

The Early Detection and Intervention for the Prevention of Psychosis Program (EDIPPP)

ISSUE BRIEF
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Preventing Psychosis in Young People: The Promise of Early Identification and Care

In 2005, social worker Sarah Lynch received an urgent call from a health center nurse at the University of Southern Maine. The nurse had just attended a seminar Lynch held to educate staff on mental illness in young adults. She was concerned about a freshman who was hearing voices and seeing shadows, feeling fearful around others, and struggling to stay in school.

Lynch immediately made an appointment to meet with the student on campus to see whether she should be referred for care. The nurse's hunch was right. The young woman, Tiffany, was showing early warning signs of psychosis. Lynch learned that Tiffany's father suffered from schizophrenia, making her genetically at risk for this condition. Lynch quickly got Tiffany into a program at the Maine Medical Center where she received treatment and counseling. She worked with university staff to make sure they had accommodations so that the Tiffany could complete college during her treatment.

Today, Tiffany is a healthy, confident, and poised young adult, completing graduate school to become a psychiatric nurse practitioner to work with patients like her father and others like herself. This early intervention effort "gave me a second chance," she says. "I don't think I would have been as successful if I didn't get this help when I did."

CATCHING SYMPTOMS EARLY

Lynch works with psychiatrist William McFarlane at the Portland-based national program office of the Early Detection and Intervention for the Prevention of Psychosis Program (EDIPPP). Launched in 2006 with support from the Robert Wood Johnson Foundation (RWJF), EDIPPP has been collecting evidence from six sites around the country on the effects of its early identification and treatment model, which focuses heavily on pro-active community. The goal is to educate families and those who routinely interact with at-risk youth—teachers, mental health professionals, and doctors—about key signs to look for in young people to identify and prevent psychosis before it starts.

"We are trying to catch these symptoms before they get worse and before they really impact a young person's life," says Lynch. "We have learned that if we can intervene earlier with these cases it can make a big difference in their future."

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Other countries, including Australia, the United Kingdom, and Norway, have embraced this approach to mental illness prevention. However, the United States has been slower to adopt this strategy. With evidence from the EDIPPP effectiveness study, RWJF hopes to accelerate action toward changing the way serious mental illness is addressed in the U.S., with a new emphasis on promoting early intervention.

LOOKING TO REPLICATE A PROMISING MODEL

The national EDIPPP study emerged from a model McFarlane established at Maine Medical Center in 2001—the Portland Identification and Early Referral program or PIER. PIER’s success in keeping kids like Tiffany from converting to full-fledged psychosis through its strong outreach to professionals and family members and its multi-faceted treatment protocols caught RWJF’s attention.

“We were really intrigued by the results the PIER project was seeing and wondered whether this could be replicated,” says Jane Lowe, Ph.D., senior advisor at RWJF. “The idea that you could identify the most at-risk youth in the community early, and that you didn’t have to wait until young people become psychotic or suicidal to intervene seemed like a promising approach that could really advance knowledge and change the way we think about how we treat serious mental illness.”

For five years, the six EDIPPP sites – Portland, Maine; Albuquerque, N.M.; Salem, Ore.; Ypsilanti, Mich.; Sacramento, Calif.; and Glen Oaks, N.Y.—have participated in a formal study examining the effect of pro-actively educating thousands of community members, health professionals and educators about the early signs of severe mental illness, with the goal of identifying at-risk teens and young adults early and getting them into immediate treatment. The study examined whether multi-pronged, evidence-based treatment interventions improved outcomes, and whether this model of care has the potential to work in communities beyond Portland with very different populations and unique cultural attitudes toward mental health.

Although the research team is still analyzing the data from the EDIPPP sites, the qualitative findings are extremely promising. In fact, California already has replicated the model in a handful of other sites including Ventura, Santa Clara, and San Diego that didn’t participate in the original study. And, these sites are showing reduced hospitalization rates among teens and young adults in treatment and fewer “conversions” to full-blown psychosis.

PAY NOW, OR PAYING LATER

Mental illness has been viewed as a disease of early adulthood. But the onset of bipolar disorder or schizophrenia typically occurs in teens and young adults. In fact, about half of all lifetime cases of mental illnesses start at age 14 (16.5 years is the average). Symptoms in three-quarters of mental illness cases appear by age 24. About one in 10 children and teens suffer from mental illness severe enough to cause some level of impairment.

