



## The Importance of Early Intervention: A School Social Worker's Professional and Personal Story (PIER Program, Portland, Maine)

Cynthia Wilcox learned the importance of early intervention with psychosis—both as a school social worker and as the mother of a son who has struggled with mental illness.

As a social worker at a middle school near Portland Maine, Cynthia Wilcox, LCSW, has long clinical experience helping young people with an array of needs, from anxiety to learning problems. But she knew little about a cluster of symptoms that may signal early psychosis until she attended a district-wide workshop for all school health and mental health practitioners in the fall of 2004.

There, an occupational therapist with the Portland Identification and Early Referral (PIER) program at Maine Medical Center, spelled out subtle symptoms that may be mistaken for other issues: being fearful for no good reason; jumbled thoughts and confusion; feeling “something’s not quite right”; declining interest in people, activities, and self-care; hearing sounds or voices that are not there; trouble speaking clearly and not understanding others; and declining mental acuity, memory, or attention.

“We realized that we did not know as much as we could have known to be effective with the children,” Wilcox said. “PIER clarified so much for us about what you can look for early on.”

The workshop was part of PIER’s community outreach program aimed at identifying young people with early, or prodromal, symptoms of psychosis, and getting them into treatment designed to prevent a full-blown psychotic episode. PIER was one of six programs around the country participating in a *National Demonstration of Early Detection and Intervention for the Prevention of Psychosis Program (EDIPPP)*, a

national program of the Robert Wood Johnson Foundation (RWJF).<sup>1</sup> Read the [Program Results Report](#) for more information on the program.

After the workshop, Wilcox and her colleagues in the school system began making referrals to PIER. Those young people assessed as being at risk of psychosis entered an intensive program of family psychoeducation, supportive counseling, employment and educational counseling, and medication management, as needed.

“It was incredibly refreshing to have someone come and say, ‘We want to help your students. Please refer to us,’” Wilcox said. “That had never happened with any kind of resources I can remember in all my years of social work. That’s what made it so unique. It filled this really big gap.”

## A FRIGHTENING PHONE CALL

Psychotic symptoms often make their first appearance in teenagers or young adults. Estimates suggest that from 1 to 3 people in 100 will experience psychotic illness, which takes a tremendous toll on those who suffer from it and their families. Youth often have a hard time maintaining friendships and staying in school or on the job, short-circuiting their progress toward productive, healthy adulthood. And families face increased stress as they attempt to care for and get help for an ill son or daughter.

This reality came home for Wilcox in 2008, when she and her husband got a call from the dean of the college that their youngest son, Joe, attended. He was in a hospital emergency room, they were told, after displaying bizarre and potentially self-injurious behavior. “We were told to come right away,” Wilcox recalled. “I can’t think of another time in my life that I was as frightened.”

After two weeks in the hospital, Joe had made some progress, but it was clear he was not ready to be back in school and needed to be in treatment. “We were going back to Portland so I thought, ‘Hmm, what is available?’” Wilcox said. “I thought of PIER.”

Though she had talked to PIER staff before on behalf of students at her school, making the call for much more personal reasons was difficult. “I was embarrassed and emotional,” she said. “They were wonderful and asked all the questions they would have asked me if I was a social worker referring a student.”

Her son was assessed and admitted to the program, and “at that point our whole family became part of the PIER program,” Wilcox said.

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<sup>1</sup> RWJF’s title for this program is *National Demonstration of Early Detection, Intervention and Prevention of Psychosis in Adolescents and Young Adults*. That is the name that appears on the RWJF website. In the field, the program is known by the title used in this report.

A primary treatment intervention at PIER is family psychoeducation that focuses in particular on the emotional aspects of the family interaction. Every two weeks, in the early evening, Joe and his parents, and sometimes his siblings, attended a group with seven other families that had a family member dealing with pre-psychotic or psychotic symptoms. With the guidance of group leaders from PIER, the families solved problems together, practiced communication skills, and learned strategies for coping with symptoms.

Being with other families helped her maintain her balance and move forward, Wilcox said. “The support I got from the other parents was such a comfort. It made me realize we were not alone as we were going through this really heart wrenching time. These things can happen to other good parents and their kids.”

Participating in the family group also helped Wilcox and her husband and son have more productive interactions at home. “It gave us food for thought,” she said. “We could go home and have conversations with our child that might not have happened without the preparation in the group.”

## **KEEP IT SIMPLE**

A key message PIER staff delivered was to “go slow and keep things simple,” Wilcox said. “That was hard for a lot of us parents, because we were all so wrought up about things.... I loved the way they focused on the strengths of the family and the strengths of the young people, in particular. We looked forward to these meetings. It was a constant for us, at a time when there were a lot of uncertainties and fears.”

Joe’s big concern, his parents learned, was falling behind in school. PIER staff stepped into address this by, first, helping him find volunteer work and then, as his symptoms stabilized, helping him sign up for courses at the local college. “They really advocated for him and for the other patients in the community,” Wilcox said. “What stood out for us was how helpful it was to attend to these concrete things, because it was those things that gave the kids a sense of hope and a sense of moving forward.”

Today, Joe is a college graduate and living and working independently. “It is still a long road for him and for us,” Wilcox said. “He is not out of the woods, but he is doing well right now. Had Joe not been recognized by his school and treated by PIER, I feel he would not be where he is today.”

Her family’s personal experience has brought home to Wilcox the importance of educating school personnel and others who work with young people about early signs of psychosis. “As a parent, when a kid starts to do different things, it is very easy to write it off as adolescent behavior or that he is just acting like his peers,” she said. “That is why it is so important that schools know what they are doing.”

Recent tragedies such as the shootings in Newtown, Conn., underscore the importance of early detection and intervention with serious mental illness, Wilcox believes. “If those young people had been recognized and attended to in middle school,” she said, “I feel in my heart, that some of those situations could have been avoided.”

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