

Briefing Summary
Early Intervention Mental Health Services for
Adolescents and Young Adults
July 23, 2013

On July 23, Women's Policy, Inc. (WPI) sponsored a briefing in cooperation with Reps. Jaime Herrera Beutler (R-WA) and Donna F. Edwards (D-MD), Co-Chairs of the Congressional Caucus for Women's Issues (the Women's Caucus); Reps. Kristi Noem (R-SD) and Doris Matsui (D-CA), Vice-Chairs of the Women's Caucus; and Reps. Jaime Herrera Beutler and Lois Capps (D-CA), Co-Chairs, Women's Health Task Force, the Women's Caucus. The third in a women's health series supported by the Robert Wood Johnson Foundation, the briefing focused on early intervention and mental health services for adolescents and young adults (a project supported by the Robert Wood Johnson Foundation). Approximately 100 guests attended the briefing, including Members of Congress, senior congressional staff, representatives of federal agencies, and health and women's advocacy organizations.

Cindy Hall, president of WPI, thanked the leadership of the Women's Caucus and Women's Health Task Force and the Robert Wood Johnson Foundation for supporting the briefing. She introduced the moderator, David C. Colby, PhD, Vice President, Research and Evaluation, Robert Wood Johnson Foundation, and thanked the speakers: Larke Huang, PhD, Director, Office of Behavioral Health Equity, Office of Policy, Planning and Evaluation, Substance Abuse and Mental Health Services Administration; William R. McFarlane, MD, Program Director, National Demonstration of Early Detection, Intervention, and Prevention of Psychosis Program in Adolescents and Young Adults (EDIPPP), and Professor of Psychiatry, Tufts University School of Medicine; and Linda Rosenberg, MSW, President and CEO, National Council for Behavioral Health.

Members of the Women's Caucus

Congresswoman Lois Capps (D-CA) noted that the Women's Caucus has a long history of taking a bipartisan approach to women's issues. She emphasized that the topic of mental health is important to the nation and to each of us personally, but is often overlooked even though one in every four adults experiences a diagnosable mental illness each year. Mental health is the leading cause of disability, and when left untreated, our schools, workplaces, and communities suffer. When caught early, even severe mental illness can be stopped in its tracks and young people can be put on a path to normal, healthy lives.

Rep. Capps noted that great strides have been made through the *Mental Health Parity Act* and provisions in the *Affordable Care Act*, but much work remains to be done to ensure that mental health benefits are available to all Americans. "Our mental health system has long suffered from underfunding and fragmentation as well as a lack of understanding about mental illness. To make sure that all children and young adults are put on a path to success, we must change the way we think and talk about treating mental illness, and we must invest in a strong health care work force." Rep. Capps supports school-based health centers, where she believes early screening can and should take place. She concluded by saying that, when we invest in mental health, we make our communities stronger, safer, and better places to live.

Rep. Doris Matsui (D-CA) described a national community health dialogue event in Sacramento, which focused on community mental health for young people. With women making up two-thirds of the 400 attendees, several mothers came up to the congresswoman after the event to talk about how their children suffer from depression or bipolar disorder. As mothers and caregivers, women are the ones who often seek help for a child who is struggling with a mental disorder. Rep. Matsui noted that, all too often, we differentiate between physical and mental health as if the brain was not a part of the body. “We conceal depression, mask anxiety, and ignore mood disorders. But mental illness impacts all of us,” and in the case of the congresswoman’s family, her own sister has struggled with schizophrenia. Rep. Matsui highlighted the important work of the early diagnosis and prevention team at the University of California-Davis, which is serving residents between the ages of 12 and 25 who are in the early stages of psychosis as part of the EDIPPP initiative funded by the Robert Wood Johnson Foundation.

Rep. Matsui said that, unfortunately, state budget cuts have undermined the ability of communities to provide mental health services. The Congresswoman mentioned legislation she has introduced, the *Excellence in Mental Health Act*, together with Representative Leonard Lance (R-NJ). The bill is designed to provide communities with incentives to provide a broad range of evidence-based mental health services. She concluded by saying that this is the time for Congress to level the playing field and ensure that everyone gets the mental health care they need and deserve.