A psychotic disorder typically emerges gradually over months or even years. But over the past two decades, mounting research has shown that there is a pre-psychotic or “prodromal” phase for those who develop these disorders. McFarlane and other experts believe that improving identification of symptoms that appear during this phase creates an opportunity to get young at-risk people into treatment early and significantly enhance their long-term outcomes. In fact, a January 2013 analysis of studies that appeared in the *Journal of the American Medical Association’s Psychiatry* confirms that intervening early can dramatically change the trajectory for those with vulnerability to psychotic illnesses.

Because early symptoms of psychosis often go undetected, there is great interest in developing public health interventions that help get young people into treatment sooner. McFarlane and EDIPPP participants hope that the lessons learned through the national EDIPPP study help influence state and federal policy-makers seeking to improve the country’s mental health system in the wake of recent events that have revealed serious gaps in the way the U.S. funds and treats mental illness.

It’s hard to overestimate the impact that severe, untreated mental illness has on an individual, a family, and society. According to the World Health Organization, the impact of neuropsychiatric disorders is greater than the burden caused by any other medical disease. Many people with psychosis don’t finish high school. They also struggle to maintain steady employment. Some become permanently disabled and are unable to work; some live on the streets or wind up in jail; and most spend their lives dependent on family support or public assistance.

Through the EDIPPP model of detection and intervention, “people now know what to do when they see these early warning symptoms,” says McFarlane. “If we can direct kids away from severe mental illness and long-term disability—that will have huge social and economic implications.” He adds that it makes no sense to wait until someone has a psychotic episode to begin treatment, particularly with young people. “If this was cancer, we wouldn’t wait if we could prevent its spread. We’re trying to intervene early to prevent a serious illness that can have lifelong consequences.”

HAVING TOOLS TO TAKE ACTION

While it may seem intuitive, EDIPPP project leaders say many health professionals, including pediatricians and nurses, who come into contact with young people at risk of serious mental illness don't always recognize it. They also don't know where they can refer a young person for treatment if they suspect the person is struggling.

A fundamental component of PIER and EDIPPP is educating community members through outreach. And it appears that this education has made a difference. According to an analysis of EDIPPP's efforts published in the *Journal of Public Mental Health* in 2012, participants across all sites said they were learning new information. Before the project began aggressive outreach and education, the majority of participants reported that they were not knowledgeable about the early warning signs of psychosis, the referral process, or EDIPPP services. But following their participation, people at each site reported large gains in knowledge in all of these areas. In fact, the study showed that referrals tended to increase as outreach activities reached more members.

"Community outreach is a big part of this," says Lynch. "You can't identify these cases without going into the community to schools, private practices, and primary care settings. Many of the professionals we reach out to don't fully understand psychosis; even people in the field, including mental health professionals, don't understand the early warning signs."

The EDIPPP model:

- Educates the community, particularly school professionals, mental health clinicians, and primary care doctors, who are likely to encounter youth;
- Identifies and equips the groups to identify young people who are displaying early signs;
- Evaluates a person's risk for actual psychosis;
- Engages individuals and families in the treatment process and equips them with the skills to complement professional support geared toward preventing full-blown episodes;
- Treats patients with counseling and, if necessary, medications; and
- Establishes networks with professionals to provide on-going educational, occupational, and social support.

For many young people and their families, getting preventive mental health care in the community is a unique experience. Too often, treatment occurs post-crisis, after they have been hospitalized, often against their will. Lynch says connecting vulnerable young people with appropriate treatment and support services early helps them learn to recognize their own "warning symptoms" and take better care of their health over a longer period of time.

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— Bill McFarlane, MD,
EDIPPP Director

A PROMISING LANDSCAPE AHEAD

As McFarlane and team gear up to report their final results, the EDIPPP model appears to be taking hold amid an environment where interest in shoring up the mental health system is at a high level. There is greater awareness and acceptance of the link between good mental health and physical health. As a result of the 2008 Mental Health Parity and Addiction Equity Act, there are opportunities to redesign mental health services and increase access and care. In addition, many communities are adopting a Mental Health First Aid initiative to foster better ways of identifying, understanding, and responding to signs of mental illness.

And states like California and Oregon are moving rapidly to expand early detection and intervention projects based on the EDIPPP model. California, which has dedicated funds for early intervention programs, has been touted as a potential national model.

The next step is figuring out how to bring this new model of mental health care to the entire country and identify sustainable sources of funding. McFarlane says he hopes that the EDIPPP results will help demonstrate that it's time to apply a new model of prevention to severe mental illness. "It would be especially tragic if we keep doing things the way we have been in spite of the fact that we know how to do otherwise."