Serious Emotional Disturbance in Children and Adolescents: Opportunities and Challenges for Psychologists

Diane T. Marsh
University of Pittsburgh at Greensburg

Approximately 4.5 to 6.3 million children and adolescents in the United States have a serious emotional disturbance that undermines their present functioning and imperils their future. However, at least two thirds of young people with a diagnosable mental disorder receive no services at all. Responding to this unmet need, psychologists are assuming new roles in a changing mental health marketplace and are adopting new intervention strategies to work with these children, adolescents, and their families. This article addresses the scope of the problem, opportunities and challenges for practitioners, the larger context of professional practice, future directions, and suggestions for psychologists.

Over a decade ago, I received a call from a single mother in my community. In a voice trembling with emotion, she told me that her 14-year-old daughter (I will call her Ellen) was hiding in the woods behind their home—terrified, confused, and very delusional. Refusing to come inside, Ellen would dart periodically into the busy highway adjacent to the property, clearly placing herself at risk. What should she do, this frantic mother beseeched me? What had happened to her daughter? In fact, her daughter was experiencing the first episode of a severe and persistent mental disorder.

Admitted to the inpatient unit of a local mental health center, Ellen received a diagnosis of schizophrenia. For the next decade, she and her mother became travelers in a tangled mental health system that left them with a paralyzing sense of hopelessness and helplessness. Over these years, Ellen experienced multiple brief hospitalizations (the “inpatient revolving door”), received several diagnoses, and was given a plethora of medications. Much of her adolescence was spent in a fog of disabling symptoms and inappropriate treatments, profoundly disrupting all aspects of her life. For example, her high school years were marked by irregular attendance and a chaotic pattern of educational placements and plans that deflected Ellen far from her expected educational course. These years were also traumatic for her younger sister, Joyce, who felt her own needs were largely ignored in the midst of repeated family crises.

Eventually, Ellen received an accurate diagnosis of bipolar disorder and began a multimodal treatment plan that included individual psychotherapy, family psychoeducation, and a mood-stabilizing medication. Collaborating with Ellen’s psychiatrist, her psychologist offered psychosocial services for Ellen and her family and monitored the psychological effects and side effects of her medication. With appropriate treatment, Ellen began to come to terms with her disorder and to reconstruct her life. Although gratified by this positive outcome, Ellen and her family paid an enormous price for the shortcomings of the mental health system. In the current era, there is much reason to hope that, with an earlier diagnosis and more effective treatment, adolescents like Ellen will lose fewer irreplaceable years of their lives and that their families will receive the support and education they so urgently need under these circumstances.

The Scope of the Problem

Actually, Ellen was one of the lucky ones. The Center for Mental Health Services (CMHS, 2003) estimates that 4.5 to 6.3 million children and adolescents in the United States have a serious emotional disturbance (SED) that significantly undermines their daily functioning in home, school, or community. Yet, in many communities, services for individuals with SED are unavailable, unaffordable, or inappropriate. In fact, CMHS reports that at least two thirds of young people with a diagnosable mental disorder receive no services at all.

The SED term encompasses certain diagnostic categories, including autism spectrum disorder, attention-deficit–hyperactivity disorder (ADHD), obsessive– compulsive disorder (OCD), other severe anxiety disorders, major depressive disorder, bipolar disorder, and schizophrenia. Although diagnosis is an important consideration, the emphasis in SED is on degree of functional impairment, as well as severity and multiplicity of symptoms. For example, the severe form of ADHD that is classified as SED is likely to be the combined type (with symptoms of both inattention and hyperactivity), to be highly comorbid, and to be at the severe end of the end of the continuum of impairment (Fabiano & Pelham, 2002).

Some of the SED disorders are typically diagnosed in childhood, such as autism and ADHD. However, other SED disorders, such as bipolar disorder and schizophrenia, are sometimes viewed as adult disorders despite their frequent onset in adolescence (Rapoport, 2000). As a result, these latter disorders are sometimes neglected in the literature concerned with child and adolescent psychopa-
thology, as well as in professional training. Too often, this neglect results in misdiagnosis and inappropriate treatment—as it did for Ellen—with devastating consequences for these young people, their families, and society at large.

