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in children's mental health

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## Caregiver ↔ Child: Mutual Influences on Mental Health



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**Summer 2008 focal point Staff:**

Janet S. Walker, [janetw@pdx.edu](mailto:janetw@pdx.edu), Co-Editor  
L. Kris Gowen, [gowen@pdx.edu](mailto:gowen@pdx.edu), Co-Editor  
Nicole Aue, [aue@pdx.edu](mailto:aue@pdx.edu), Assistant Editor





## Caregiver ↔ Child: Mutual Influences on Mental Health

Lived experience and common sense both support the idea that caregiver and child mental health impact one another. It seems to go without saying that a thriving child is a source of joy and affirmation for a parent or other caregiver. Similarly, it seems obvious that children's thriving is promoted when their caregivers have robust mental health and the emotional reserves that are required to provide patient, positive, engaged parenting. On the other hand, it is equally clear that parents—and other caregivers who love a child—will experience distress when they see that child struggling or suffering, and that that distress will be greater if the caregiver feels ineffective in his or her efforts to reduce the child's struggles. It also seems evident that children will become distressed when their caregivers are struggling, and that that distress may be increased if the caregiver lacks the support, energy or capacity to provide reassuring, consistent parenting. Finally, it is not hard to see that these mutual impacts can build upon each other. Thus, regardless of whether distress “starts” with the caregiver or the child, both are affected, and because of the ongoing mutual

impacts, both caregiver and child distress can become amplified over time.

Yet the field of children's mental health has been slow to fully explore and acknowledge the ways that caregiver and child mental health mutually influence one another. Similarly, mental health service systems have been slow to develop and implement programs and interventions that take this mutual influence into account. There is, however, a growing body of research that offers a clearer view of the mechanisms through which caregiver and child mental health impact one another, and there is growing awareness of the implications that this research has for providing mental health care. This issue of *Focal Point* seeks to summarize some of this accumulating wisdom—from personal, lived experience as well as from practice and research—about the mutual impact of caregiver and child mental health, and about practical strategies to promote positive outcomes for children and caregivers who experience mental health difficulties.

Below, we describe some of the major pathways or mechanisms by which caregiver and child mental health/distress influence each other.\*

Unfortunately, a great majority of the studies that examine these pathways are focused on evidence of risk and negative outcomes, so a discussion of the studies has an inherent focus on deficits. This does not mean, however, that the information from these studies has not been used to create service and support strategies that focus on building positive caregiver and child interactions and capacities. A number of such strategies are mentioned here, as well as in other articles contained in this issue of *Focal Point*.

### Evidence of Mutual Influence

A great deal of the research that examines influences between caregiver and child mental health focuses on outcomes among children of mothers with serious mental illness. These studies generally show increased risk of adverse outcomes—including difficulties in social, emotional, and behavioral functioning—among children whose mothers have depression<sup>12,1</sup>, bipolar illness<sup>1,6</sup>, or schizophrenia.<sup>12</sup> Recent studies suggest that these risks can be set in motion even before a child is born. For ex-

\* Much of this information comes from research reviews prepared by other authors. For the most part, the citations here refer to these reviews, rather than to the original studies that are included in the reviews. Information about the original sources can be found in the cited reviews.

ample, it appears that high levels of anxiety or stress during pregnancy (characteristic of mothers with mental illnesses<sup>4,12</sup>) have an impact on fetal development, particularly the development of the stress response. As a result, when the baby is born, he or she may have a more sensitive temperament and may be more vulnerable to stress throughout his or her life. This emerging information is important for making decisions about mental health care during pregnancy. The article by Diane Solomon (page 26) takes on this issue, examining the benefits and risks associated with using medication to treat depression during pregnancy.

A much smaller body of research has examined the impact of a child's emotional or behavioral difficulties on maternal mental health. The majority of these studies document the impact on maternal mental health of having a child with a disruptive behavior disorder, including attention-deficit hyperactivity disorder (ADHD). Typically, such studies show higher rates of depressive symptoms among these mothers.<sup>4,9</sup> Other studies show elevated rates of depression among mothers whose children are referred to mental health services for any reason.<sup>4</sup> More positively, several programs that have been shown effective in reducing children's behavior difficulties have also been shown to have beneficial impacts on caregiver mental health.<sup>4,8</sup>

Knowing that maternal mental illness is associated with certain child outcomes (and vice versa) is certainly important, but these kinds of findings represent only a small part of what is clearly a far more complicated picture. Until quite recently, there were few efforts to describe the influences from child to caregiver and from caregiver to child at the same time. Furthermore, there had been little exploration of the possible factors—within individuals, within the family, and within the larger social and economic environment—that might affect the interrelationship between caregiver and child mental health. For example, will the presence of another caregiver—like a father or a grand-

parent—buffer a mother from the impact of having a child with challenging behavior? Exactly why does a lack of economic resources exacerbate the risk of negative mutual impacts between child and caregiver mental health? Are there certain abilities or characteristics that make a child resilient, so that the impact of having a caregiver with mental health difficulties is less than might otherwise be expected?

Knowing more about exactly how caregiver and child mental health are connected is clearly important for the design of more creative, and more effective, interventions. Below, we describe some of the main strands of research that are contributing to this



knowledge and informing the development of new intervention and support strategies.

