# HANDBOOK OF SERIOUS EMOTIONAL DISTURBANCE IN CHILDREN AND ADOLESCENTS

## **Edited by**

Diane T. Marsh and Mary A. Fristad



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# Dedicated to the families that keep us grounded:

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## **Foreword**

Mental illness is devastating to anyone personally affected by it, but for those who are young it is particularly dreadful. At a time in life when the expectation of well-being is nearly universal, and when deviant behavior or poor psychological health is neither understood nor well-tolerated by friends, family, or teachers, emotional disturbances take a profound and painful toll. Mental illness, when it hits the young, is often pervasively destructive: It affects the ability to learn, remember, and to think coherently; it damages peer relationships at a time when they are most critical; and it removes pleasure from a time of life that is otherwise a remarkably rich period of delight and exploration.

Yet, as a society, we have for far too long overlooked, outright denied, or turned our back on mental illness in children and adolescents. This has resulted in an unconscionable level of unnecessary suffering and death, for mental illness is relatively common in adolescents, and far from rare in children. Suicide is responsible for more deaths in adolescents than AIDS, cancer, heart disease, stroke, and kidney disease *combined*. Parents, educators, religious leaders, and physicians need to be far more informed than they are and much more proactive. So, too, do mental health professionals.

It is fortunate that there is now an excellent text available, the *Handbook of Serious Emotional Disturbance in Children and Adolescents*. The editors, Diane Marsh and Mary Fristad, have done an outstanding job in putting together a book that so expertly covers the major areas of importance: clinical and scientific information about the disorders themselves (attention-deficit/hyperactivity disorder, obsessive-compulsive disorder, anxiety and mood disorders, psychosis, and substance abuse); research and training issues; and important information about the legal, educational, and primary care systems within which parents and patients are likely to find themselves. The editors have also made sure that the adolescents and college students who suffer from these illnesses have had a voice: Their first-hand accounts are included, as well.

No single book can capture everything there is to know about such complex problems, but this handbook is a terrific place to begin.

> Kay Redfield Jamison, PhD Professor of Psychiatry The Johns Hopkins School of Medicine

# **SECTION I**

# Introduction

## **Chapter 1**

## INTRODUCTION

DIANE T. MARSH AND MARY A. FRISTAD

The Handbook of Serious Emotional Disturbance in Children and Adolescents is designed to fill the need for a current and comprehensive resource that targets the most severe and persistent mental disorders of childhood and adolescence. The need for such a handbook is compelling. As indicated in the surgeon general's report on mental health (Satcher, 2000), one in five young people experience a diagnosable mental disorder during the course of a year. Approximately 5% have a serious emotional disturbance (SED) accompanied by extreme functional impairment that undermines their present lives and imperils their future.

The term *SED* serves as an umbrella term for certain diagnostic categories, including autistic and other pervasive developmental disorders, attention-deficit/hyperactivity disorder, schizophrenia, bipolar disorder, major depressive disorder, obsessive-compulsive disorder, and other severe anxiety disorders.

These disorders typically do not remit spontaneously, although effective psychosocial and psychopharmacological treatments are rapidly becoming available, with treatment outcomes comparable to those of adults. Yet at least two thirds of young people with a diagnosable mental disorder do not receive *any* mental health services at all, and many others are underserved (Satcher, 2000). The price of this neglect is unconscionable for these children and adolescents, for their often-desperate families, and for a society that is deprived of their contributions.

The challenges that accompany professional practice with the SED population are considerable. Many systems are involved in meeting the diverse needs of these children, adolescents, and families, including the mental health, educational, child welfare, juvenile justice, substance abuse, and primary health care systems. Thus, effective SED services require multisystemic coordination and collaboration. As Sybil Goldman (2000) has observed, many additional challenges mark the SED territory. Some of these challenges involve treatment access, including scarcity and fragmentation of services; racial, ethnic, and economic disparities in insurance coverage and treatment; financial barriers that discourage families from seeking or continuing services; inadequate assessment and diagnosis; poor public understanding about mental health concerns; and social stigma. Other challenges reflect the need for a sufficient supply of well-trained mental health professionals; for an adequate knowledge base to guide SED systems, services, and treatments; and for synergy among the worlds of system builders, clinicians, and researchers.