Other terms are sometimes used to describe these disorders, including serious mental illness (SMI), which is used for severe and persistent mental disorders in adults. The SMI term has traditionally been defined in terms of diagnosis, duration, and disability (Fed. Reg., 1993). Specifically, the term refers to mental disorders (a) that carry certain diagnoses, such as schizophrenia, bipolar disorder, and major depression; (b) that are relatively persistent (e.g., lasting at least a year); and (c) that result in comparatively severe impairment in major areas of functioning, such as vocational capacity or social relationships. In addition, the term early-onset mental illness is occasionally used to convey the overlap between the SED and SMI disorders. Further complicating the conceptual territory, the SED term is more often used in educational than in clinical settings, a conceptual mismatch that can limit dialog between school personnel and mental health practitioners and complicate the referral process.

Whatever the term, it is clear that these disorders have a profound impact on young people, compromising their present lives and imperiling their future. When adolescents speak of their experience with SED, they mention their suffering and desperation; their sense of being “marked,” invisible, and very alone; their awareness of “going crazy” and of being “such a disappointment”; and their traumatic encounters with providers (Mowbray, Megivern, & Strauss, 2002). SED also has a cataclysmic effect on families, as one mother conveys. “We are the parents of three little boys—one of whom has a severe mental illness,” she wrote. “His illness literally took over our life, and almost destroyed us as a family” (NAMI, 1999, p. 9). It is not just parents who are affected but all members of the family, including siblings: “I was 16 when my 14-year-old brother had his first psychotic episode. He was hospitalized for most of my adolescence. His illness was the most devastating episode of my entire life” (Marsh & Dickens, 1997, p. 109).

As one former director of the National Institute for Mental Health (Hyman, 1997) asserted, the unmet mental health needs of our children and adolescents constitute a national emergency. Indeed, untreated or undertreated SED disorders are associated with a cascade of negative consequences for individuals and families. One of the most serious is the risk of suicide, which is the third leading cause of death among young people (Centers for Disease Control and Prevention, 2003). According to the World Health Organization, by the year 2020, mental disorders among youth are expected to rise proportionately by over 50%, nationally, to become one of the five most common causes of morbidity, mortality, and disability (National Institute of Mental Health, 2002).

At the same time, there are many encouraging signs. Children’s mental health has been receiving increasing attention at the highest levels of government, as shown in the groundbreaking publications, Mental Health: A Report of the Surgeon General (U.S. Department of Health and Human Services [USDHHS], 1999) and Report of the Surgeon General’s Conference on Children’s Mental Health: A National Action Agenda (USDHHS, 2000). In 2003, the New Freedom Commission on Mental Health highlighted the importance of early childhood mental health interventions and recommended a national effort to focus on the mental health needs of young children and their families through expanded screening, assessment, intervention, training, and financing of services.

In addition to these constructive developments, an expanding body of research concerned with SED now provides a solid foundation for effective practice with these young people and with their families. In the following sections I discuss the opportunities for practitioners, describe the challenges that accompany professional practice in the SED area, examine the larger sociopolitical context of practice, mention some future directions, and offer suggestions for psychologists.

Opportunities for Practitioners

From the perspective of clinical practice, the SED domain clearly represents a large and underserved population. Responding to this unmet need, psychologists are expanding the boundaries of their practice to provide services to these vulnerable young people. Building on their existing competencies, practitioners are welcoming new opportunities, assuming new roles in a changing mental health marketplace, applying new models of professional practice, and adopting new intervention strategies to work with these children, adolescents, and their families.