### Interpersonal Relationships and Interpretations

**Early Interactions.** How a primary caregiver understands and responds to her infant's behavior has implications for the caregiver's own mental health and functioning as well as for the baby's development. Mothers with schizophrenia or depression are more likely than their peers to be withdrawn, and less sensitive and responsive to their infants.<sup>4,1,12</sup> In turn, this is associated with infant unresponsiveness, as well as fussiness and disturbed sleep. And of course, a fussy, sleepless infant places a high level of demand on his or her mother, thus contributing to caregiver distress. A mother whose child is fussy or unresponsive may come to feel ineffective as a parent, blaming herself and

further increasing stress.<sup>4</sup> This type of interactional pattern is stressful for the infant as well, and increases the risk that the baby will develop ongoing difficulties in regulating his or her emotions and interacting with others.<sup>4,12</sup> A number of successful programs have responded to these kinds of findings by screening pregnant women and new mothers for depression, and offering support and treatment that helps prevent an escalating cycle of mother-child distress during this critical early childhood period.<sup>12,8</sup> The article by Carrie Mills and Anne Riley describes some of these strategies in more detail. (See page 28.)

As is typical of the broader literature on caregiver-child influences on mental health, this research seems to tell a story in which the problem starts with a mother who has mental health difficulties. Yet it is also quite possible to envision a different scenario, in which the experience of mothering a very difficult baby actually initiates feelings of inadequacy or depression in a mother. Regardless, the reciprocal nature of caregiver-infant interaction provides a good illustration of how, in the absence of any sort of buffering or intervention, distress in caregivers and infants can become amplified in their interactions with each other.

**Discipline.** Caring for a child with behavioral difficulties—including caring for a child with ADHD—presents ongoing challenges for caregivers, and greater stress in the parenting role.<sup>4,5,10</sup> If the child has difficulties in emotional regulation, he or she may be particularly challenging to parent effectively. If the caregiver has ADHD, this may create additional challenges in providing appropriate emotional response, as well as consistent discipline and follow through.<sup>13</sup> Having schizophrenia or depression can also make it difficult for a caregiver to provide consistent, firm, involved discipline.<sup>4,12</sup> If the caregiver has difficulty providing consistent discipline, the child's behavior may become yet more challenging.

**Family Interactions.** Maternal mental health difficulties and child emotional or behavioral difficulties each affect, and are affected by, other

stressors within the family. This can lead to patterns of interaction that exacerbate stress and conflict within the family and between parents, which in turn can decrease the quality of child discipline and increase child behavioral and emotional difficulties.<sup>4</sup> Rates of divorce and separation are elevated among adults with mental illness and among those with ADHD,<sup>10,3</sup> and it appears that rates are high among parents of children who have significant emotional or behavioral disorders as well, though this has not been formally studied.

There is a wide variety of treatments aimed at improving caregiver-child interactions. In general, it appears that providing treatment to a mother and (separate) treatment for her child at the same time enhances the effectiveness of both treatments.<sup>4</sup> However, newer approaches more explicitly exploit the mutual influences between children and caregivers by treating both within the same intervention. Evidence is emerging for the effectiveness of several of these programs,<sup>4,12</sup> and research on these programs is contributing to understanding not just how parent and child mental health influence each other, but also which specific factors in the family context work to amplify or reduce these mutual influences. As Elgar and his colleagues put it, "...each mechanism that mediates [these] mutual influences... is a fulcrum of better interventions"<sup>4</sup> (p.452). An important recent study, which examines mutual influences as well as these "mediating" factors, is described in the article on Early Head Start by Catherine Ayoub and Rachel Chazan-Cohen (page 15).

### Social and Economic Resources

Rates of mental health difficulties and diagnoses are higher among people with low incomes than among people with more economic resources. This is very much true for caregivers with depression. The rate of depression among mothers generally is estimated to be between 5 and 25 percent; however, for mothers with low incomes, the rates appear to be in

the 40 to 60 percent range.<sup>8</sup> While not as well documented, it appears that depression rates are also high for fathers and grandparent caregivers with low incomes.<sup>8</sup> The article by Sandra Bailey and Bethany Letiecq (page 22) focuses on depression among grandparent caregivers in rural Mon-

tana, many of whom have very low incomes. The article also focuses on Native American grandparent caregivers, who suffer from higher rates of depression than their majority culture counterparts.

Caregiver or child mental difficulties can both contribute to and be exacerbated by economic difficulties, which in turn can exacerbate caregiver and child distress. For example, it is well recognized that having mental health difficulties can make it hard for a person to obtain and maintain employment. It is much less well recognized that having a child with emotional or behavioral challenges can also make it hard for a caregiver to maintain employment. A caregiver's work can be constantly interrupted due to the high levels of parenting demands and the ongoing need to interact with service providers, including day care facilities and/or schools.<sup>2</sup>

Unfortunately, caregivers with low incomes often lack access to mental health care.<sup>8</sup> What is more, treatments that are available often have low rates of engagement and retention among these caregivers. Kris Gowen (page 17) reviews some studies that examine reasons for this apparent mismatch between available services and the needs and preferences of depressed women with low incomes. Interventions that respond more appropriately to the needs and circumstances of caregivers with low incomes can be quite effective, however.<sup>8</sup>

In general, strong social support and interpersonal relationships act to buffer people from various risks and adversities. People with mental illnesses are likely to have fewer interpersonal relationships and less social

support than their peers. This is also true of caregivers of children with emotional or behavioral disorders,<sup>9,11</sup> who are often shamed and shunned because of their children's behavior. There is some evidence that support groups and various forms of supportive therapy may be helpful in promot-

ing positive maternal-child interactions, particularly where parenting stress is high.<sup>12</sup>

### Mobilizing Positive Influences

Knowing about risks—and about processes that contribute to risk—draws attention to negative outcomes. However, various studies have shown that many children of parents with mental illnesses are resilient. Like Felicia Brown, whose story begins on page 20, they are successful across life domains, including education and interpersonal relationships.<sup>1,12</sup> Indeed, having a parent with a mental illness appears, at least for some children, to confer—or to promote the development of—possible benefits ranging from increased empathy<sup>1,12</sup> to increased creativity.<sup>7</sup> The assets and capacities that promote resilience can be found in children, in parents, and in the family system and its social environment. Thus, the risk of difficulties in children is likely to be much decreased if a mother with a mental illness has effective parenting skills, stable family relationships, and a high level of partner support and social/financial resources.<sup>12</sup> From studying resilience, researchers have developed interventions to help parents who have mental illness promote resilience in their children.<sup>1</sup> These interventions appear to have success not only in preventing emotional or behavioral difficulties in children, but also in reducing parent guilt and improving family communication.

