

The Application of Behavior Change Theory to Family-Based Services: Improving Parent Empowerment in Children's Mental Health

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Abstract We describe the development of a parent empowerment program (PEP) using a community-based participatory research approach. In collaboration with a group of dedicated family advocates working with the Mental Health Association of New York City and state policy makers, academic researchers took an iterative approach to crafting and refining PEP to better prepare family advocates to help bridge the gaps in service access among children with emotional and behavioral problems. Despite the growth of family-led, family support programs nationally, research that demonstrates the positive benefits of such programs is scarce in the children's mental health literature. The PEP model is based on research data about barriers families face in mental health service utilization (e.g., stigma, perceptions of providers, attitudes towards mental illness, service availability, etc.). PEP is premised on (a) the concept of empowerment as a process, (b) the need to engage parents in becoming active agents of change, and (c) the application of an integrated framework to empower parents, called the Parents as Agents of Change model. Our paper focuses on describing the

application of a Unified Theory of Behavior Change as a theoretical framework to help activate parents as change agents in meeting their children's mental health needs. Based on an integrated model of grassroots driven Principles of Parent Support and research-based Unified Theory of Behavior Change, PEP's Parents as Agents of Change model provides a conceptual framework for testing the effectiveness of family support services in children's mental health, a much-needed area for future research.

Keywords Parent empowerment · Behavior change theories · Family support · Children's mental health service access

Introduction

Despite dramatic advances over the last decade in identifying effective interventions to prevent and treat childhood mental health problems, significant gaps persist in families accessing and using mental health services. The gaps between mental health care need and actual service delivery are especially pronounced among minorities, and more so for mental health care than other forms of medical care (Kataoka et al. 2002; U. S. Department of Health and Human Services 2001). Yet, existing services are often underutilized or inefficiently delivered, with high "no-show" rates and low rates of service use, particularly among low-income, urban and minority children (McKay et al. 1998). Those children with the most serious problems and those with the most complex social situations are less likely to use or be retained beyond the first session, more likely to attend treatment inconsistently, and to terminate services prematurely (e.g., Griffin et al. 1993; Kazdin et al. 1997).

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A variety of models and theories have been proposed to understand factors that influence mental health service access from provider, organizational and family perspectives (Stiffman et al. 2004). Family perspectives of their experiences in the mental health service system have mainly been qualitative. These largely atheoretical models have focused on two primary domains: (1) structural barriers; i.e., transportation, childcare insurance, service availability (Kataoka et al. 2002; Kazdin et al. 1997; Owens et al. 2002), and (2) attitudes, beliefs and perceptions about mental health services, i.e., negative attitudes about services, mistrust towards mental health professionals, prior negative experiences with the mental health system, stigma, belief in the transient nature of child social and behavioral difficulties (Owens et al. 2002; Pescosolido et al. 2008). Beyond the structural, perceptual, and attitudinal barriers reported by families as obstacles to mental health service use, family contextual factors (e.g., parent stress and social supports) also influence whether families stay in treatment and the extent to which they benefit from treatment over time (Dadds and McHugh 1992; Kazdin and Wassell 2000; McKay et al. 2001). Understanding and directly addressing barriers to service access and use is thus critical to improving children's mental health outcomes.

To address problems in access, several family-based service models have been developed with the common goal of supporting families' engagement with or knowledge about mental health services. For example, Bickman et al. (1998) developed a theory-based "parent empowerment" intervention designed to increase parents' self-efficacy in advocating for their children's mental health care needs. While this intervention constitutes the sole controlled study to date testing empowerment methods in the area of children's mental health, other types of family support models have been developed to address specific types of mental health issues. These include education and psychological support for families of youth with bipolar disorder (Fristad et al. 2002); support interventions addressing parent stress and other familial barriers to service use among families of children with disruptive behavior disorders (e.g., Ireys et al. 2002; Kazdin and Whitley 2003; McKay et al. 2009; Ruffolo et al. 2006); strategies to address problems of clinician engagement and retention of families in services (McKay et al. 1998); parent support interventions to promote flexible service planning using wrap-around services (Bruns and Hoagwood 2008) and peer-led interventions to facilitate parent connections with services (Koroloff and Elliott 1996; Kutash et al. 2006).