As Ringeisen and Hoagwood (2002) affirmed, this is a time of hopeful anticipation in children’s mental health. Recent years have seen dramatic increases in our understanding of successful strategies for the identification and diagnosis of SED disorders and for their treatment and service provision. In Ringeisen and Hoagwood’s review, they noted the availability of a variety of efficacious interventions, including psychosocial and psychopharmacological treatments, integrated community and prevention services, and school-based approaches. As documented in an expanding body of research findings, Ringeisen and Hoagwood reported that these interventions can successfully reduce symptoms of psychopathology, improve adaptive functioning, and sometimes serve as a buffer to further long-term impairment.

In addition to increased knowledge of diagnosis and treatment for the specific SED disorders, there is now general agreement regarding the services that are needed for these children and adolescents, as well as the way in which services should be delivered (see Marsh & Fristad, 2002). These young people often have problems in multiple functional domains and require services from several systems. For example, children and adolescents with SED often experience problems in school; indeed, only 42% of these adolescents graduate from high school (U.S. Department of Education, 1998). Moreover, some 50% to 75% of youth in foster care have mental health problems (Webb & Harden, 2003), as do between 60% and 75% of those who are served by the juvenile justice system (National Council on Disability, 2002). Almost 43% of young people who receive mental health services have a cooccurring substance abuse disorder (Substance Abuse and Mental Health Services Administration, 2002).

In light of their multiple problems, children and adolescents with SED are best served by an integrated and coordinated multidisciplinary service system, namely, by a system of care. As delineated by Stroul and Friedman (1986), a system of care must be driven by the needs and preferences of the child and family; offer comprehensive, individualized, and flexible services; and embody a community-based, culturally sensitive, and multisys-
A central feature of the larger context is the corrosive stigma that accompanies the diagnosis and treatment of mental disorders in our society. Indeed, for many individuals and families, social stigma is the most oppressive burden associated with mental disorders. Costs of stigma include the marginalization and ostracism of people with mental disorders; discrimination in housing,
employment, and insurance; an adverse impact on all aspects of functioning; and decreased likelihood that they will receive treatment. Often internalized by individuals and families, negative social attitudes and expectations may result in a debilitating sense of hopelessness and helplessness, lowered self-esteem, damaged family relationships, and feelings of isolation and shame (Lefley, 1996).

Future Directions

The preceding discussion suggests several promising directions for the future. As Ringeisen and Hoagwood (2002) discussed, effective treatments can be successful only if they reach those families in need. Given the evidence that a large majority of youth with SED are unserved or underserved, they suggested several strategies for minimizing the barriers to mental health care, including the intensification of outreach and engagement efforts. Because children and adolescents do not typically refer themselves for treatment, outreach efforts must focus on multiple referral sources, including parents, schools, courts, primary-care settings, and social service agencies. Working with individual children and families, practitioners can assist them with financial and transportation hurdles, ensure that treatment is responsive to their needs and preferences, and offer appropriate services to culturally, ethnically, and linguistically diverse children and families.

Working in the larger context, psychologists can use many strategies to reduce barriers to mental health care. They can counter the pervasive stigma associated with mental disorders through public education, including informative articles in mainstream publications, presentations before community groups, and diverse media activities. Legislative action may be required to reduce or eliminate some financial barriers, including the absence of health insurance for many millions of Americans and the limited access to mental health services in some insurance plans. More generally, psychologists can contribute to the development of public policy and to the reshaping of political attitudes concerned with mental health care. Public policy advocacy can offer substantial benefits to the many individuals and families who are not currently served by the mental health system.

When these children, adolescents, and their families are successfully engaged, their mental health care should incorporate evidence-based treatments and service delivery models. Using the broad definition adopted by the Institute of Medicine (2001), evidence-based practice (EBP) consists of three components: best research evidence, which refers to clinically relevant research; clinical expertise, including the ability to use clinical skills and past experience; and patient values, such as their unique preferences, concerns, and expectations. This approach to EBP recognizes the value of various kinds of evidence, increases the likelihood that interventions will have clinical utility in typical practice, and improves prospects for patient satisfaction with treatment.