Other, newer interventions have been developed in order to mobilize positive impacts through the various pathways of mutual influence. Thus

*Strong social support and interpersonal relationships act to buffer people from various risks and adversities.*

we see promising newer interventions that treat caregivers and their children simultaneously, and/or that work to support enhanced interaction or bonding between caregivers and children (or between family members more generally).<sup>4,12,8</sup> Other recent interventions have achieved initial success at least in part through a focus on increasing parents' social support and peer networks.<sup>8</sup> In short, "Just as there is evidence that untreated problems in children or mothers can deleteriously influence the health of the other, there is also evidence that interventions that exploit these [mutual] influences can extend the benefits of individual treatments to other family members"<sup>4</sup> (p. 453).

Perhaps most interesting, yet still relatively unstudied, are programs that offer comprehensive support and intervention. These programs are designed to respond holistically—and in an individualized manner—to the needs of families in which a parent has a mental illness, and thus mobilize a variety of positive influences and factors to impact caregiver and child mental health. Such programs include attention not just to family relationships, but also to promoting family members' successful participation in social and community settings, including school and employment. Chip Wilder and Betsy Hinden (page 7) provide a description of one such program, while "Mary" (page 10) gives a personal perspective on what it is like to be a program participant. Finally, Joanne Nicholson, Kathleen Biebel, Valerie Williams and Karen Albert (page 11) summarize findings from a research project designed to identify the essential characteristics and components of these kinds of comprehensive programs to support parents with mental illness and their families.

Despite the variety of emerging intervention and support approaches, there is an obvious need for much further work. In particular, there is only sparse research on caregivers other than mothers, or on interventions that include a focus on building resiliency or bolstering social support. The more comprehensive programs are also not yet well evaluated. And while some attention has been paid to developing treatment approaches that

engage low-income parents and parents from ethnic or racial minorities, this is another area where research is thin. Continuing efforts in research and program development will be needed to help build effective strategies for supporting positive mutual influences between caregiver and child mental health.

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## Author

Janet Walker is Co-Editor of *Focal Point* and Director of Research and Dissemination at the Research and Training Center on Family Support and Children's Mental Health at Portland State University.

## Family Options: Supporting Parents with Mental Illness and their Children

**T**he heat rushed out around the loose windows in Ann's sparse, but immaculately kept apartment. February's heating bill would be more than her disability check, and her phone had been disconnected for a month. Her depression and anxiety prevented her from getting to the grocery store without a companion. She was preoccupied by her 12-year-old son, Billy, who had recently transitioned to day school from his residential program, but was missing a lot of school and getting suspended. Years before, when Ann's illness was severe and there was domestic violence in the home, Ann's two other children had been placed in foster care. These experiences left Ann distrustful and intensely fearful that Billy would also have to go away. With all of these stressors present in her life, Ann found it very hard to talk at meetings with the service providers. Billy's therapist felt ineffective, and when wraparound and intensive, home-based services were attempted, the team reported that Billy would not engage and that Ann did not seem to be able to learn new parenting strategies.

### Parents with Mental Illness

Like other parents, parents in re-



covery from mental illness report that the parenting role is a primary and positive life role, and that they want to be the best parents they can be. They express the same joys and concerns about parenting and their children as parents without psychiatric diagnoses.<sup>3</sup> Families in which parents have mental illness are often the same families in which children have severe emotional or behavioral challenges. These families represent a substantial subgroup of families participating in children's systems of care, and tend to have poorer child functioning and

greater caregiver strain at intake, and over time.<sup>1,2</sup>

Many forms of intensive support, such as home-based services and wraparound, are predicated on active parent involvement. Active parenting is particularly difficult for parents struggling with psychiatric symptoms and the social and environmental conditions (e.g., stigma and poverty) that accompany mental illness. Effective service delivery for these families requires modification and enhancement of currently existing wraparound processes to reflect and respond to these families' unique experiences and complex needs. The *Family Options* program is an innovative effort to fill this gap and to advocate for systems change with respect to the needs of parents with mental illness and their children.

### Family Options

*Family Options* is founded upon the belief that recovery from mental illness is a family process, and that parenting and family relationships are a critical part of recovery. *Fam-*

ily Options is organized in accordance with two mutually reinforcing mental health care delivery approaches: one typically used with adults, and one used with children and their families. The first approach, psychiatric rehabilitation, is a strength-based, recovery-focused approach that emphasizes empowerment of adults with mental illness to manage life tasks successfully through resource and skills development.<sup>4</sup> The second approach, wraparound, is a conceptually allied approach used with children and their families. This blending of models with parallel values and principles from child and adult service sectors allows *Family Options* to provide effective strengths- and community-based care that identifies and responds to the needs of parents who are recovering from mental illness, and to the needs of their children.

### Families, Staffing and Components

Referrals to *Family Options* come from both the child- and adult-focused service sectors, with the majority from child welfare. Parents report a range of primary diagnoses, with 69% reporting a history of trauma co-existing with other psychiatric diagnoses. A family is eligible for the program if the parent has a diagnosis of major mental illness, is receiving mental health treatment, and has a child between the ages of 18 months and 17 years living at home. Fifty-six percent of the children involved with *Family Options* meet criteria for a range of mental health diagnoses, and 58% are involved with special education services. Seventy-five percent of the children have Medicaid as their primary health insurance.