Increasingly in service interventions such as these, parents are viewed not as recipients of services but as *agents of change* (Hoagwood 2005). In a recent review of the empirical literature on family-based services since 1990, 41 rigorous studies of specific program models of

family processes were identified. This review identified no core set of constructs, definitions, or theoretical foundations upon which to base the thin set of studies. The purpose of this manuscript is to describe the development of a Parent Empowerment Program (PEP) in New York State. Using a community-based participatory research approach, a parent empowerment program (PEP) that integrates grassroots-driven Principles of Parent Support and a research-based Unified Theory of Behavior Change was developed in an iterative process to support parents as change agents in the engagement of effective services for their children and family.

Parent Empowerment: The New York State Family Advocacy Network

In 1998, New York State's Office of Mental Health (NYSOMH) created a network of Family Advocates (also called Family Support Specialists) to bridge the gap between parents of children with mental health needs and mental health service systems. These advocates, typically parents of children with special needs themselves, serve as peers to model, coach, and support parents in their journey to understand, cope with, advocate and negotiate various service systems. Further, family advocates serve as important linkages to families facing similar situations, thus decreasing family isolation, increasing opportunities for families to develop a support network, and providing opportunities for advocacy at the individual, systems, and legislative levels.

Currently New York State supports 107 separate family support programs throughout the state and these programs employ approximately 400 advocates. The network is coordinated in New York City (NYC) through a set of Parent Resource Centers, which provide technical assistance, training, and support to advocates throughout the five boroughs. In addition, eight regional advocates work with the state's Bureau of Children and Families to engage family support programs throughout New York's 62 counties. An additional 76 advocate programs operate under the independent auspices of hospital centers, county-operated mental health agencies, private providers of clinical services, and separately incorporated advocacy programs. Approximately 10,000 families annually access training, discrete services, and general support through family advocacy programs. In a newly emerging model of family support services, NYSOMH recently announced a statewide plan to expand the number of family advocates, support training and credentialing of family advocates, and recognize family-to-family support as a billable service under state regulations (New York State Office of Mental Health (NYSOMH) 2008).

The availability of family support staff is not unique to New York, and nationwide there has been an increase in parent advocacy and parent support programs (Hoagwood et al. 2008; Koroloff and Friesen 1997). Despite this growth and despite the fact that advocates are often working with the most highly distressed families (Hoagwood et al. 2008), they typically receive limited systematic training on how to effectively support parents of children with mental health needs. With shrinking funding available for mental health services and an increasing number of clinics operating in fiscal deficit (Schoenwald et al. 2008), family advocates have become a valuable adjunct to traditional clinical mental health services. We describe below the background, rationale, and thinking behind the development of a training program targeted at family advocates.

Background to the Parent Empowerment Program (PEP)

In collaboration with a group of dedicated family advocates working with the Mental Health Association of New York City, policy-makers from NYC and NYSOMH, academic researchers from Columbia University and Mount Sinai took an iterative approach to crafting and refining a parent empowerment program to better prepare family advocates in NYC to more effectively address the needs of families whose children have mental health problems. PEP is modeled in part on the Fort Bragg service empowerment intervention, the only empirically based model of parent empowerment for children in the mental health arena (Bickman et al. 1998). As a first step to its adaptation in NYC to make it appropriate for use with low-income, urban populations, a group of family advocates, state policymakers, and researchers has been meeting for over 6 years to adapt, refine, and pilot this model throughout NYS. Using a community-based participatory research approach, PEP developed through an iterative process, focusing specifically on (a) the concept of empowerment as a process, (b) the need to engage parents in becoming active agents of change, and (c) the application of an integrated framework to empower parents, called the Parents as Agents of Change model.

Empowerment: Developing Parent Competencies as Agents of Change

Within the child mental health field, the impact of family education and empowerment interventions is not well studied (Farmer et al. 2004). However, parent involvement has been documented to influence the likelihood of treatment attendance, treatment completion, improve parent-child relationships, increase confidence in parenting skills,

decrease parental stress, and improve behavior and academic outcomes (e.g., Chacko et al. 2009; Kazdin and Wassell 2000; Ruffolo et al. 2006). Thus, to address the gap between children's mental health needs and effective service utilization and outcomes, parents must be empowered to become actively involved in the mental health care of their children.