Congresswoman Sheila Jackson Lee (D-TX), Co-Chair of the Children’s Caucus, said she could not think of a more important effort than providing mental health services to young people. She noted that we have always been a step behind in providing resources and services for all those who need mental health services, especially children and adolescents. In her district in Houston, Rep. Jackson Lee is fighting to save a program that serves children who have aged out of eligibility for foster care, many of whom need mental health services. With the right kind of treatment, these children can overcome mental health problems but only if services are available. She and Representative Ileana Ros-Lehtinen (R-FL), Co-Chair of the Children’s Caucus, want to introduce an omnibus bill to address treatment for the mental health problems of adolescents and young adults. She also is concerned about the serious problem of bullying, which needs to be addressed with best practices including mental health treatment practices.

Speakers

Dr. Colby said that the Robert Wood Johnson Foundation is the largest US philanthropy devoted solely to improving health and health care, and to fostering a new culture in this country that will enable Americans to live healthy and productive lives. Over the last 41 years, the foundation has awarded \$9 billion in grants to every state and the District of Columbia in order to help Americans live longer and more productive lives. The foundation’s programs are helping to reduce obesity among children, improve the quality of care, reduce the costs of health care, and help the most vulnerable among us. The foundation has focused on building the emergency medical system; reducing addiction to tobacco, alcohol and drugs; leading the fight to improve care for those with HIV; improving the care seniors receive at the end of life; training health professionals; and advancing U.S. health care policy. “As we

look to the future, the foundation's vision is one where individuals, business, government, and organizations work together to foster healthy communities and lifestyles.”

Dr. Colby noted that one in ten young people suffer from mental illness today and severe mental illness affects more adolescents and young people than any other illness. Half of mental illness starts by age 14, and three quarters by age 24. Severe mental illness affects more adolescents and young people than any other illness, and it accounts for many of the suicides in this population. Starting in 2007, the Robert Wood Johnson Foundation has provided \$16.9 million for early detection and prevention of psychosis among young people in six sites across the country. Building on the Portland Identification and Referral Model (PIER), the foundation has provided funds to scale up the model, develop the clinical evidence to validate the approach, build awareness and demand for the model, and develop expertise within the treatment community to disseminate and implement the model. Dr. Colby said that the importance of this model is that it brings together the entire community to identify and address the problems of severe mental illness among children and adolescents.

Larke Huang, PhD

Dr. Huang thanked Cindy Hall and the congresswomen for bringing this issue of mental health among young people into the light of day. The age cohort of interest is adolescents and young adults, a life stage when mental and emotional disorders first occur along with substance abuse problems. Dr. Huang explained that mental health problems can derail a young person's developmental path and stressed that the stigma around mental illness persists: “When someone comes home from cancer treatment, the community rallies around that individual and family, but when someone comes home from a psychiatric hospital, that individual and family often receive little or no support.”

Dr. Huang noted that the new scientific term for young adults is “emerging adults.” This is a period when the brain architecture is not yet set, family relationships are reconfiguring, and navigation of social relationships is critical. Emerging adults are establishing their self-identity and competence in a relational context while often engaging in significant experimentation. Emerging adults need to establish critical, problem-solving abilities in order to respond appropriately in relationships while also completing school and preparing for employment.

Dr. Huang explained that emerging adults are vulnerable to mental and emotional disorders. Half of all lifetime cases of mental illness start around age 14. For three quarters of individuals with mental illness, symptoms appear by age 24. One in ten children and teens suffer from a serious emotional disorder, and 90 percent of people who develop a mental disorder show warning signs as teens. Because mental illness starts young, the lifetime burden of mental illness is significant. This is the reason that it is so important to look for early warning signs of mental illness, and to intervene early. Early intervention also can help to prevent the overlay of a substance abuse disorder. Dr. Huang noted the strong relationship between childhood trauma (e.g., violence, assault, sexual abuse) and the onset of mental health and substance abuse disorders.