*Family Options* is currently staffed by a director with extensive wraparound experience; three family coaches, each of whom works with a maximum of eight families at a time; a parent peer coordinator; and a consulting research and clinical psychologist. *Family Options* has developed a model in which the family coach has three central functions: 1) to identify and prioritize, with the parent, the needs and strengths of each family member; 2) to work with the parent



to build a trusting partnership that supports learning and skill-building related to identified family strengths, needs, and recovery goals; and 3) to provide a wraparound team process that is enhanced by the parent–family coach relationship and by procedural modifications that provide a safe, manageable, and highly supported role for the parent. *Family Options* also has a 24-hour, 7-day-a-week support line; a parent support group; and flexible funding to support activities essential to successful outcomes for each family.

### Family Coaching

Parents recovering from mental illness often feel deeply betrayed by and suspicious of providers, and this is particularly true for parents for whom child custody loss is, or has been, a threat. To overcome this distrust, the family coach meets weekly with the parent to focus on parent-driven learning, behavioral modeling, direct support, and skill-building experiences. Trust and partnership develop as parents and children learn that they can rely on their coach to be available when needed—to listen, to respond, and to support. Sometimes the coach responds by “doing for” families, but more often the coach helps families develop strategies and skills, or supports them to make connections to community resources so they can “do for themselves.”

Initially, Ann’s family coach needed to understand and respond to Ann’s anxiety about paying utility bills and rent, going to the supermarket, and getting Billy off to school. This required the coach to access flexible funds, accompany Ann to the market, and provide last-minute transportation on school mornings. As the partnership developed, Ann was able to work with her coach on longer-term, sustaining goals, such as finding affordable housing and finding ways for Ann to get Billy off to school without outside help.

### Family Teams

In order to be effective with this population, the *Family Options* program has modified the “traditional” wraparound team planning process. While preserving wraparound’s commitment to a strengths-based, need-focused, parent-driven, collaborative team process, the *Family Options* model requires that coaches have additional areas of knowledge and skill. Parents with mental illness are often socially and personally isolated due to their histories and mental functioning, as well as social stigmatization and the system’s unresponsiveness. The coach’s efforts to establish a trusting partnership—through supportive, parent-driven learning and skill building—creates a critical bridge for the parent’s participation in the family team process. In addition

to doing careful team preparation and debriefing with the parent, the family coach must be knowledgeable about the process of recovery, understand and support the symptomatic and environmental challenges that can compromise parenting in general and parent participation on the team in particular, address the real life needs of the parent and her children, and structure the meetings to maximize parent participation.

Another modification includes the family coach's role in educating team members about mental illness and its relationship to parenting, and advocating for strengths-based strategies that appreciate and respond to these needs. In spite of the need to overcome Ann's distrust of Billy's school, her coach was unsuccessful in getting the school to understand and respond differently to Ann's trauma-based trust issues. Instead, Ann and the family coach worked with the local school district to transfer Billy to a different school where the staff was able to engage Ann, and this resulted in her agreement to bring the school into the team process.

In addition, for families affected by mental illness, family teams must have the capacity to give equal focus to the needs of parent and child recovery. Family coaches must, therefore, work to engage both the adult's and the child's formal and informal resources in the team process. Family coaches' access to adult team resources is facilitated by *Family Options'* location in an adult clubhouse, a self-help program in which staff and members who have a mental illness work collaboratively to achieve members' employment, educational, housing, and social goals.

### Transition Planning

Since recovery for both parent and child is not a linear process, *Family Options* provides careful post-program transition planning. Acknowledging the mutual importance of the parent-family coach relationship, and recognizing and celebrating the skills and accomplishments of the parents and children, are important transition activities. As Ann remarked, for a long time there were only two people she

could talk to: her coach and God.

Secure housing, public sector case management, effective treatment, and strengthened informal supports have been some of the important components of transition planning. Ann's and Billy's transition planning will focus on solidifying the relationship between parent and school, and securing affordable, safe housing and effective mental health treatment. *Family Options* offers post-program supports that can include continued participation in the parents' group and less intensive access to family coaching.

Families in which parents have a mental illness and children experience emotional or behavioral difficulties/disorders pose challenges to children's systems of care, requiring modification and enhancement of service delivery processes to meet their complex needs. *Family Options* advocates for systemic expansion of programming for this population and for the re-alignment of child and adult mental health services to reflect a family recovery approach to care delivery.

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### Authors

**Betsy Hinden** is Program Consultant for *Family Options*.

**Chip Wilder** is Director of *Family Options*.



## Family Options & Recovery from Mental Illness: A Parent's Perspective

**F**amily Options provides psychiatric rehabilitation and wraparound family teams for parents with mental illness and their children. Mary (a pseudonym) talked about her experience as a parent with mental illness, her recovery, and her experience in *Family Options*. “Six months before I started *Family Options* I was very depressed, suicidal, hearing voices, and having flashbacks; my kids were out of control; and my apartment was atrocious.” Describing the home-based services she received before *Family Options* Mary reported, “She [the home-based clinician] helped out with behavior charts and plans about cleaning up the house, but the kids did not follow through. It didn’t work. I was too depressed to do anything.”

Child welfare referred Mary to *Family Options* at a time when she had to move. Mary said, “Linda [Mary’s family coach at *Family Options*] started to help me clean. She talked to the kids and got to know them. She helped me to move. She saved me \$1,800 by finding people from the club to help [*Family Options* operates out of a clubhouse program]. She even brought me to lunch and wouldn’t let me pay.” Mary continued, “It surprised me that Linda was giving me all this direct help. DSS [Department of Social Services] said she wasn’t supposed to but it felt really good that someone was helping



me because I felt too depressed to do it myself.”

