Adolescent Psychiatry, 2012, *2*, 146-152

In the First Person: A Window into the Experience of Early Psychosis and Recovery

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Abstract: This article contains first person accounts in narrative and visual form created by clients and family members who have participated in the Early Detection and Intervention for the Prevention of Psychosis Program (EDIPPP). By the time most individuals join EDIPPP they have been experiencing a confusing constellation of thought and behavior changes. For most, EDIPPP signifies the next step in a journey of trying to reclaim a sense of agency in their lives and promise for the future. Understanding the process youth and families go through to make meaning of a "high risk" indication is critical for the clinicians who work with these families. By highlighting these first person accounts and the story they tell, we strive to contribute to this understanding and thereby enrich our discussion of the early detection and intervention for psychosis with the perspectives of individuals participating in our study. These narratives point to the potential value of further research focused specifically on how youth and families come to understand being at risk for psychosis.

Keywords: Adolescents, first person accounts, psychosis, schizophrenia, prodromal psychosis, high risk, recovery.

This article contains first person accounts in narrative and visual form created by clients and family members who have participated in the Early Detection and Intervention for the Prevention of Psychosis Program (EDIPPP). EDIPPP is a Robert Wood Johnson Foundation funded 6-site treatment and research project identifying young people aged 12-25 at risk of developing a psychotic illness and providing a multi-disciplinary treatment approach consisting of psychosocial and pharmacologic interventions. The program is based on the PIER model, created by the Maine Medical Center in Portland, Maine, which also served as one of the six sites for EDIPPP. The five other sites include the University of California, Davis Medical Center in Sacramento, California; Mid-Valley Behavioral Care Network in Salem, Oregon; Washtenaw Community Health Organization in Ypsilanti, Michigan; Zucker Hillside Hospital in Glen Oaks, New York; and University of New Mexico in Albuquerque, New Mexico.

In EDIPPP, individuals identified as high-risk for a psychotic illness meet regularly with an individual therapist, occupational therapist and psychiatrist/nurse practitioner for up to two years. The focus of these interventions is to improve and/or maintain functioning (in particular role and social functioning), reduce problematic symptoms, and prevent or delay onset of a psychotic episode. Family involvement is critical to the program and, as such, family members are encouraged to participate in all aspects of the treatment, including attending a day-long psychoeducation workshop as well as bi-weekly multifamily group therapy. The multifamily group intervention aims to enhance problem-solving and communication skills within the family. Additionally, individuals and their families also agree to participate in multiple research appointments over the time of study participation, some of which can last up to a full day. Thus, joining EDIPPP represents a significant investment of time and energy for the individual and their family.

By the time most individuals join EDIPPP they have been experiencing a confusing constellation of thought and behavior changes. For some individuals and families, identifying these experiences as "high risk for psychosis" is a relief; for others it is a frightening declaration. In either case, for most it signifies the next step in a journey of trying to reclaim a sense of agency in their lives and promise for the future.

Understanding the process youth and families go through to make meaning of a "high risk" indication is critical for the clinicians who work with these families. It is for this reason that with the development of this special issue, the EDIPPP clinicians and researchers wanted to ensure that the voice of study participants was included. Each of the six sites approached participants who they thought might be interested in submitting a personal narrative or piece of artwork to this article. The contributors chose their own formats for expression and, in most cases, the works are printed here as they were submitted, with only minor grammatical editing. These accounts are not meant to be representative of the EDIPPP participant population. Instead, they are meant to give the reader a window into the personal narratives of a few individuals with whom we have had the honor of working. And yet, several themes emerge through

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2210-6774/12 $58.00+.00

the work; most notably the confusion the individual and their family felt at the onset of difficulties, the relief at finding a caring treatment team to partner with, and the critical role of rediscovering a sense of hope and purpose. Collectively these works tell a story emblematic of more than these author/artist's individual experiences.

Highlighting these first person accounts and the story they tell enriches our discussion of the early detection and intervention for psychosis with the perspectives of individuals participating in our study. These narratives point to the potential value of further research focused specifically on how youth and families come to understand being at risk for psychosis.

While families at all six of the EDIPPP sites were approached for submissions, the works that follow come from individuals at four of the six sites including Maine, Michigan, New Mexico and Oregon. Some of the individuals submitting works wanted their names included; others did not. As a result, each piece will be introduced with basic information about the contributor but, based on individual preference, may not include a name.