Dr. Huang stressed that there is a tremendous amount of unmet need among adolescents and young adults. One federal study showed that whereas 59 percent of adults had not received mental health treatment within three months of intake, 78 percent of adolescents aged 12 to

17 and 73 percent of young adults aged 18 to 25 had not received treatment within that time period. She also noted that from 2005 to 2011, females aged 18 to 24 had twice the incidence of past-year major depressive episode (10.3 percent to 12 percent) in comparison to their male counterparts (5.2 percent to 5.8 percent). By contrast, the prevalence of past-year substance use disorder (i.e., illicit drug or alcohol dependence or abuse) was higher among males aged 18 to 24 (28.3 percent to 27.0 percent) than among their female counterparts (16.4 percent to 17.5 percent).

Dr. Huang concluded by discussing the implications of severe mental and emotional disorders for life outcomes: Young people with severe mental and emotional disorders are more likely to drop out of high school and less likely to be employed in comparison to their counterparts who do not have these disorders. Maternal depression interferes with the parenting of young mothers, and their children have higher rates of depression. The good news is that mental disorders can be treated, and the federal government is funding programs that provide early intervention, treatment, and supports that show positive outcomes. Going forward, the federal government is utilizing its grant programs as important learning labs and thinking about how to scale up these programs to state-level programs. The President's Report, *Now is the Time*, supports early intervention to identify and treat mental illness through schools and other community institutions.

William R. McFarlane, MD

Dr. McFarlane said that we have the possibility of a new dawn for addressing a set of illnesses that most people do not understand. These mental illnesses usually land in the lap of women, because it is typically the mother who deals with the mental illness of the child and carries the greatest burden. Dr. McFarlane noted that the nation has put billions of dollars into curing cancer, and the greatest success has been with early identification of cancer and early intervention. The same functional version of prevention can be applied to severe mental illness. He explained that two to three percent of young people develop schizophrenia or a severe psychotic mood disorder, and 75 percent of those who have psychosis (especially schizophrenia) are permanently disabled. Between 12 and 15 percent of these individuals commit suicide. The current annual cost of schizophrenia is \$61 billion. Most of the disability from these disorders occurs at the first episode between the ages of 12 and 25, which is the reason that early identification and intervention are so important.

Dr. McFarlane described an evidence-based intervention model for mental illness (PIER) that was first developed in Portland, Maine starting in 2000. With the goal of reducing the incidence of mental disorders in a defined population by early detection and treatment, this model employs an old fashioned public health and community mental health approach. Dr. McFarlane and his colleagues go into communities to talk with a variety of groups about how to understand the early stages and symptoms of mental illness and where to go for consultation, specialized assessments, and rapid treatment. The target groups include family practitioners and pediatricians; mental health clinicians; professionals in schools and universities; and military personnel. The focus is to keep individuals with mental illness engaged in the community, school, and jobs so that they remain in and adjust to their lives.

In 2006, the Robert Wood Johnson Foundation funded a national replication of the Portland model (EDIPPP) in six sites. The foundation continued to fund the program in Portland, along with replication sites in Glen Oaks and Queens, NY; Ann Arbor, MI; Salem, OR;

Albuquerque, MN; and Sacramento, CA. The goal was to replicate the model in a broad cross-section of communities in order to assess whether this approach could work in different settings. Teams were sent into each replication site to educate professionals and providers about the model.

One of the key findings from the replication effort was that the communities employing the model for the longest period of time had higher success rates in identifying young people who were expected to have severe mental illness: In Portland, where the model had been in place for 8 years, 63 percent of those with expected mental illness were identified early, whereas only 12 to 17 percent of those with expected mental illness were identified in the New York and New Mexico sites where the model had been in place for 1.5 years. These results show that identification rates can improve over time as the right people learn about the importance of identifying and referring individuals at risk for severe mental illness. Dr. McFarlane said that there are now ten studies and a major meta-analysis showing that the Portland model results in a two-thirds reduction in risk of conversion to psychosis. According to follow-up research conducted in Portland, most of these gains have been maintained over time. Dr. McFarlane concluded that a major lesson from this research is that we can successfully address severe mental illness among youth in this country. Early identification and intervention for psychosis provides an enormous opportunity for reducing the burden of disease in the United States.