#### 4 Introduction

In spite of these challenges, there is now general agreement regarding the services that are needed for children and adolescents, as well as the way in which services should be delivered. A system of care must be driven by the needs and preferences of the child and family; must provide comprehensive, individualized, and flexible services; and must embody a community-based, culturally sensitive, and multisystemic approach. At the same time, stakeholders in child-serving systems are working to reduce the use of restrictive services, to enhance service integration and coordination, to reform mechanisms for financing services, and to increase cost-effectiveness and provider accountability. Another trend is the renewed emphasis on prevention and early intervention.

Assuming new roles on multidisciplinary teams, service providers can now offer an array of innovative and evidence-based child/adolescent, family, and community interventions. Such innovative interventions include intensive case management, crisis intervention and emergency services, in-home services such as family preservation and family support services, respite care, wraparound services, school-based-services, mentoring/coaching, therapeutic group and foster family care, and multisystemic interventions.

The Handbook of Serious Emotional Disturbance in Children and Adolescents delineates the SED territory and provides a comprehensive review of current SED theory, research, practice, and policy. The content has important implications for mental health practitioners and graduate students in all related disciplines, as well as administrators, system planners, policymakers, managed care organizations, educators, families, and mental health advocates. The distinguished contributors bring a wide range of expertise to the handbook, which is divided into four sections: section I: Introduction; section II: Practice, Research, and Training Issues; section III: SED Disorders; and section IV: Systems of Care.

In the introductory section, following this overview, we feature the voices of adolescents themselves, who convey their experience of SED with power and eloquence. They describe the impact of SED on their lives, share what has been helpful (and what has not), and offer suggestions for practitioners. In chapter 2, Harriet Bicksler offers a forum for four teenagers who have been diagnosed with a variety of emotional and behavioral disorders. In chapter 3, Carol Mowbray, Deborah Megivern, and Shari Strauss provide a retrospective look by college students at their high school experiences with SED.

Section II encompasses a wide range of practice, research, and training issues. In chapter 4, Heather Ringeisen and Kimberly Hoagwood delineate clinical and research directions for the treatment and delivery of children's mental health services. In chapter 5, Susan McCammon, James Cook, and Ryan Kilmer outline the process of integrating systems-of-care values into university-based training. Adrienne Dixon discusses culturally competent SED practice in chapter 6. In chapter 7, Marsali Hansen underscores the need for competence in children's mental health services. In the final chapter of this section, Linda Knauss examines supervisory issues related to the treatment of SED.

Section III explores specific SED disorders and their evidence-based treatments. In chapter 9, Tristram Smith, Caroline Magyar, and Angela Arnold-Saritepe describe autism spectrum disorders. Gregory Fabiano and William Pelham Jr. present a com-

prehensive treatment program for attention deficit/hyperactivity disorder in chapter 10. In chapter 11, Susanna Chang and John Piacentini examine obsessive-compulsive disorder and related disorders. Olivia Velting, Nicole Setzer, and Anne Marie Albano consider a range of anxiety disorders in chapter 12. In chapter 13, Mary Fristad, Amy Shaver, and Kristen Holderle provide a current perspective on mood disorders. Fred Volkmar and Katherine Tsatsanis discuss psychosis and psychotic conditions in chapter 14. In chapter 15, Joseph Hovey and Cheryl King analyze the spectrum of suicidal behavior, which is closely linked to SED disorders. Ramon Solhkhah and Marie Armentano address the problem of adolescent substance abuse and psychiatric comorbidity in chapter 16.