A MOTHER'S PERSPECTIVE

Ellena Mundy, the Mother of an EDIPPP Participant

We were used to Sam being different. At 18 months I was pushing him through the grocery store, and he pointed above a set of doors and said, "Exit. E-X-I-T. That spells exit." At age three he knew the corresponding number to every letter in the alphabet, and referred to himself as 19-1-13 instead of Sam. By four he knew his timetable, and when he had a neuropsychiatric evaluation in fourth grade, he scored 12th grade, 9th month in math.

At that time Sam was diagnosed with ADHD, and was said to have some "shades of Aspergers." Sam was never the most popular child in the class, but he always had a few good friends. He was never going to be captain of the football team or give me a chance to truly become a "soccer mom," but he was happy with who he was. His identity was mostly tied up in his intelligence, and for me, his intelligence kept him safe. However peculiar or atypical he seemed, his IQ would always insure he was successful and respected. There would always be an admirable place for Sam in the world—as a professor, a scientist, an inventor. After all, he certainly had more social skills than an idiot savant. The medication he was taking, Concerta® (methylphenidate) was helping to keep his impulse control and attention issues at bay. He was more a stereotypical genius than anything else.

Perhaps this is why something splintered inside of me when he became prodromal symptomatic. I'm no stranger to mental illness, so my feelings of despair surprised me. I have a son with bipolar disorder and another with attention deficit hyperactivity disorder and anxiety. I myself have battled depression and anxiety. I have a brother with obsessive compulsive disorder. I guess it seemed I had already accepted what was different about Sam, and assumed his intellectual strengths were what would save him. When he became "prodromal," that backup was taken away. His biggest symptom was an inability to think clearly or concentrate on anything that mattered—or at least anything that mattered in his world.

In the fall of 2008 (Sam's junior year in high school) he began to suffer from extreme insomnia and a difficulty to focus and concentrate, even when on his stimulant medication. He began to withdraw from several of his friends and seemed to be affected by stress that he had seemed oblivious to before. He described himself as suffering from constant "brain fog." He was increasingly absent from school, barely verbal and gaining weight. He was lethargic and uninterested in things that he once cared a lot about, like math and music.

Because of my younger sons, I have an arsenal of doctors and therapists in town, and I took Sam to all of them. I also had a sleep study, an MRI and an EEG done. I had blood tests done for everything from streptococcal infection to Lyme disease. I spent a year hearing people tell me they did not know what was wrong with him. I spent a year thinking he might have a brain tumor or some rare disorder. I spent a year crying and feeling hopeless in a way I had never felt before, not even with my son with bipolar disorder.

Meanwhile Sam had dropped out of school, and it did not look like he was going to be able to return. My husband and I went from assuming that Sam would graduate at the top of his class in prep school and go onto MIT, Stanford or Princeton, to hoping he might be well enough at some point to get his GED. It wasn't that we felt the former was the only acceptable path, it was that the thing that had made Sam "Sam" had inexplicably been stolen from him.

By the fall of 2009 we decided that we had used up our resources in Albuquerque, and it was time to go out of state. We felt the Mayo Clinic in Rochester, MN was our best bet. I sat my younger children in front of a new video game, and spent endless hours on the phone. I faxed and emailed slews of documents. Finally, we had our appointment. It would be a week long appointment, and we would start in the pediatric neurology department.

Once we got to the Mayo Clinic and Sam had spent two days in pediatric neurology, we were sent to the psychiatry department. Sam had a complete neuropsychological exam as well as a psychiatric evaluation. Despite his feeling of "brain fog," he scored very highly on the IQ tests, with the exception of tests of executive function.

I was told by the neuropsychologist that Sam probably had a thought disorder, and by the psychiatrist that Sam had "prodromal" schizophrenia. The word "prodromal" was new to me, but I came to understand it meant the early stages. I also learned that there were negative and positive symptoms of schizophrenia. Sam had none of the positive symptoms, but seemed to have most of the negative symptoms.

It was enough of a diagnosis for my husband and I to take it seriously, but there was always some doubt in our minds that he would ever suffer from actual psychosis. This is when the EARLY program came into our lives. After several conversations with staff at the program, Sam was brought in for interviews and evaluations. He was found to be in the high risk group, and was admitted into the program.

The sense of relief and hope that we had been searching for in the last year was finally in reach. We felt that we finally had some ammunition in our arsenal. Even Sam, who seemed to have been going along for the ride while in some sort of daze, seemed to have a bit of hope.