Linda Rosenberg, MSW

Linda Rosenberg opened by noting that this is the 50th anniversary of President Kennedy's signing of the *1963 Community Mental Health Act*. The law marked the beginning of the end of an era of state hospitals and the start of a community-based approach to treating mental illness. Fifty years later, we can take another step forward. Ms. Rosenberg said that we now know how to treat mental illness and, when individuals receive effective treatment, it works. In fact, treatment for chronic psychiatric disorders is just as effective as treatment for chronic physical problems: For example, the success rate for those treated with bipolar disorder is 80 percent in comparison to a success rate of 70 to 80 percent for those with asthma or diabetes.

Ms. Rosenberg reported that availability of services to treat mental illness has remained flat. In the case of substance use, only 10 percent of the 23 million people who need treatment receive treatment. By contrast, 84 percent of the 28 million individuals with diabetes receive care. Most of those with mild to moderate emotional disturbances receive their care through poorly managed primary care, which typically provides only medication. And many individuals with severe mental illness do not receive help before or during their first episode. One result is that schizophrenia is a chronic illness for 75 percent of those diagnosed with the disease. Left untreated, severe mental illness has spillover effects on employment, education, the criminal justice system, and physical health – and can result in terrible tragedies.

Can we turn this around? Ms. Rosenberg highlighted several positive developments in the identification and treatment of mental illness. As a result of legislation requiring parity, insurance plans now must cover mental health and substance abuse problems in the same manner as they cover other disorders. She pointed to the important work undertaken by Dr. McFarlane and his colleagues, as well as a major project funded by the National Institute of Mental Health (NIMH), *Recovery After an Initial Schizophrenia Episode* (RAISE). The goal of RAISE is to change the trajectory and prognosis of mental illness through coordinated and

aggressive treatment in the earliest stages of illness in sites across the country. Also highlighted was an evidence-based program called *Mental Health First Aid*, which has delivered early identification and intervention with mental health services to over 100,000 Americans.

Ms. Rosenberg emphasized that it is critical to increase awareness of the early symptoms of mental illness among young people, and to ensure that these individuals are identified and receive treatment. Most Americans do not know the signs of mental illness, addiction, or suicide -- or how to find help. All youth with mental illness must be assured of access to comprehensive treatment services, regardless of their insurance status or source of coverage. Ms. Rosenberg called for the creation of regional treatment centers for mental illness that are not dependent on funding from a foundation or a government funding source, such as NIMH. Several policy ideas were offered: the creation of a new disease-based category for mental illness in Medicaid eligibility under 42 USC §1936A [state plans for medical assistance]; the implementation of a Medicaid wrap-around benefit for those who have private or other insurance; the extension of the Medicaid benefit for the duration of the disease; and the creation of a grant program to educate and train practitioners and providers to deliver the interventions. Ms. Rosenberg concluded by saying that we have the science, and now we must have the will.

Discussion

Dr. Colby opened the discussion by posing the question of whether professionals in schools and universities are open to identifying children in need of mental health services. Dr. McFarlane has found that schools, universities, and pediatricians are eager for information about how to help young people with mental health problems. Additional questions and discussion focused on the importance of disseminating effective screening and assessment tools; conducting outreach to professionals, practitioners, teachers, and parents; and expanding the capacity to provide mental health services, as well as the long-term benefits to society of intervening early with children and adolescents who have mental illness.

Cindy Hall concluded the briefing by thanking the moderator and panelists for their excellent presentations, and by thanking the Robert Wood Johnson Foundation for funding the briefing and the briefing series. She also thanked the cosponsors of the briefing and the Members of Congress who offered their remarks. The webcast of the briefing can be viewed by clicking [this link](#).