Providing EBP to the young clients and families who can benefit from it requires a sufficient supply of child and adolescent mental health workers who have the knowledge, skills, and attitudes to work with the SED population (Hansen, 2002; Roberts et al., 1998). As recommended by APA (2002), opportunities for professional training can be enhanced by investing in human resource development of the nation’s child and adolescent mental health workforce, promoting workforce diversity, and expanding interdisciplinary training.

Because children and adolescents with SED typically receive mental health and other services in a variety of service systems, we also need to improve coordination among service providers by increasing cross-systems collaboration, implementing flexible funding mechanisms, and encouraging facilitative policy changes (APA, 2002). Concurrently, graduate and continuing education programs should prepare psychologists to participate effectively in multisystemic approaches (see Hansen et al., 2004).

Finally, it is essential to close the gap between research and real-world practice (Lonigan & Elbert, 1998; Ringeisen & Hoagwood, 2002). Researchers might productively focus on facilitating the transportability of EBP into existing service settings, examining mental health services in addition to individual interventions, using theory-driven research designed to improve on current interventions or to create new ones, looking beyond symptom-based outcomes to meaningful changes in everyday life, and learning more about what actually works and why it works.

Suggestions for Psychologists

Returning to the opening vignette, how might practitioners have helped Ellen and her family? Here are some suggestions:

First, psychologists can enhance their knowledge and skills in the SED area so they are better prepared to provide an accurate diagnosis for adolescents like Ellen and to offer effective child, adolescent, and family interventions. When planning to offer services in new areas or to use new techniques, therapists can develop the necessary competencies through appropriate study, training, supervision, and consultation. Opportunities for continuing education in the SED area are increasingly available at state and national conferences and through state psychological associations.

In Ellen’s case, there are a number of empirically supported treatments for bipolar disorder. In addition to mood-stabilizing medications that are often prescribed, these include interpersonal and cognitive–behavioral therapy (Fristad, Shaver, & Holderle, 2002). When working with adolescents who receive multimodal psychosocial and psychopharmacological treatment, psychologists can play an essential role in evaluating the effectiveness of medications by monitoring their psychological effects and side effects. There is also strong support for the value of family psychoeducation in the treatment of bipolar disorder (Miklowitz & Goldstein, 1997). Components of family psychoeducation generally include (a) establishing an empathic, validating, nonblaming, task-oriented alliance with the family; (b) offering education about bipolar disorder and its management; (c) teaching coping skills, such as communication and problem solving; and (d) providing social support, especially through contact with other families. Research is currently underway to evaluate the benefits of family psychoeducation in the treatment of early-onset mood disorders (Mackinaw-Koons & Fristad, 2004).

Second, psychologists can work with such gate-keeping systems as schools and primary healthcare to improve the early identification and referral of children and adolescents with SED (Cook-Morailes, 2002). If her teacher or pediatrician had recognized Ellen’s mental health problems, early intervention might have reduced the risk of long-term impairment. On the other hand, school personnel often have little training in SED, so there is the danger of overidentification and labeling. Clinicians can increase the likelihood of appropriate identification and referral by working with gate-keeping systems as consultants, on-site providers, or
independent practitioners who accept referrals. Psychologists can also offer school-based, intensive mental health treatment, such as the Intensive Mental Health Program (IMHP) designed for elementary school children ages 5 to 12 years (Vernberg, Roberts, & Nyre, 2002).

Third, practitioners can use a family-focused approach to SED practice. Initially, they need to learn about the family experience of SED, including the issues and concerns of parents and siblings (Mackinaw-Koons & Fristad, 2004; Marsh, 1998, 2001). In sessions with parents and siblings, such as Ellen’s mother and younger sister, therapists can listen to their stories, answer their questions, and offer individual assistance (see Fristad & Sisson, 2004). A single informed and caring professional can make a significant difference in the lives of these beleaguered families.