Section IV focuses on systems of care. In chapter 17, Thomas Grundle describes wraparound care and presents some exemplary programs. Jean Adnopoz explores home-based treatment for children with SED in chapter 18. In chapter 19, Robert Murphy examines mental health, juvenile justice, and law enforcement responses to youth psychopathology. Turning to the family system, in chapter 20, Marsali Hansen, Ann Litzelman, and Beatrice Salter offer an array of collaborative models for working with families that include a child with SED. Chapters 21 and 22 focus on the school system, beginning with a consideration of the home-school-agency triangle by Valerie Cook-Morales, who writes from the dual perspectives of a professional and a parent of a child with SED. Complementing that chapter is a discussion of school-based intensive mental health treatment by Eric Vernberg, Michael Roberts, and Joseph Nyre. In chapter 23, Ronald Brown and Wendy Freeman depict the role of the primary health care system in SED. Last, in chapter 24, John Gavazzi provides a primer on child and adolescent psychotropic medications for the nonprescribing mental health professional.

The future holds tremendous opportunity for children's mental health, as well as tremendous challenges. It is our hope that the science contained in this book becomes outdated within the decade, as new studies that provide clear clinical guidelines for the care of children with SED and their families are made available at an increasing rate. It is also our hope that the four areas represented in this book—namely, the voices of the children and families themselves; general practice, research, and training issues; specific knowledge regarding particular disorders; and systems of care—continue to advance together, with progress in each individual area enhancing progress in the remaining areas.

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# LISTENING TO THE VOICES OF ADOLESCENTS WITH SERIOUS EMOTIONAL DISTURBANCE

HARRIET S. BICKSLER

"I think I'm pretty normal," Nina said when I asked her how her illness has affected her life. That may be the most important point to remember when listening to adolescents with serious emotional disturbance. All adolescents want to be normal, to fit in with their peers, to do the same things that every other teenager likes to do. As I listened not only to Nina, but also to Michael, Savannah, and Markel tell their stories about their illnesses, I was struck by how much like other adolescents they all are.

Nina, Michael, Savannah, and Markel (not their real names) have all been diagnosed with a variety of emotional and behavioral disorders. They have all been hospitalized in psychiatric inpatient units at least once and have had significant contact with Pennsylvania's child and adolescent mental health system through outpatient, residential, partial hospitalization, wraparound, and other services. They have also participated as youth members of the planning committee for the youth track of Pennsylvania's annual children's interagency conference focusing on clinical best practice in children's mental health services. They have told their stories to two major audiences—first at the Pennsylvania conference and then at the annual convention of the American Psychological Association.

They are telling their stories again here as a reminder to mental health professionals that real children and adolescents are at the receiving end of their services. For this chapter, I personally interviewed each adolescent (one in person and three over the phone), and I had a copy of the transcript of their appearance at the APA convention in August 2000, where they were interviewed by Dr. Diane Marsh. I also heard each of them speak at our Pennsylvania conference. Three of them chose their own fictitious names for this chapter. (I chose the fourth fictitious name.) Their individual stories follow, after which I will conclude with a few summary observations. Keep in mind that their stories were current at the time of this writing, and their circumstances may have since changed.

#### **NINA**

Nina is 17 years old. Her parents divorced when she was 6 years old. She has one brother, two half sisters, and one half brother. She currently lives with a foster family—a mom, dad, brother, and sister.

Her parents' divorce triggered Nina's mental health problems. She lived with her mother, whom she blamed for the divorce. She had been very close to her father. Nina's anger toward her mother built up and eventually led to two suicide attempts that each resulted in hospitalization. Between ages 12 and 15 she was in and out of the hospital, a residential treatment facility, and a partial hospitalization program, and she attended emotional support classes at school. She also has been diagnosed with learning disabilities, including attention-deficit/hyperactivity disorder (ADHD). At one point she was diagnosed with bipolar disorder as well, although she is not sure about that diagnosis. She knows that sometimes she feels very depressed, and other times she feels energized and happy to be alive. She has lived with her foster family for almost 2 years and now attends regular classes as a junior at a public high school.

Family and cultural attachments are very important to Nina. She says that the most difficult aspect of her illness is not being with her family. "Even though they have done a lot to make me not want to be with them, they are still my family and I miss being with them," she says. She also misses the diversity of the city where she used to live and being with people of her own Hispanic culture. She describes herself as "louder" and more outspoken than others in the mostly white neighborhood where she lives with her foster family, and says that sometimes they do not understand her. She sees her birth mother a couple of times a year, but rarely sees her father, especially because he is currently in jail. "I don't want to talk to him while he is in jail," she notes.