The process of parent empowerment has been conceptualized as a "process of recognizing, promoting and enhancing [parents'] abilities to meet their own needs, solve their own problems, and mobilize the necessary resources in order to feel in control of their own lives" (Gibson 1995). According to Gibson (1995), parent empowerment involves a dynamic process, encompassing four key components: (1) understanding and acceptance of a child's diagnosis, (2) critical reflection of themselves and their situation by taking stock of their strengths, capabilities and resources, (3) taking charge of their child's care through advocacy, learning how to deal with the health care system, learning to persist, driving interactions with providers, establishing active partnerships with those involved in their child's care through mutual respect and open communication (the doctor knows the diagnosis and the parent knows the child), and (4) persevering in their efforts over time. Through this process, parent frustrations with various service systems and providers, with their families and with themselves serve as an important driving force for action. Through critical reflection, empowered parents channel their frustrations involved in caring for their child, enabling them to develop a sense of competence and power to face the reality of their child's diagnosis, take charge, and persevere over time (Gibson 1995).

Consistent with this concept of empowerment, the PEP training focuses family advocates on meeting parents where they are at in this process, and learning to identify strategic points of interventions in order to help parents effect change in their sense of self-efficacy, expectations, attitudes and beliefs about their possible roles as an effective agent of change for their child. The goal of PEP is to work with parents to address barriers to their capacity as change agents, provide the necessary knowledge to alter attitudes and beliefs, and foster specific skills and competencies for navigating and interacting with various providers, systems and legislation, thereby ensuring that their child's care is consistent with their beliefs, values, and goals.

Addressing Barriers: Need for Engagement

Family advocates in NYS are often challenged in helping disenfranchised and economically-disadvantaged families from highly diverse backgrounds develop the knowledge

and competencies necessary to ensure that their needs are met. Consistent with the literature on barriers to mental health care, especially among families with complex social situations, family advocates often cannot effectively begin the process of empowering families, without addressing the perceptual obstacles that families face, such as the stigma of mental illness, beliefs about child social and behavior problems (e.g., child needs discipline; problems will go away), and attitudes about mental health services (lack of trust, negative experiences with providers). Even when such perceptual barriers are addressed, many of these families are stressed by living situations and personal challenges, and often lack the requisite knowledge, skills and support to effectively advocate on behalf of their children's needs. Thus, a significant component of PEP integrates specific and pragmatic engagement strategies for increasing parent engagement (McKay et al. 1998) and links such strategies to lessons from theories of behavior change in order to activate parents of children with mental health needs as agents of change (Fishbein 1980; Jaccard et al. 2002, 1999).

Parents as Agents of Change: An Integrated Framework for Action

Below, we articulate the two bodies of knowledge that we integrate as our framework for empowering parents as agents of change.

Principles of Parent Support

Drawing from grassroots knowledge about family support, PEP adheres to a set of principles that were developed collaboratively by family advocates and researchers working with Kansas Keys Inc. These principles serve to ground the work of family advocates as they work with parents to develop goals consistent with family beliefs and values, even as they are challenged to operate under the various constraints of their job context (Table 1).

Applying the Unified Theory of Behavior (UTB)

In developing a theoretical framework for helping parents become active agents of change as they work towards family goals for their children's mental health care needs, we simultaneously drew upon a substantive literature on factors that influence behavior and behavior change. Several hundred studies of health-related behaviors, including substance use, risk-taking, and sexual behavior, have relied on a small group of theories derived from social and health psychology (Fishbein 1980; Jaccard et al. 1999, 2002). While the various theorists do not agree on the core

