

# Family Perspectives on Evidence-Based Practice

Laurie M. Flynn

*Carmel Hill Center for Early Diagnosis and Treatment, Division of Child and Adolescent Psychiatry,  
Columbia University, 1775 Broadway, Suite 715, New York, NY 10019, USA*

“I’m not exactly sure what evidence-based practice (EBP) means, but I’m pretty sure we’ve never seen one!” That is what a parent who is a longtime friend said to me when I told her I was drafting this article and wanted to get input from families. Her comment, although a little sarcastic, reflects a reality: There is no agreed-upon definition for EBP. The term is widely used to describe all types of mental health programs and practices. So pervasive is the current focus on EBPs that some parents with whom I talked referred to this as “the latest buzz words,” “a new trend for professionals,” and “currently fashionable research.” Comments like these point out the difference between what captures attention in the world of mental health care professionals and what seems important to parents. In this article, I draw on more than 20 years’ experience of working with families and my own personal experiences with mental health services and providers to explore the concept of EBPs and the differing perspectives between professionals and the consumers and families they serve.

## History of the evidence-based practice movement

Quality and accountability have become watchwords in health and mental health services. EBPs are a means to achieve both ends. To achieve the objective of accountable, high-quality services by implementing EBPs, however, much of what characterizes the current system must change [1]. The movement to demonstrate and document EBPs is one of the most powerful ideas in medicine. It was hailed as one of the most influential ideas of the year 2001 by the *New York Times Magazine*. The concept was developed in the wake of the managed care revolution of the 1990s and accompanying efforts to restrain the rise in health care costs. The idea was to create greater consistency in the treatment of major medical conditions and achieve better results by focusing on science-based interventions [2]. Reimbursement was linked in many health plans to the implementation of “practice guidelines.” Providers were expected to justify their use

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*E-mail address:* flynnl@childpsych.columbia.edu

of expensive or intensive interventions by referring to evidence of effectiveness as documented in peer-reviewed literature. Instead of relying on clinical experience or individual preference, practitioners were increasingly required to use treatment with a published record of successful outcomes.

Mental health care has a long history of being criticized for ineffective and inefficient practices. Treatment approaches have reflected strong belief systems rather than a strong research base. The range of providers and therapies used has not been subjected to rigorous review. It is not surprising that the research base on the efficacy of various interventions is weak in child mental health services. Only a few treatments have been reasonably well documented and studied, including the use of stimulants for attention deficit hyperactivity disorder, parent management strategies for behavior problems in young children, interpersonal therapies for depression, cognitive-behavioral therapies for children with anxiety, multi-systemic therapy for aggressive and delinquent youth, and some emerging work on engagement techniques and certain school-based interventions [3].

In addition to the gaps in scientific research in children's mental health care is the lack of real standards for determining what constitutes an EBP. A professional consensus does not exist on when practices and interventions have reached readiness for community dissemination and can become the new standard of care [4]. Although the movement to provide treatment with an evidence base is widely praised, there is no clear agreement among professionals about what actually meets the definition of EBP. How much evidence is enough? How can we reconcile the results that emerge from controlled research settings with the "messy real world" conditions that characterize most service settings? EBPs must continue to evolve to meet these challenges. Research must address several critical issues, including strengthening the scientific underpinnings, practical matters of adaptation, and dissemination and problems of disparities in an uneven health care economy. To have maximum positive impact on mental health care for children and adolescents, however, the perspectives and priorities of families must be understood.

### **Evidence-based practices: the real world reality facing families**

A recent review of the literature reveals that in child psychiatry and child mental health practice, there is an evidence base for only a small number of interventions [4]. We have much to learn to improve child mental health practice and treatment outcomes. Only in the past few years have researchers begun a systematic review of the many medications and therapies provided to children and adolescents. Although the National Institute of Mental Health has tripled its investment in research in child and adolescent mental disorders over the past 15 years, the field is still underdeveloped and underfunded. Diagnosis often is tentative, and most treatments are untested. It is common for a youngster to receive several different diagnoses over the first few years of mental health treatment.

The various disciplines that provide services for children and adolescents have widely varying training and often see the same symptoms as indicating different

conditions, which causes parents understandable confusion and concern. The press has reported a fourfold increase in prescriptions of psychotropic drugs to children, but most of these medications never have been tested on children. Many of these drugs are prescribed “off label” and largely by non-psychiatrists. Parents frequently express discomfort with the gaps in knowledge and worry that their kids are being used as “guinea pigs” for research. “It’s really hard to know what to believe,” one mother told me recently. “The school and the doctor keep telling us to try medication but nobody seems to know if it will really work or what side effects might be. It’s scary.”

Younger and younger children are being diagnosed with mental health problems, even preschoolers in some cases. We still know almost nothing about the long-term effects of psychiatric medications on the developing brain. With several new drugs for attention deficit hyperactivity disorder and depression, how do parents determine what is best for their child? There is a dearth of evidence to guide their decision making; however, there are many opinions and controversy surrounding appropriate use of medications. A recent hearing held by the US Food and Drug Administration illustrated the heightened public concern about the widespread “off label” use of powerful psychotropic drugs. Prescription of these medications has increased exponentially during the past decade in an effort to treat a growing number of youngsters with a psychiatric diagnosis. Most doctors who prescribe such medications for children and adolescents are non-psychiatrists, however.