Despite missing her birth family and culture, Nina has nothing but good things to say about her foster family. She especially appreciates living in a two-parent family where there is a strong bond between the husband and wife and their children. Nina says, "They are like my real parents. They make me realize what I didn't have with my own family, and now I understand what a real family feels like." Her foster family has been "100% and more" supportive. They are always on her side, understanding her and helping others to understand her, too. Her advice to other families is to offer the same kind of unconditional support to their children: "Whether you're yelling or screaming, just be there and understand them, even when they're saying they hate you."

Nina talks about how difficult it is to find friends who understand what it feels like to have mental health problems. People say things that can easily be offensive and sometimes talk about her behind her back, and it is often hard for her to function and do things the way everyone expects, not the way she wants to do them. She says she has one really good friend from whom she receives a lot of support.

Nina is not on any medication right now, although she has taken various antidepressants, as well as Ritalin. She believes the medications didn't really help her. She continues in therapy, however. When asked what has been most helpful about therapy and her relationships with mental health professionals, she mentions "having someone to talk to who understands me and translates what I say to others so they can understand, too." She is also adamant that "professionals should not jump around from job to job." Responding to a question about what has not been helpful, she is quick to criticize therapists who are "always leaving." She points out that it takes a long time to learn to trust a therapist, and she wishes she could have a single therapist for the entire duration of her therapy.

Her advice to kids with similar problems is to have faith and know that their mental health problems are not the end of the world. "Don't worry about what anyone else says. Believe in yourself—there can be no failure if you believe in yourself," she declares confidently. Nina plans to graduate from high school, and then she hopes to go to an art institute to pursue an art career based on her interests in photography, drawing, sketching, and painting.

#### **MICHAEL**

Michael is 17 years old and lives in a major metropolitan area with his mother and father and four siblings. He is the middle child—flanked by two older sisters and a younger brother and sister. He is a junior in high school and for 3 years has attended an approved private school that he likes.

Michael's mental health problems started when he was in the fourth grade. First he was diagnosed with attention-deficit/hyperactivity disorder (ADHD), then depression, then obsessive-compulsive disorder (OCD) and oppositional defiant disorder, and then he found out he had bipolar disorder as well. At one point Tourette's syndrome was also suspected. He describes himself as "inattentive, getting into lots of fights, hyperactive." "I knew I was hyper and I couldn't pay attention," he says. He has been hospitalized once and was in a partial hospitalization program for a while. Currently, he receives in-home treatment and services, mostly for OCD and bipolar, from a therapeutic staff support worker, a mobile therapist, and a behavioral specialist consultant (all positions that are part of his state's array of public behavioral health rehabilitation services, or *wraparound*).

Michael has attended private schools because he wasn't able to function in public schools and "teachers couldn't handle me." He has been frustrated by teachers who either don't know how to deal with kids like him or don't want to try: "One year you'll have a great teacher, the next year it will be the total opposite. One will work with you, the next one won't. It's like playing Ping-Pong." In public school, he didn't have any friends and often got into fights even though he tried to have friends. Michael still gets into fights at home; as he puts it, there is "lots of arguing and a little bit of physical fighting. Everybody gets tired of the fighting."

The most difficult thing, Michael says, is "being obsessive-compulsive and not being able to keep my mouth shut. I get myself in trouble. Things get taken away, like sports equipment, or I'm grounded. I use inappropriate language. I can't stop counting, or turning out lights." His problems mostly happen at home because he manages to control himself outside the house, and then he lets it all out when he gets home. He also knows that the repetitive actions characteristic of OCD increase when he's feeling particularly anxious about something. He says he experiences many of his symptoms on almost an hourly basis.

Michael's family has been very supportive, especially his parents. He suggests that families have to work together because "the kid can't do it himself." Families need to support each other, he says.