Many families may also benefit from more formal family interventions, such as family consultation, psychoeducation, and support groups, that are designed to meet their needs for information, skills, and support (Marsh, 2001). Particularly at the onset of the disorder, these families need information about SED, its treatment, and community resources. They also need effective communication, stress management, and problem-solving skills, as well as support for themselves. Once these needs have been addressed, some family members may be appropriate candidates for traditional clinical services, such as individual, marital, or family therapy.

All of these interventions might have been helpful for Ellen’s family members. Informed of the available services, Ellen’s mother might have chosen to receive consultative services from her daughter’s therapist, to attend a time-limited multifamily psychoeducational program, or to participate in an ongoing parent support group. Likewise, Joyce might have benefited from an educational support group for siblings. In addition, Ellen’s mother and younger sister might have profited from individual or family therapy. Unfortunately, relatively few family services are available in most communities, and none were offered to Ellen’s family. Moreover, when family services are available, they tend to focus on adult mental disorders. If family-focused services for SED are not available in their communities, psychologists might consider offering family consultation, psychoeducation, or support groups through their individual or group practice (Marsh, 2001) or in partnership with family or provider organizations (Fristad & Sisson, 2004).

Fourth, many general principles of effective child and adolescent mental health practice assume special importance with young children who have SED. For example, clinicians can work with families to develop a comprehensive treatment plan designed to address the changing needs of the child or adolescent with SED, of other family members, and of the family unit. In Ellen’s case, the plan might have included consultation with other mental health professionals involved in monitoring her medication and providing inpatient treatment, as well as with school personnel responsible for her individualized educational plan. Focusing on their strengths as well as their problems, the plan should reflect the needs and preferences of Ellen and her family.

Fifth, multisystemic interventions are of particular importance in the treatment of SED because these young clients so often require services from multiple systems. Assuming a variety of roles in multisystemic interventions, psychologists can serve on multidisciplinary teams, conduct assessments, and provide clinical, supervisory, and consultative services for a variety of services. Increasingly, therapists are assuming new roles in 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. See the discussion by Hansen and her colleagues (2004) of roles for psychologists in multisystemic interventions.

Last, practitioners can partner with family advocacy organizations, such as the National Alliance for the Mentally Ill (NAMI), which has a Child and Adolescent Action Center, and the Child and Adolescent Bipolar Foundation (CABF). Information about local affiliates is available on the Web sites of these organizations (NAMI.org; bpkids.org). The educational and supportive services offered by these organizations are a valuable resource for families. Psychologists can also benefit from their participation in these organizations as consultants, program presenters, or partners in advocacy efforts.

Many other resources are available in the SED area, including an expanding professional literature (Henggeler, Schoenwald, Rowland, & Cunningham, 2002; Marsh & Fristad, 2002; Rapoport, 2000). Useful online and published materials are available from professional organizations such as APA, government agencies, and advocacy organizations. For example, the online National Mental Health Information Center of the Substance Abuse and Mental Health Services Administration (USDHHS, 2003) offers links to many child, adolescent, and family organizations.

Conclusion

This is an opportune time for psychologists to reach out to children and adolescents with SED. These young people and their families need and deserve accessible, affordable, and effective mental health services. Unfortunately, although effective psycho-social and psychopharmacological treatments are now available for the SED disorders, too often, appropriate services are neither accessible nor affordable. The price of this neglect is incalculable for these children and adolescents, for their often-desperate families, and for a society that is deprived of their gifts. Untreated or undertreated, these disorders often result in suffering, disrupted lives, unfulfilled potential, isolation and shame, and lost hopes and dreams.

Benefiting from the dramatic advances in the understanding, diagnosis, and treatment of SED, psychologists can offer SED services in a variety of community venues, including mental health, educational, child welfare, juvenile justice, and healthcare settings. As practitioners and advocates, psychologists can assist these vulnerable young people and their families in accessing appropriate services, mounting a resilient response to the challenge of SED, and improving the quality of their lives.

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