Table 1 Principles of parent support

1. Parent support is individualized and tailored to the specific needs of families
2. Parent support facilitates linkages of parents to agencies, services and to other families
3. Parent support is respectful and culturally competent
4. Parent support builds skill through hands-on training, role modeling and mentorship, and other skill-building activities
5. Parent support increases parents' knowledge to help them make informed decisions about their child's service needs
6. Parent support is engaging; it actively partners with families to meaningfully involve them in programs and services
7. Parent support problem solves by focusing on needs and solutions and by identifying successes of the past and options for continued success
8. Parent support focuses on outcomes and success and is goal oriented
9. Parent support broadens horizons by expanding the possibilities for parental involvement (from their own community to policy levels) and cultivates a community of peer support
10. Parent support promotes advocacy

elements that influence behavior and behavior change (Fishbein et al. 2001; NIMH Workshop Report 1991), they did agree upon a general framework that has since been expanded to the Unified Theory of Behavior (UTB) (Jaccard et al. 1999, 2002).

According to UTB, a person's behavior can be conceptualized along two dimensions: those pertaining to the *immediate determinants* of behavior (Fig. 1) and those pertaining to the determinants of the willingness to engage in a given behavior (Fig. 2). The first dimension relates to an individual's behavior, which is immediately influenced by five factors as depicted in Fig. 1; these factors in combination have been found to determine behavior. In general, any given behavior is more likely to occur when the variables are aligned in favor of its enactment (Jaccard et al. 2002).

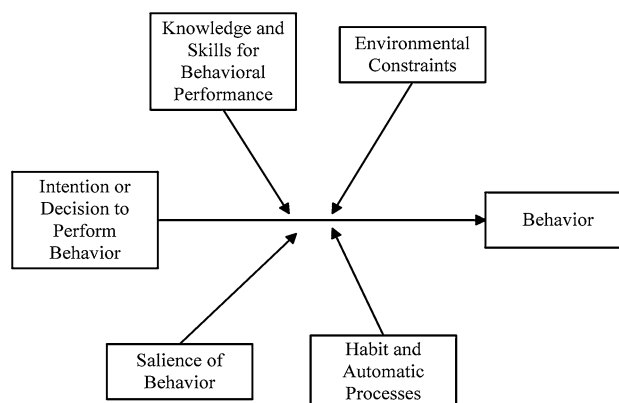


Fig. 1 Immediate determinants of behavior

The second dimension of UTB focuses on factors that influence an individual's willingness, intention, or decision to perform a behavior. Behavior intentions capture the motivational factors that influence behavior that is under volitional control (e.g., parents deciding to follow through with initiating a mental health evaluation for child). According to UTB, six factors comprise this category (see Fig. 2). In combination, these six variables are thought to influence an individual's intention to engage in a behavior.

Taken together, the 11 variables represented in both of these figures have both a solid theoretical and empirical basis in the behavioral sciences, with hundreds of studies over five decades supporting their validity. The variables collectively comprise an integrative set of explanatory constructs that have been called the Unified Theory of Behavior (UTB), following Jaccard et al. (1999). According to UTB, in order to understand individual's decision to engage in a behavior, one should consider the factors (attitudes, expectancies, normative beliefs, self concept, affect, self efficacy) that influence behavioral intentions. However, even if a person makes a decision to engage in a behavior, the decision will not necessarily translate into action. More immediate determinants of behavior such as knowledge, skills and abilities, the presence of environmental constraints or facilitators, the priority attached to the behavior, and existing habits can also interfere with behavior performance. Thus, based on UTB, strategies that address both determinants of behavior intentions as well as actual behaviors may be necessary to effect behavior change.

The relative importance of the variables in Figs. 1 and 2 in influencing behavior differs from population to population, from behavior to behavior, and across various