The situation with psychotherapy is no better. The intervention with the strongest evidence base is multisystemic therapy, and it has been tested mostly as an intervention with juvenile offenders [3]. There is promising work on cognitive behavior therapies with adolescents, but its applicability for younger children is not yet well known. Many clinicians believe that a combination of medication and psychotherapy is ideal, but few studies have been conducted to examine the combination, so little evidence exists to support this contention. In the real world of community providers, families are offered a range of unproven treatments with decidedly mixed results. Most often, families are referred for services to providers who describe their approach as “eclectic.” Therapists are highly individual, and many are not certified in any particular technique. They do what they have been trained to do and rely on their instinct and ability to create a therapeutic alliance. Although a good rapport with a patient is a fundamental part of healing, it is not sufficient to relieve suffering.

### Case vignette

A father I know recounted his family’s frustrating experience over a 16-month period:

When our son was 11 he began to have real problems, especially at school. We worked with the school counselor for several months. She believed the issue was adjustment to middle school, along with some academic problems. Then when things got worse, we went to a licensed social worker with an early adolescent

practice. She put our son in group therapy twice a week and told us working things out in the group and practicing problem solving was critical. But some of the kids in the group were a lot older than our son and several were court-committed juvenile delinquents. My boy actually told me he felt intimidated in the group and wanted to quit after only 2 months. Next we were referred to a clinical psychologist. He reviewed the case history and said we should begin family systems therapy. His theory was that we had screwed up family communication and inconsistent discipline. This meant all five of us were expected to spend Wednesday evenings in the doctor's office. It was a serious disruption in the family schedule and really added to my other child's anger. Plus my son also had weekly individual sessions. Each new professional seemed to have their own ideas and opinions and none of them spoke to the other people we had seen. I got really worried and angry about all the time and money we were spending yet things with my son were no better. The whole experience left me feeling very frustrated. How are you supposed to get good professional help when everyone has a different idea of what's wrong and how to fix it?

He did not realize it, but this father and his family were relatively lucky. At least they had the financial means to go to various mental health care providers. Around the country, thousands of families have problems with access to care. Coverage for mental health care in many insurance plans is limited, and managed care policies restrict choice and access to many providers. Because there are too few child psychiatrists, most youth with more severe symptoms are treated by a pediatrician or other primary care physician. Although they have good intentions, most of these family doctors have no training in psychiatric diagnosis and psychosocial or pharmacologic treatment. Not surprisingly, they may misdiagnose, undertreat, or overtreat, which further confuses a difficult situation and erodes parental trust in mental health care services.

Even in communities in which a full range of providers is available, there often are long waiting lists. The continuing lack of full parity in health insurance also means that mental health treatment is unaffordable for many families and children. Cost, not evidence, drives decisions about treatment for most parents. Differential insurance caps and co-pays make continuity of care difficult and expensive. Managed care restrictions mean that only a limited number of providers accept a case. Families report that it often takes many months of trying various services before they begin to understand what is wrong and what help they need. By then, thousands of dollars in coverage have been used up, with no real improvement in the youngster's functioning. In some cases, exhausted families are finally told they must give up legal custody of their child to access treatment through the public sector.

### **Families' perceptions of evidence-based practices**

Parents are most focused on the practical issues in dealing with mental health services. The ideas behind EBPs seem remote from their daily experiences. The National Alliance for the Mentally Ill (NAMI), where I served for 16 years as

executive director, has a growing number of members focused on child mental health policy and practice. Ken Duckworth, MD, NAMI's medical director, regularly convenes a telephone conference call with local and state leaders on issues of interest to families. On February 6, 2004, the group discussed EBPs in children's mental health. The lively 90-minute conversation elicited some key concerns and perspectives from parents with experience in the arena (D. Gruttadaro, MD, personal communication, 2004). A key observation was that although EBPs are a hot topic in policy and professional circles, the current health care system is not designed to serve children and adolescents with mental illnesses. Many parents are frankly doubtful that grafting EBPs onto a failed and fragmented system will succeed.

To some parents, the current controversy surrounding selective serotonin reuptake inhibitors and potential increased suicide risk, which recently led to another US Food and Drug Administration review of research evidence, makes clear that even government regulation is not a guarantee of quality. This has created considerable doubt in the one area that parents had previously trusted as an evidence-based treatment. As one parent I know said plaintively, "I'd like to use evidence-based psychiatry but I'm not sure how to find it." This remark mirrors the concerns for NAMI advocates who participated in the conference call from across the country. As informed consumers of mental health services, they are painfully aware that there is not much science yet on what works for kids. Even more disturbing is the shortage of licensed professionals to treat our children and adolescents. "Evidence-based practices aren't much help if there's nobody who will see my child," said one mother. In many communities, problems with access to care—any kind of care—have reached crisis proportions.