### Mary’s Family Coach

Mary talked about her work with her family coach. “It took me a few months to trust Linda. I have flashbacks and depression. I have a hard time trusting people. With Linda, I decided what we would do. I really felt that she understood my pain and my worries. We talked about ways to handle my depression, and my kids, who have ADHD and bipolar disorder. She talked to me and helped me to calm down a lot.” Mary continued

that her family coach saw her “... fighting with my children. I was really embarrassed. I was afraid to have DSS see it but it was OK that Linda saw because she needed to see it so she could help me out.” Mary described how her family coach motivated her to accomplish tasks. “Linda motivated me to do things. At first she would clean the house when I couldn’t do much. Then she had me clean with her. One day Linda just held the bag open and said now I could do it myself. And now, I am doing it myself!”

Mary described how her connection to her coach and the program provided other support. “Linda kept urging me to call the [*Family Options*] hotline. At first, I did not want to bother anybody. I always do not want to bother anyone. But I was very depressed and suicidal, so I called it. The hotline was helpful because I knew the people, they knew my story, and adult conversation helped put me in reality and calmed me down.”

### Mary’s Family Team

*Family Options* staff, Mary’s coach, and the director conduct Mary’s wraparound family team meetings. The regularly attending members have been her mother, her children’s father, her child welfare worker, her children’s therapists, and the director of the youth and family service

program of her town. Periodically, school personnel have participated on the team.

"I thought team meetings would be a good idea," Mary reported, "because I wanted something done to help me focus more on my kids and my recovery. We worked on their behaviors and their responsibilities, their mental illness, and getting help with their behaviors in school and with each other... a lot had to do with mental illness."

Mary described her involvement with the team. "At first I was nervous. There were a lot of people and I didn't know what to expect. We talked about progress that had been made and things that still needed to be done." Mary's family coach would talk with her before meetings to determine what Mary wanted to make sure was addressed. Mary said, "Now, I

feel like I am being heard and listened to. It's better to have a team because we wouldn't get so far in school and counseling without one." Mary reflected, "I am more outspoken now than before... a good thing... I got comfortable with the people in the meeting."

### Recovery

Mary discussed the changes that occurred since her family began *Family Options*. "I have a job now. I don't need to call the hotline as much. I am getting more sleep and I'm not yelling as much at my kids." She continued, "I can calm myself better than before. And I have healthy goals for myself and my family now." She added, "I do feel that *Family Options* goals are the goals that I want to get done and I have not had that experience before

with other programs."

Mary talked about her recovery from mental illness. "Recovery for me is healing; work; going to counseling two times a week; coming to *Family Options*' parent group and the clubhouse; making sure my kids are in counseling; getting as much support as I can; and paying attention to my health and losing weight. Recovery is in my hands. It's time... no one can change me but myself...and I know that I can do it!"

Mary concluded that for recovery, "You have to have good therapy and people that can empathize. Linda is awesome. She is like a good friend even though she not a friend. She always talks to me and helps me out. And definitely *Family Options* is about people that listen to you, that walk the walk, not just talk the talk."

## Building the Foundation for the *Family Options* Project

Adults with mental illness in the U.S. are as likely to be parents as those who are not living with mental health disorders. Over two-thirds of women and about three-quarters of men with serious and persistent mental illness (SPMI) living in the community are parents.<sup>8</sup> Often, parents have mental illnesses that occur in combination with other mental illnesses, substance use disorders, or physical health conditions as well. In secondary analysis of data on biological parents of children with serious emotional disturbances receiving services in systems of care programs, 52% had a biological family member with a history of mental illness, 59% had a family member with a history of substance abuse, and 36.5% had histories of both mental illness and substance abuse disorders.<sup>1,6</sup> Family disruptions—parent-child separations and permanent loss of contact or custody—may also be common occurrences in families where parents have mental illnesses.<sup>9</sup> Data from various



small-scale studies indicate that 25% to 75% of mothers with mental illness no longer have custody of their children.<sup>7</sup>

### Overlapping Needs

The needs of families in which a parent, and sometimes a child as well, has a mental health condition are complex and intimately intertwined, requiring an array of services and supports. "Family-centered treatment" has evolved as a concept in the children's mental health services world. The Comprehensive Mental Health Services for Children and Families Program has led to the development of intensive, community-based approaches such as systems of care and wraparound services, tailored to meet the needs of children with the most serious emotional and behavioral difficulties. However, the unique needs of their parents are not necessarily addressed through these programs.<sup>4</sup> Thus, parents with mental illnesses are likely to be members of families that use multiple, uncoordinated services in both the child and adult service sectors, or who receive no appropriate services at all. While the former

comes at great cost to public and private payers, the latter potentially cost even more to society, as communities and family members themselves bear the costs of untreated mental illness.

The needs of adults as parents are not necessarily a focus of evidence-based practices in mental health. The Assertive Community Treatment (ACT) model, typically touted as the “state of the art” case management model for adults with serious mental illness, is embraced by many state mental health authorities as the model of choice. However, parenting is not routinely identified as a desired role for adults with mental illness, nor are treatment goals relevant to parenting typically set by ACT team members.<sup>2</sup> Previously-tested parenting interventions do not consider the characteristics and concerns of adults with mental illnesses.<sup>10</sup> Parents with mental illness often find these models irrelevant, as they do not address the illness-specific issues parents identify. However, intervention strategies can be drawn from these models, combined with one another, and tested for effectiveness among parents with mental illnesses.