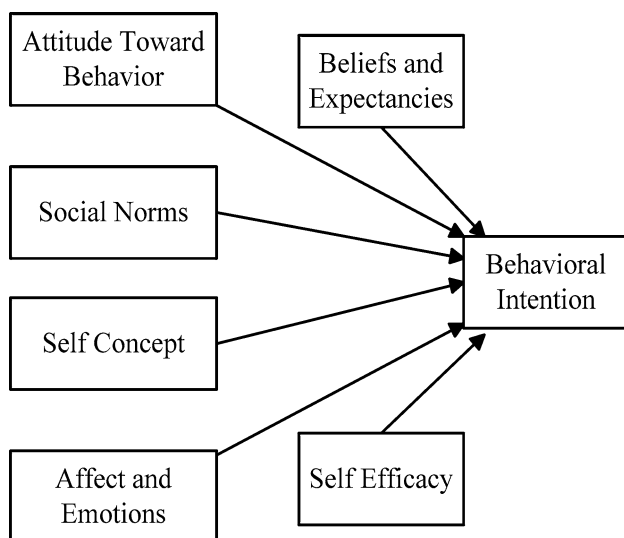


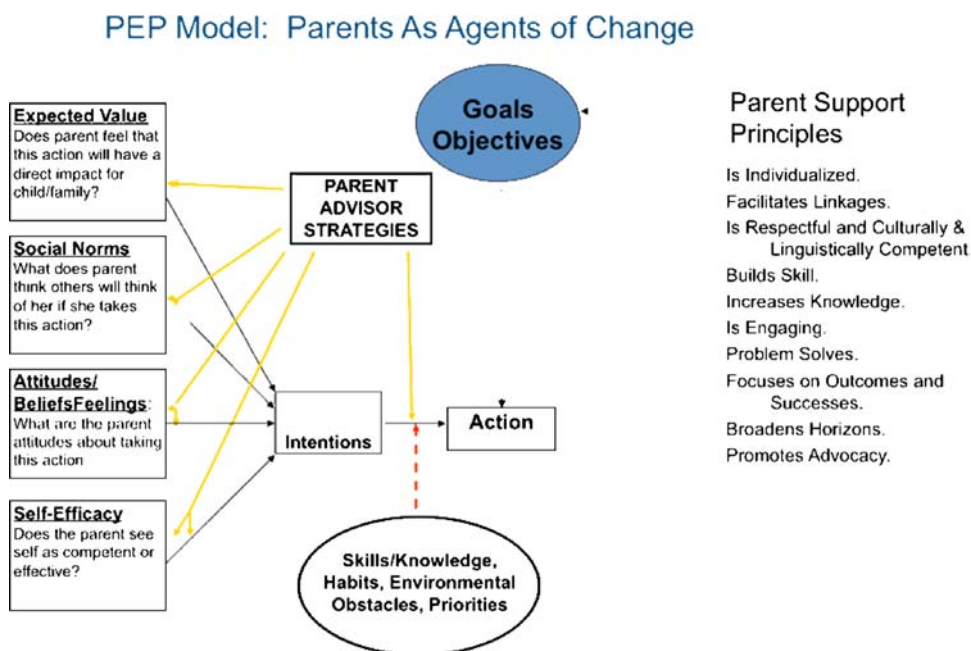
Fig. 2 Immediate determinants of behavior intention

situations. For example, for some individuals, normative influences may be a primary determinant of the decision to perform a behavior (e.g., “People from my culture do not seek help from mental health professionals”). For other individuals, attitudes of mistrust towards health care providers (e.g., “I’m afraid they will think I am a bad parent and take my child away”) may be a primary determinant of behavioral intentions. In other situations where an individual may have decided to initiate or participate in mental health services, intervening obstacles or events (e.g., work conflict, long wait lists at clinics) may interfere with actual behavior.

Developing the PEP Model of Parents as Agents of Change

In applying UTB to PEP, we adapted the UTB framework to fit existing knowledge from the literature about barriers to mental health care as well as feedback based on the practical experience of various family stakeholders. The resulting PEP framework (see Fig. 3) emphasizes four primary determinants of behavior intentions. Using this framework, advocates apply the Principles of Family Support to help parents set priorities and identify family goals and actions. As parents act to achieve identified goals, family advocates systematically utilize the Parents as Agents of Change framework to help them understand factors that may be operating to influence their intentions and behavior with respect to goal attainment. Based on the UTB premise that behaviors can often be predicted from an individual's intentions, a starting point in working with parents involves assessing parents' behavior intentions, and as necessary, working to increase motivational factors that might influence such intentions. In PEP, the primary determinants influencing parent intentions to initiate or participate in mental health care involve four key variables. (1) Beliefs and expected value: the degree to which a parent is likely to initiate or participate in treatment depends on how he or she perceives the benefits (e.g., child will be less disruptive at school and at home) and whether these benefits outweigh the perceived cost or barriers that must be overcome (e.g., arranging time off from work to get service vs. less likely to be called out of work for child's misbehavior at school). (2) Social norms or pressure: whether a parent is motivated to participate in care may depend on what he or she thinks other parents in their situation do and whether important people in their lives (e.g., spouse, other family members) are supportive of it. (3) Attitudes toward mental health problems and the mental health care system: parents' understanding and perception of mental illness (e.g., stigma, child just needs better discipline) as well as past experiences with the mental health care system can also influence their motivation to seek