At that point, as part of the EARLY Program, Sam started to see a new psychiatrist, have visits with the clinical psychologist and occupational therapist, and attend the multi-family therapy group meetings. We went through some medication trials and attended group and other appointments religiously.

Gradually we started to see a change in Sam. He became a bit more social and verbal again. He didn't speak up much in group at first, but he always listened very carefully. Group turned out to be a safe and structured environment for him to try socializing again. Not too much pressure, but enough encouragement to listen and to say a few words. As group continued, Sam became more and more engaged with the other members and the topics at hand. With the help of EARLY, he began to set goals, and started to achieve them. In the end, we found a mix of medications that still seems to work.

As Sam healed, he went back to the thing that always grounded him, and the thing that we all seemed to identify him by, his intelligence. He began studying high level math on his own, buying countless graduate level text books. He started to teach his former Calculus teacher from high school Number Theory and tutor friends for free. He started to write a math text book.

Most importantly, he got his GED and started college at the University of New Mexico. He began last semester part time, taking a graduate level math course, and a freshman level English course. He is also tutoring a graduate student in math. He will increase his load to three classes next semester. His social behavior continues to improve - not the least of which was cutting his hair, strange as that might sound. He once sported a hairdo that would rival Medusa. It really served as a barrier between him and the world. You couldn't see the expressions on his face, much less his eyes. But that has all been cleared away now. He is open to the world around him. It wasn't the path we had all assumed he would take, but it is a fine path now indeed.

At this point, his Psychiatrist isn't sure he sees "prodromal" symptoms in Sam. He may suffer from a somewhat deceptive case of Anxiety and Depression. We will never know for sure, and that could always change. And if it does, we are better prepared to deal with it thanks to the EARLY Program and the professionals we have found there.

THE JOURNEY TOWARD RECOVERY—AND POSITIVE ASPECTS OF MENTAL ILLNESS

Nathan Edmunds, an EDIPPP Participant and Peer Support Specialist

Having a major mental illness, depression and schizoaffective, has made me look at the true value of life. Being depressed for many years inspired me to start my journey towards recovery. Before I was in full recovery, I needed to find an inner strength to start taking steps towards my goal.

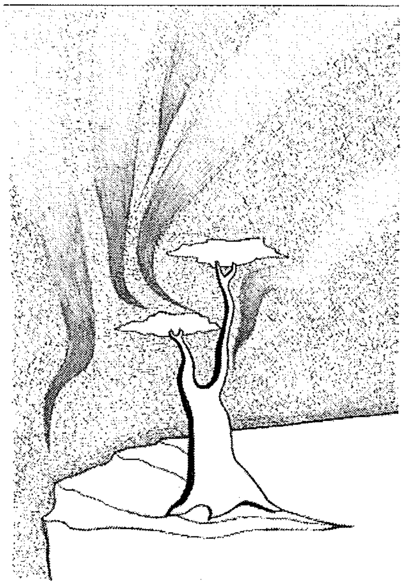
Playwright August Wilson said, "Confront the dark parts of yourself, and work to banish them with illumination and forgiveness. Your willingness to wrestle with your demons will cause your angels to sing. Use the pain as fuel, as a reminder of your strength." I think that when anyone has a mental illness he or she loses touch with the "light" in his or her life. I found the darkest part of my life to be when I had the illness, leaving me without a sense of reality. Forgiveness is the key to recovery and happiness. You have to forgive yourself for the things you did and things you didn't do. Rather than dwelling on the fact that having depression has caused me to miss out on things in life, I embraced it and used it to aspire to become someone happier and stronger. With the acceptance of happiness and strength came a struggle that was the basis of my inner conflict.

Wrestling with my "demons" was a necessary strength to make me realize that there was light at the end of the tunnel. One of the hardest moments that I endured was in the beginning of 9th grade when I thought that life wasn't worth living and took steps toward ending it. Having thoughts like these was a hardship that I couldn't overcome by myself, and ended with me in the hospital. It was there that I realized that living like this was not for me and I needed to do something about it.

My road to recovery, a self-realization, looked at how my illness impacted me in both positive and negative ways, and it affected those around me. A strong driving force that led me to where I am today was the fact that I wanted to go to college and succeed in life. With college in mind, I learned that helping people was what I wanted to do. Helping others with their goals of recovery is important to me because I always wished that I had someone to be there with me and to guide me through life when times were tough.

This submission was a part of Mr. Edmunds' college admission essay.

A DRAWING



Submitted anonymously by an EDIPPP participant, male, age 24