In a national review of existing programs for parents with mental illnesses and their families, which included program surveys and site visits, program participants, staff, and collaborating providers identified essential intervention characteristics and components.<sup>12,3</sup> Regardless of theoretical orientation, providers and family members across programs attributed successful outcomes for parents and children to a family-centered, strengths-based approach to intervention. That is, the entire family, rather than an individual adult or child, is the “unit of service.” Parents and family members are engaged in a process that focuses on building on strengths, rather than emphasizing deficits or failures. Essential intervention components include: (a) availability of and access to formal services and natural community resources to meet basic needs; (b) coordination of multiple services and providers when their involvement is necessary, and the facilitation of communication among multiple providers; (c) emotional support in the context of trusting relationships with providers

and peers; (d) flexible funds to provide concrete assistance, and meet unique family and individual needs; (e) availability of staff, 24-hours a day, seven days a week; and (f) education for parents regarding child development, parent-child relationships, and parenting tasks.<sup>12,13</sup> Potential outcomes include enhanced well-being and functioning; and supports and resources for adults, children, and families. These outcomes may be reflected in variables such as a decrease in emergency hospitalizations for parents, a decrease in out-of-home placements for children, increased employment for adults and improved school attendance for children, better access to medical and mental health care, greater parent competence, and enhanced child safety.

We have added trauma-informed interventions as an essential approach to working with these families.<sup>9</sup> For families receiving services in systems of care, a family history of mental illness and/or substance abuse is associated with other child and family risk factors, including child physical or sexual abuse, child psychiatric hospitalizations, child history of substance abuse, and history of domestic violence within the family.<sup>5</sup> Adults living with mental illnesses often have histories of violent victimization, or are currently at risk.<sup>9,15</sup> Strategies for engaging and sustaining helping relationships in interventions with these families must be informed by the likely impact of trauma on the ability and willingness of those who have experienced violence to participate.

### The Employment Options/ University of Massachusetts Partnership

The *Family Options* pilot program and research studies were born out of a long-standing partnership between Employment Options, Inc., a psychosocial rehabilitation agency in Marlborough, MA, and the University of Massachusetts Medical School’s (UMMS) Center for Mental Health Services Research. This partnership is unique in its duration and productivity. Lead personnel and staff have worked together for over a decade on behalf of individuals and families living with mental illnesses. Lead per-

sonnel from each organization serve on the advisory groups for the other organization, and work together to identify and bring new initiatives to fruition.

### Highlights in a Program of Research

1995: UMMS conducted focus groups with mothers with serious mental illnesses and case managers from the Massachusetts Department of Mental Health to identify the challenges these parents face.<sup>13, 14</sup>

1997: The National Institute on Disability and Rehabilitation Research (NIDRR) funded the four-year Parenting Options Project. This important project, which involved consumers in all aspects of design and implementation, resulted in the development and distribution of a series of newsletters and fact sheets for parents and providers, as well as numerous presentations and publications, including *Parenting Well When You’re Depressed: A Complete Resource for Maintaining a Healthy Family*.<sup>11</sup>

1999–2002: UMMS received funding from the Substance Abuse and Mental Health Administration (SAMHSA) to conduct survey and site visit studies of interventions for families living with parental mental illness. This was the first step in an effort to begin developing an evidence base by identifying common and effective program components.<sup>12,13</sup>

2002: Employment Options, Inc., with the technical assistance of the UMMS Center for Mental Health Services Research, was awarded a Community Action Grant from SAMHSA for the community consensus-building initiative, Strengthening Families’ Recovery from Mental Illness. Local stakeholders were engaged in the process of considering the feasibility of implementing an intervention for families living with parental mental illnesses. Through a consensus-building process, existing program models were reviewed, determination was made to pursue development and implementation of a similar intervention, a strategic plan was created, barriers to intervention implementation and participation were identified, and relevant modifications were recommended for the development of the

## FAMILY OPTIONS RESEARCH STUDIES

In the Fall of 2005 UMMS received funding to study the *Family Options* program. UMMS is currently conducting parallel implementation and outcomes studies.

### Program Evaluation Study

*Principal Investigator: Joanne Nicholson, Ph.D.*

Using a developmental evaluation model, the experiences of and outcomes for parents and their children are being studied. Findings will contribute to refinement of the program logic model.

- The intervention group is being compared with those receiving "services as usual" in a comparable community sample.
- Blended qualitative and quantitative methods are being used.

### Program Implementation Study

*Principal Investigator: Kathleen Biebel, Ph.D.*

The implementation study documented the process of implementing *Family Options* within *Employment Options*, studying the agency's paradigm shift from serving individual adults to working together with families over almost two years.

- Community stakeholder agency interviews were conducted to collect information about services available to families and eligibility criteria for those services, so that information could be used to develop a resource guide for program staff and families.
- Focus groups with program and agency stakeholder groups were conducted to assess the organizational climate of Employment Options in regard to the acceptance of and readiness for the new *Family Options* program.
- Key informant interviews were conducted to identify and describe key domains critical to the implementation of the program.

Findings will contribute to the national scientific dialogue about the implementation of evidence-based practices, as well as facilitate the replication and further testing of the *Family Options* model by providing broader guidance and greater specificity regarding implementation challenges of and strategies for the standard operating procedures document.

For more information about *Employment Options* programs: <http://www.employmentoptions.org>

For more information about UMMS/CMHSR research on families living with mental illnesses:

<http://www.umassmed.edu/Content.aspx?id=38838> and [www.parentingwell.org](http://www.parentingwell.org).

*Family Options* model.

2005: The *Family Options* project began.

### Service Program Highlights

1995: The original Family Project was first implemented by Employment Options, Inc. The program provides supports to non-custodial parents, including parent education and peer support, liaison with other programs and agencies, and visitation with children. Funding has been provided over the years by the Massachusetts Department of Mental Health and the United Way.

1999: The Clubhouse Family Legal Project was established. The project is a collaborative effort of Employment Options, Inc. and the Mental Health Legal Advisors Committee in Boston. The program provides pro bono legal representation to low-income parents with mental illness. In addition to providing legal referrals and direct legal counsel in family law cases, the Clubhouse project leads advocacy efforts in the legal system on behalf of persons with mental illnesses. Funding for the program is provided by Massachusetts Bar Association and Massachusetts Department of Mental Health.