Fig. 3 PEP model: parents as agents of change



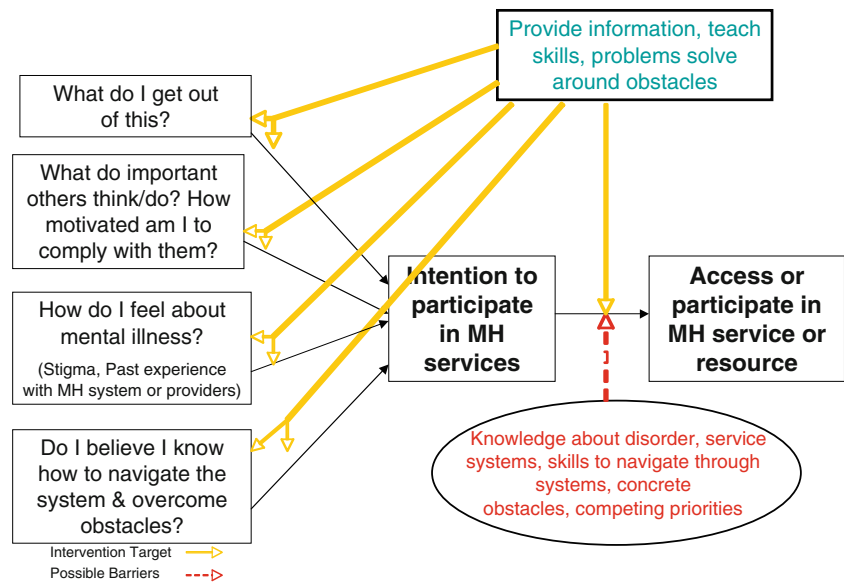
help. Lack of knowledge or misconceptions about child mental health problems (e.g., this problem will go away with time) and negative experiences with health care providers (e.g., they treated me like I caused this problem in my child) can be key motivating factors in some parents' willingness to participate in care. (4) Self-efficacy: a parent's perception of how difficult it might be to initiate care, access resources, or participate in treatment also influences their behavior. This perception is assumed to reflect past experience, second-hand information, experiences of acquaintances and friends, and anticipated obstacles or the presence or absence of requisite resources and opportunities. Thus, a parent who believes that they have the skill, knowledge, information or resources available to support their likelihood of success will be more likely to follow through.

While the UTB model also includes the constructs of self-concept and affect as variables that influence behavior intentions, in PEP, the focus is on four primary constructs (beliefs and expectancies, social norms, attitudes, and self-efficacy), with self-concept and affect operating through the four primary constructs. For example, how a parent feels (affect) about initiating or participating in mental health services may be influenced by what they expect to get out of it and/or beliefs or attitudes toward mental health problems. A parent who believes that a child's behavior is simply a result of poor classroom management or who is mistrustful of mental health providers is likely to feel negatively about initiating mental health services. Similarly, how participating in mental health services may fit in with their self-image could also be influenced through their

beliefs and attitudes toward mental health problems ("my child has this problem because I am a bad parent") or through social pressure ("my family thinks I just need to discipline him better").

Figure 4 depicts the practical application of this framework that we use to provide examples of how family advocates can systematically assess motivational factors in order to identify specific intervention strategies. For example, if a parent is reluctant to engage in mental health services, underlying factors (e.g., belief that child will outgrow problem, concerns about stigma, fear of blame by providers, belief that they lack the competence to overcome obstacles in getting services) that may influence intentions or behavior are assessed and specific strategies targeted to strengthen their intentions or action (e.g., provide education about the nature of the disorder, specific information and skills to improve perceived competence).