NAMI families reported that the cost of implementing EBPs is perceived as high, and local and state officials are facing budget shortfalls. Others observed that before EBP became a big focus, there was a lot of talk about "wraparound services" and systems of care for children. More than a decade after these ideas first entered the field, however, we do not see much improvement in the basic service structure. One participant asked, "How useful are all these good ideas if they never get implemented?" Meanwhile, the day-to-day burden of care and much of the case management still fall on parents.

When families talk about what they are looking for from evidence-based mental health services, the emphasis is on outcomes that go far beyond reduction of symptoms. Parents want to see their children improve in their school performance. They want treatment to help their kids relate better with friends and family. They also look to increased self-confidence and independence over the long-term as critical measures of treatment effectiveness. These are not the measures typically built into clinical research studies. It is clear that researchers should work more closely with parents and family advocacy organizations as they develop studies and define outcomes measures.

Another theme from the conference call was the importance of recognizing the impact of culture on treatment efficacy. Many parents of various ethnic and cultural backgrounds reported feeling unheard and even disrespected by mental

health care professionals. Families play a crucial role in a fragmented system and are essential to recovery. A colleague recently commented, “Why haven’t we found out more about how to work effectively with families? We’re always reading about how families are part of their kids’ problems, but not enough is known about the tremendous strength and endurance of families who deal every day with a disturbed child with almost no help.”

Stigma is another burden borne by families, and its impact may be underestimated. In a culture that still views children as a direct reflection of their families, parents whose children have behavioral disorders often feel ashamed and inadequate. Support for the families’ role in treatment is frequently missing, or parents are relegated to serving as transportation to get their youngster to therapy. Some service providers focus attention exclusively on the child and ignore the needs and insights of parents. Others assume that most children with mental disorders come from “dysfunctional families” and that parents are the cause of a child’s symptoms. These ideas and attitudes are readily perceived by parents, who often report feeling marginalized in their child’s mental health care treatment.

Strong evidence exists from research with adults that caregiving is distressing and demanding. It can lead to impaired health and reduced quality of life for the caregiver. The additional burden of a professional community that is perceived as rejecting makes life even more difficult for parents. Many parents report feeling isolated and overwhelmed [5]. For parents who are trying to cope with an out-of-control child, upset or neglected siblings, ongoing financial and marital stress, and usually two full-time jobs, the reality is that negotiating with the child mental health and educational systems is a nightmare. Families repeatedly seek help in managing all these competing priorities and spend evenings and weekends searching for the latest evidence-based treatment solutions.

Schools often are another major battleground for parents. Several NAMI families noted that youth with untreated mental illness in middle and high schools are frequently viewed as delinquent and often end up in juvenile justice systems because of aggressive behaviors. Some parents reported that they and their ill child are told they must accept the special education programs offered—however inadequate—because the only alternative is referral to juvenile justice.

There is a real need to focus on school-based programs that are specific to kids with mental illnesses—not just kids with learning difficulties. Parents reported that traditional approaches frequently mix emotionally disturbed kids with kids who are coping with a wide range of other disabilities. “There is this one-size-fits-all mentality,” noted one parent, “but not much is done beyond attempts at behavior modification through extensive use of ‘time-outs.’ What my daughter needs is more ‘time-in’ so she can learn how to interact and participate effectively in class.”

The areas of highest interest to families as we pursue the work of defining and disseminating EBPs in child mental health include

- Improving family engagement
- Providing effective family education

- Supporting caregivers
- Medication decisions and managing side effects
- What works in psychotherapy
- Promoting independence and emancipation for severely disabled adolescents

Parents want to see improved school-based programs and worry that the presence of a mental disorder is the single greatest predictor of school dropout.

Beyond these specific concerns, there is overwhelming frustration with the slow pace of change in professional attitudes and practices. The effective partnership among researchers, leading professionals, and the family/consumer advocacy community that has defined standards of care in adult mental health must be built for children. The advocacy focus must be on expanding availability of effective outpatient treatment and creating a broader evidence base for service development. Until such a strategic partnership is in place, efforts at large-scale dissemination of EBPs will be difficult to achieve [6]. Accelerating the pace of community replication requires greater understanding of the realities of real world practice settings and policies.

Families must play a much greater role in identifying, developing, and promulgating EBPs. As individuals and through organized advocacy, families can facilitate research that speeds implementation of existing and new EBPs. Parents can be engaged in leading efforts to promote policies that support the adoption of EBPs through education and advocacy. They can influence provider behavior by acting as a “demand-side” for needed reform in practice. Families can help define an action research agenda that is motivating to policymakers, who often wonder about the results of programs they fund. These kinds of strategies generally have been relegated to a lower level of importance by professionals. Neglecting to ensure the “buy-in” of families and advocacy groups leads to poor results in the struggle for attention and resources, however. A more concrete and practical agenda for EBPs research and implementation could energize advocates and give families a real voice in this important scientific endeavor [7].

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