2005: Employment Options Inc. and the UMMS Center for Mental Health Services Research received funding for the development, pilot testing and refinement of *Family Options* for parents with mental illness and their families. (See box.)

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## Authors

**Joanne Nicholson** is Professor in the Department of Psychiatry at University of Massachusetts Medical School, Associate Director of the Center for Mental Health Services Research, and Principal Investigator of the *Family Options* research projects.

**Kathleen Biebel** is a research assistant professor and Co-Investigator of the *Family Options* projects.

**Valerie Williams** is a research instructor, and Co-Investigator and Statistical Analyst for the *Family Options* projects.

**Karen Albert** is Project Director for the *Family Options* projects.

## Promoting Maternal and Child Well-Being: Research from Early Head Start

Pregnancy and the post partum period have been associated with episodes of significant clinical maternal depression, particularly for women who lack economic resources. The effects of depression on new mothers can lead to difficulties in parenting, which, in turn, place children at risk for longstanding impairment.

We believe that Early Head Start and Head Start programs offer one important vehicle through which to identify and address depression in a context of enhancing parenting and parent-child relationships. This notion is confirmed in a recent evaluation of Early Head Start (EHS), a program that serves young children (ages one to three) and their families, providing child development services and parent support through services such as parenting education and/or home visits. Seventeen Early Head Start programs were selected to participate in the national study. Sites were selected according to proportional national geographic distribution, representation of major programmatic approaches and settings, and a diversity of family characteristics typical of Early Head Start families nationally. Sites were also selected on the basis of the strength of the local research team.

The 17 EHS research programs recruited 3,001 families to participate in the evaluation. Programs were expected to recruit the same way they would have done in the absence of the research, with special instructions to include all types of families they were designed to serve (including those whose babies had disabilities). Children and families were randomly assigned to the program or control group by a national contractor. Control group families did not receive EHS services, but could access other services in the community. Sample enrollment, baseline data collection, and random assignment began in July 1996 and were completed in September 1998.

The Early Head Start Research Project found a high rate of depressive symptoms in both mothers and



fathers. At the time of enrollment, about half scored higher than the clinical cutoff for depression. One third of mothers of 1-year-olds and one third of mothers of 3-year-olds had elevated symptoms. For some women (12%), depression was chronic; that is, these mothers scored over the clinical cutoff both when their children were 1 and 3 years old. Rates of depressive symptoms for EHS fathers were also notable. Eighteen percent of EHS fathers reported enough symptoms to be considered depressed when children were 2 years old; 16% met those criteria when their children were 3 years old. At the time of exit from EHS (when the children were 3 years of age), 23% of the families reported that at least one caregiver had received mental health services. Twenty-one percent reported that a caregiver had received treatment for an emotional or mental health problem, and 5% reported that a caregiver had received drug or alcohol treatment. Thirty-two percent of mothers who were depressed at enrollment reported that at least one caregiver had received mental health services.

Comprehensive, continuous programs like Early Head Start have demonstrated effects on helping parents and their children. The evaluation study showed that children in EHS

were protected from some of the negative effects of their parents' depression, as illustrated by their outcomes at age three and again before they entered kindergarten. First, the EHS research found that, among children who had a depressed parent, children who were in EHS had lower levels of aggression and scored better on the Child Behavioral Checklist (CBCL) than children who were not in EHS. Children in EHS also demonstrated higher vocabulary levels and were reported to have higher levels of engagement and attention. In other words, program participation enhanced positive outcomes for a child experiencing parental depression. In addition, compared to the control group, those depressed mothers who were able to enroll in EHS were more positive and less negative in interactions with their children. This is what we have called a change in the parenting context of the depression for families receiving EHS services. These findings, in part, led to the Early Head Start Infant Mental Health initiative, a search for ways for programs to address mental health more directly.

In addition, when children were approximately 5, two years after the end of the program, for the first time there was an impact of Early Head Start on reducing maternal depression. While statistically significant, the impact was modest (effect size = .10).<sup>1</sup>

We conducted analyses to explore what earlier impacts of the program led to this later-emerging impact on maternal depression. This study affirmed what had been shown previously in other studies: Child behaviors and abilities can exacerbate later maternal depression, and conversely, interventions that improve child outcomes appear to have an indirect buffering effect on maternal well-being as well.<sup>2,3,4,8</sup> These findings highlight the importance of focusing on child development within supportive interventions.

The range of family factors that could act to buffer or exacerbate ma-

ternal depression included positive factors such as maternal supportiveness during play, support for learning and development in the home environment, and daily reading and reading at bedtime. Family risk factors that exacerbated maternal depression included family conflict, parenting stress, and parent report of physical punishment. The study showed that the EHS program reduced some of these negative factors.

Similarly, the study identified child factors—behaviors and abilities—that either buffered or exacerbated maternal depression. Positive behaviors or abilities included cognition and vocabulary as well as child engagement with parents during play. Negative factors included parent report of aggressive behavior in the children as well as child negativity toward the parent during play. When all of these child factors are combined, only aggression and cognitive functioning remain significant. These findings support the literature showing that while child aggression is clearly very salient in terms of parent well-being, and echoes the linkages between child difficult temperament and maternal depression, children's vocabulary and cognitive abilities are also important mediators of maternal depression.<sup>2,3,4,5</sup>

### What are the Implications for Program Development?

Jane Knitzer and her colleagues<sup>6</sup> suggest three categories of emerging efforts to address depression in the context of parenting young children. These are: screening and follow-up for women in obstetric and pediatric practices; targeted intervention to reduce maternal depression and improving parenting through home visiting and EHS; and promoting awareness to the general public about the impact of maternal depression, with an emphasis on low-income communities and health and early childhood practitioners.