On the other hand, if parents have decided to seek or participate in their child's mental health care (i.e., behavior intentions are in place), understanding and problem solving around factors that may influence the actual behavior (e.g., providing specific knowledge or information about who to call, what to ask for, and how to prepare, teaching assertiveness skills, figuring out who can help with transportation or child care issues, etc.) can help increase the likelihood of follow through. Understanding where parents are at in this process and what specific factors stand in their way is important as it can help family advocates focus their intervention efforts. Because behavior change is a process and not an all-or-nothing phenomenon that occurs immediately or not at all, a parent's difficulty in activating

Fig. 4 Practical application of the PEP model of change

change should be seen as an important opportunity in the intervention process. Systematically reviewing factors that might have gotten in the way of action can often uncover previously overlooked or unforeseen obstacles (e.g., family pressure against mental health services, mistrust due to past negative experience with helping institutions, lack of skill, change in insurance, lack of available services, etc.). Thus, parent difficulties with activating change can be seen as opportunities to problem solve around barriers, or to make appropriate adjustments to an existing action plan.

In the PEP framework, assessment of where parents are at in the help seeking process is key. Using this framework, family advocates are trained to systematically consider key factors that might influence a parent's intentions to engage or to participate in their child's care. Based on this assessment, family advocates can apply a variety of strategies to address motivational issues or problem solve around barriers that may interfere with their intentions or actual behaviors. Such intervention strategies may include providing specific information to change or shift a parent's expectancies, attitudes and beliefs, coaching to improve specific skills, providing support to boost parent's sense of efficacy, or problem solving around concrete obstacles. Clearly, the PEP framework is not meant to capture all possible variables (e.g., personality variables, family demographics, provider characteristics) that might influence a parent's willingness to initiate or to participate in their child's mental health care. Motivating factors and barriers to change can and do vary from parent to parent and from situation to situation. This framework provides a starting point to better understand motivations and barriers, thus identifying points of leverage to effect change.

Implications of the PEP Model for Practice and Research

The individual-level analysis implied by the PEP framework when applied to the complex issues involved in a parent's level of activation and involvement in their child's care has important limitations. Broader and more systemic variables may be more operative or influential in determining the help seeking behavior than mere behavioral intentions. For example, consistent with ecological theories in social work and social psychology, Jaccard et al. Jaccard et al. (1999, 2002) have described five broad classes of distal variables that may also affect behavioral change. These include demographics (e.g., race, ethnicity, gender); familial characteristics (e.g., parental stress, history of psychiatric illness); social networks (e.g., social support); personality variables; and provider characteristics (e.g., service setting). However, even beyond these variables, there exists a range of larger systemic variables, including but not limited to organizational culture and climate, governance, financing, and policy legislation that influence the delivery and access of mental health care services for children. While addressing many of these broader variables are beyond the scope of the PEP model, such variables often significantly constrain the ability of families to seek and participate in services. The PEP model does not propose that family advocates ignore such realities; it does take into account the potential influence of environmental obstacles in the process of behavioral activation and helps advocates put into context the issues parents face in trying to meet the needs of their children's mental health. Thus, while advocates may often not be able to change systemic barriers in the short run (e.g., long wait lists at clinics, lack

of insurance coverage, lack of provider sensitivity), they can help provide important emotional support while helping parents problem solve around more malleable barriers (e.g., exploring alternatives to clinic care in interim), help parents develop specific competencies (learning how to more effectively communicate needs to get needed attention), and link parents to other resources (including other parents) across various service systems to more efficiently meet the unique needs of their children and family. Moreover, the PEP model recognizes implicitly, if not explicitly, that change agency is not merely an individual act. Parent activation can also facilitate more collective action to promote and advocate for macrosystemic change.

From a research standpoint, this model provides a theory driven approach to studying the impact of family support and empowerment, an area of research that is much needed to guide and lend greater legitimacy to an increasingly growing area of need within the field of children's mental health.

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