn Terrell, MSW -- Centers for Medicare and Medicaid Services

Wilma Townsend, MSW -- WLT Consulting

ASPE Representatives -- Ruth Katz, William Marton, and Vidhya Alakeson

Lewin Representatives -- Karen Linkins, Sarah Lash, and Steven Baxter

This issue brief was prepared under contract #HHS-100-03-0009 between the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy (DALTCP) and the Lewin Group. For additional information on this subject, or to view the other briefs in this series, you can visit the DALTCP home page at http://aspe.hhs.gov/office_specific/daltcp.cfm or contact the ASPE Project Officer, Helen Zayac, at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201, Helen.Zayac@hhs.gov.



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