When it comes to therapists, the most helpful ones are those who stick around. Michael also likes therapists who "listen—really listen—and treat kids as though they are on the same level." Michael notes that just because they have experience (as clinicians, with other kids who have mental health problems, and so on) doesn't mean they

have to talk down to kids like him. He also says that lots of therapists "try to put words in your mouth and make you sound like you said things you didn't. Then they tell your parents you said something you didn't." He talks positively about his mobile therapist and behavior specialist because they worked as a team and listened to him. But just as he felt he was starting to get better, the behavior specialist left because he had too many patients and had to drop some.

Michael advises other kids to take their medication. Even though he forthrightly declares, "Medications suck!" he knows he has to take them. He says he has been on lots of stuff that has not worked and has had adverse side effects. Right now he is taking Depakote and clonidine, but says only half jokingly that he thinks he's been on every medication in the Physician's Desk Reference (to go with what he hyperbolically calls his "5 million diagnoses").

Three years ago, Michael wrote about what it felt like to live with mental illness:

I know I make it very hard to live with me. I make my sisters cry and don't exactly know why. They don't want to spend time with me because of the things I say to them. I don't mean to, but I can't help it. If I get too excited or too angry, I can't control what comes out of my mouth. I feel sad and guilty for making them sad, but it doesn't seem to help much. I wish I could change things and make the last several years completely different for my family and myself, but I can't. I'm sorry for that, but I am what I am and I wish people could just accept that. (Palan, 1998)

One of Michael's dreams for the future is to be a professional hockey player. He also wants to work in telecommunications, doing something like installing different kinds of systems. To qualify for that kind of work, he hopes to attend college and major in electrical engineering.

#### SAVANNAH

Savannah is the middle child of five and lives in a midsize city. She is 16 years old.

Midway through my interview with her, she told me to watch Girl Interrupted, a movie about a young woman who spent time in a psychiatric hospital in the 1960s— "That's my life, my friend and me. I'm Angelina Jolie and my friend is Winona Ryder" (the actresses in the movie). The comparison is somewhat apt. Savannah tells a rather dramatic story of police officers coming to her house because she was threatening to kill herself and her younger brother. Her older sister had called the police because "I tried to go after my sister." She was taken by police car to the hospital.

Savannah refers to her grandmother's death about 7 years ago when she was in the second grade as the beginning of her mental health problems. The permanence of that death settled in on Savannah several years later, and she became severely depressed. She has been hospitalized twice. The second time, she was discharged to a partial hospitalization program where she went to school for a year and a half. Her depression was so severe that she was unable to go outside and do the things that normal children do. With the help of therapy during the past 2 years, she has been able to go out in public more, including to a nearby city every 2 weeks for modeling classes, and she's back in public school.

Savannah's memories of the psychiatric hospital are unpleasant. She talks about one day when she felt no one was listening to her and her parents had not visited because they were told not to come. She lay on the floor and rubbed her chin and forehead on the carpet until the skin came off. She continues, "They put me on so many medications, with so many side effects, I don't remember being there half the time. I was freezing when everyone else was sweating. People thought I was high most of the time, even though I've never gone near any drugs."

She says one effect of her illness is more attention, but "I don't like that." On the other hand, she thinks her illness has brought her family closer together, especially her and her older brother. The transition back to public school has also been difficult: "Before this year, in the partial hospitalization program, everyone had the same problems at school. I could talk to someone when I needed to. Now I'm back in a large public school, people don't remember me, I can't talk to people as easily, and I have to be in classes at certain times." She feels shy and claustrophobic sometimes, and she has had some medical problems as well.

Savannah criticizes professionals who do not listen, or who just listen so they can write something down in their charts. "Listen while you write," she says. "Often, professionals won't ask if they're not sure what I'm talking about. I know they're not listening." Her first psychiatrist, however, stands out in her mind: "She was one of the nicest doctors you could ever meet. She really listened to my problems. There need to be more like her." She also speaks highly of the counselor in her partial program who helped her get through each day. Much of her day-to-day support, however, seems to come from friends and family.

Although Savannah does not like medications because of the side effects, she acknowledges that they have been helpful, and she is grateful for professionals who have prescribed medications that have worked. She expects she will be on some kind of medication the rest of her life.

Her advice to kids with similar problems is to answer all the questions professionals ask. "I didn't tell them everything, so I didn't really benefit." To parents, she says, "If you realize your kid is having a problem, listen." She thinks that families exhibit a lot of denial about problems until kids get in trouble with the law. "My father has definitely changed," she goes on. "Now he asks me if he thinks there is a problem. He also encourages me to try to be the best at anything I do."

Thanks to her father's encouragement and support, Savannah has been able to take modeling classes. She has other goals as well—to graduate from high school, to go to college, and to become a forensic scientist. She feels that she finally has control over her disability, and she's optimistic about her future. Savannah ended the interview with one word of advice to herself and others: "Smile!"

#### MARKEL

Markel is 21 years old and has lived all his life in a large city. He used to live with his mother, but now lives with and provides care for his grandmother, who has diabetes. He works as a message delivery person in the center of the city.

Markel was diagnosed with depression when he was 9 years old. He had difficulty

concentrating in school, and a counselor suggested he see a therapist. He was first diagnosed with a learning disability, then depression. He also has struggled with his feelings of low self-esteem and has had difficulty getting along with his mother. Markel has tried to commit suicide four times—the first time when he was 12 and most recently when he was 18. His first hospitalization was at age 13, when he spent 3 months in a psychiatric unit.

Friendships have been difficult for Markel, and he often feels isolated from other people. He says, "I've never had any true friends and haven't been able to sustain a relationship because of my insecurities. I missed a lot of school activities, like the prom. I've felt stigma from other kids. I never had money to dress like other kids, and I wasn't popular." He says he's always afraid that people are talking about him and don't like him, and he feels "like I'm not an interesting person, and a disappointment to everyone." However, he actively tries to improve his situation and "show people that I'm not that weird of a person and include myself in conversations."

His illness has also affected his relationship with his mother and siblings. "I thought my mother loved my siblings more. I was always arguing with my mother, and they would get mad at me. It wasn't good for them to be around me all the time. My therapist decided I should live with my grandmother because there would be less turmoil. Sometimes my mother goes through depression as well, and she takes offense at things I do."

His grandmother and his music have been the most helpful to him. He likes to listen to music and write songs. He writes love songs and socially conscious songs. When asked what he does with the songs he writes, Markel said, "I just keep them. I'm too nervous to have anyone look at them or read them. I'm afraid I would be laughed at." He longs to find someone else with whom he can connect, talk to about his problems, and know the person will not laugh at him.

When it comes to professionals, Markel says that out of eight or nine therapists over the years, there have been only two with whom he has felt an instant connection. They are frank enough to point out exactly what is wrong and "help me see what I should do, get to the root of the problem, and help me see myself." Others would leave or resign just as he would feel he was getting close to them.

With some therapists, he felt like he was simply getting a long lecture, or they would talk to his mother more than listen to and talk with him. He suggests that professionals should not think of what they are doing as just a job, but "as though one of their own family members was going through the same situation." He adds, "Try to add a little humor, be down-to-earth, instead of trying to speak like a textbook." Markel still has a mobile therapist, although he does not see her very often anymore. He also says he does not think he ever actually had a bad therapist, but it has been hard to have to get attached to new people all the time.

Although he has taken a variety of medications, including Prozac, lithium, and Zoloft, he is no longer taking any medication. Instead, he tries to cope by going to church. Markel acknowledges that medication helped his depression "on the inside," and therapists helped him figure out what to do with his life "on the outside."

He wants to let other kids know that mental health problems are not their fault. "Just as some people are born to be short or tall," he says, "so some are born with depression genes." He advises others to take their medications because they can help them to live "a regular life." He asks parents to have patience and pray for kids like him. "Try not to have too high expectations," he says. "Help us find ourselves. Trust us to make the right decisions." He tells siblings not to judge or have negative feelings, to understand that even though parents may love all their children equally, some kids need more help.

Markel's care for his grandmother, who is diabetic, carries over into his hopes and dreams for the future. He does a lot of volunteer work and would like to work in a hospital, perhaps as an orderly where he can give personal attention to people. He isn't interested in a big car, lots of money, or a nice house. Instead, he says, "helping people, smiling—that's what's really important when it comes right down to it."

#### **SUMMARY**

Several common threads emerge from Nina, Michael, Savannah, and Markel's stories. First, each adolescent is extremely articulate in his or her own way, and each has a lot to say about his or her experiences in the mental health system. They are not shy about saying what they like and don't like about the way they have been treated in the system. Second, like all teenagers, they want people to listen to them—really listen. Third, they do not like "the revolving door" of therapists. Far too many therapists seem to come into and go out of children's lives at will—just when they need constancy, stability, and secure relationships. Often this isn't the fault of the therapists but rather reflects the systemic issue of low salaries and high turnover rates in public sector services. Nevertheless, according to these four adolescents, it is an issue that has a direct and negative impact on them.

Fourth, they want to be treated as "real people." They dislike therapists who talk past them to others in the room or who seem not really interested in them personally. For Nina, Michael, Savannah, and Markel, the best therapists are ones who treat them as individuals and for whom serving children and adolescents is much more than a job. Finally, Nina's claim that she is "pretty normal" rings true for all four, especially in their hopes and dreams for the future. Essentially, their goals are to settle down and have the kind of life that every normal person wants. In this they are no different from anyone else.

Pennsylvania's public mental health system is patterned after a federal National Institute of Mental Health initiative in the 1980s called the Child and Adolescent Service System Program (CASSP). As CASSP developed in Pennsylvania, the state formalized a set of principles for mental health services for children and adolescents with, or at risk for developing, severe emotional disturbance and their families. Treatment and services provided according to Pennsylvania's CASSP principles are (a) child-centered, (b) family-focused, (c) community-based, (d) multisystem, (e) culturally competent, and (f) least restrictive and least intrusive.

When I listen to Nina, Michael, Savannah, and Markel—just four of many adolescents with serious emotional disturbance—I hear their desire for these principles to be practiced on their behalf. Their message is consistent with a model of service delivery that does not pathologize children and adolescents and their families, but rather rec-

ognizes the individual strengths and needs of each child, works with the family in a genuine partnership, and treats each person with respect and dignity.

#### REFERENCE

Palan, P. (1998, June). One family's story of the effect of mental illness on the family. PA CASSP Newsletter, 7(2), 7–8.

# COLLEGE STUDENTS' NARRATIVES OF HIGH SCHOOL EXPERIENCES: COPING WITH SERIOUS EMOTIONAL DISTURBANCE

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Adolescents with serious emotional disturbance are rarely asked to tell others about their experiences in coping with teenage issues and a psychological disorder at the same time. This chapter offers readers the opportunity to listen to the voices of youths sharing their thoughts, opinions, and feelings about living with mental illness. The individuals who contributed to this chapter are currently attending college or are recent graduates, so their narratives are told retrospectively, as they contemplated their adolescent years.

Research has demonstrated that the transition to college from high school is especially challenging for adolescents with serious emotional disturbance. In contrast to students with other types of disabilities, students with emotional disturbances have the lowest high school completion rates (45%). A 1999 report by the U.S. Department of Education stated that high school students with emotional disturbances failed more courses, earned lower grade point averages, and missed more days of school than adolescents with any other disability. In a longitudinal study of youth with disabilities, Blackorby and Wagner (1996) found that between 3 and 5 years after high school completion, approximately 25% of those with serious emotional disturbance were enrolled in postsecondary school. Only students with mental retardation or multiple disabilities had lower postsecondary school attendance rates. In comparison, youths without a disability had postsecondary school enrollment rates of approximately 68%.

Despite the dismal outcomes for educational completion as documented here, other studies suggest that adolescents who experience mental illness can achieve success in higher educational environments. For example, Offer and Spiro (1987) found that approximately 10% of students entering college were experiencing emotional/behavioral problems that began in adolescence. Conclusions about what contributes to educational outcomes for these students, however, are difficult—there are just too few studies available with relevant information. Furthermore, the available studies use limited sources and perspectives. That is, in preparation for writing this chapter,