It is increasingly clear that maternal depression is a barrier to ensuring that young children experience relationships that will provide them with the potential for healthy development and enhance their school readiness. Knitzer proposes that we continue to build on family-focused, multi-generational, culturally responsive ap-

proaches that bring together resources from multiple public systems.

Knitzer offers “on the ground” examples of programs that address maternal depression in early childhood settings. The first is the Family Connections Project, based in Boston, which is a strength-based prevention project that builds competence and resilience in Head Start and Early Head Start staff in order to strengthen staff's ability to engage around issues of depression and adversity. As a system-wide program it also directly enhances parent engagement and parenting skills, strengthens meaningful teacher-child interactions, and identifies and plans for needed services through training and mental health consultation. The second program, Every Child Succeeds, based in Cincinnati, embeds cognitive behavioral therapy into three different home visiting models. The third example is the Community Mom's Program in New York City, which provides health education workshops, support services, home visiting and screening, and referrals for depression. Finally, the Louisiana Nurse-Family Program augments the standard nurse intervention with extra training and with mental health professional consultation in order to deal with depression and other mental health issues.

We know that parental emotional distress and depression can in many cases be mitigated by consistent, high quality services targeted at families with young children.<sup>7</sup> Our work is to continue to build from the information that we have been given through research and to put this knowledge into practice in early childcare and health care settings.

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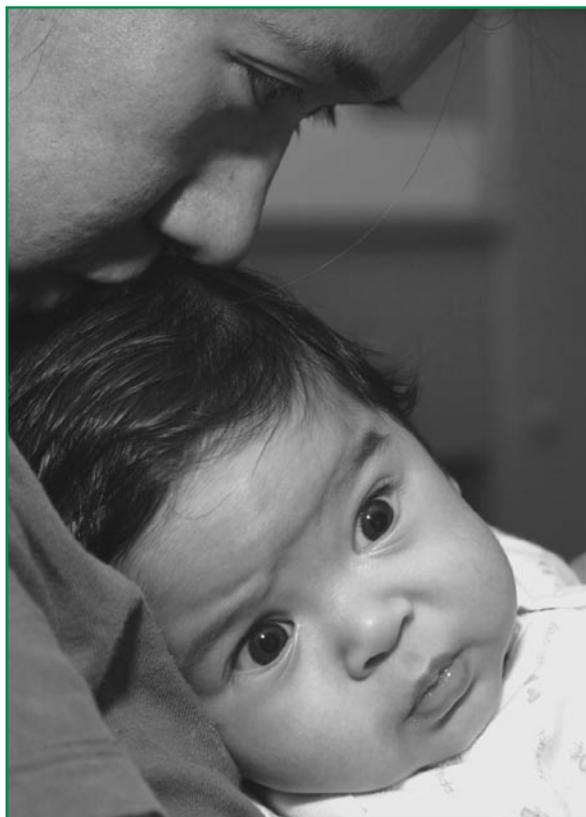
**Catherine Ayoub** is an associate professor at The Harvard Medical School with affiliations at Boston Children's Hospital and Massachusetts General Hospital.

**Rachel Chazan-Cohen** is a senior research analyst in the Office of Planning, Research and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services.

## "You'd Be Depressed Too": Treatment Acceptability among Mothers who are Economically Disadvantaged

Although mothers who are economically disadvantaged have high rates of emotional distress, the rate of their use of mental health services is relatively low. What accounts for this underutilization of care? Although there is evidence that insurance coverage and access to care account for some of this disparity, barriers to mental health services reach beyond basic access issues. When considering why some choose to seek mental health care while others do not, it is important to consider treatment acceptability among low-income mothers.

Treatment acceptability is the extent to which recipients of care perceive that care as "reasonable, justified, fair, and palatable" (p. 158).<sup>5</sup> In other words, it is not enough to make care accessible; it also has to be acceptable, or relevant to the consumer. And the more consumers view treatment as relevant or important, the more likely they are to work to overcome other barriers to seek mental health care. After all, mothers are more likely to overcome obstacles in order to get the care needed for their children than they are to get care for themselves.<sup>3</sup> Therefore, other factors



must play a role in order to explain why low-income mothers do not get care for their own mental health.

One of the best studies addressing mental health treatment acceptability in low-income mothers was conducted by Carol Anderson and her colleagues.<sup>1</sup> Researchers interviewed 127 women who initiated treatment for their children at one of four community mental health centers based in disadvantaged communities. Of these women, 40% were African-American. The women had an average of 2.6 children, and more than half had a household income of less than \$15,000. Based on a routine screening,

all interviewees met the criteria for significant mood and anxiety disorder and were referred for mental health services—yet only 29 had seen a mental health professional in the past two months.

The interviews explored the mother's view of her life, problems and distress; her response to being diagnosed and referred for mental health services; and the reasons why she did or did not seek treatment following her referral. Overall, the study identified four themes that were connected to mothers' reluctance or refusal to accept mental health treatment: (1) agreement with diagnosis; (2) perceptions of the causes of the distress; (3) reactions to being referred for mental health treatment, and; (4) perceptions of their children's and other mental health services.

### Agreement with Diagnosis

Virtually all the women interviewed agreed with the assessment results that suggested they were depressed or anxious. Simply disbelieving their diagnosis was not a barrier to seeking care. So, lack of care was due to either access or acceptability issues,

or a combination of the two. Because access issues seemed to be less likely in this sample, given that (1) these mothers were getting care for their children, and (2) they had a referral and place to go to get mental health care, it appears that other acceptability factors were a barrier to receiving mental health treatment.

### Perceptions of the Causes of Distress

Depression and anxiety are internalizing disorders; that is, they are generally understood as mental health conditions that originate from within oneself. However, the women interviewed by Anderson and her colleagues did not see the origins of their distress in this way. These mothers most often believed that their mental health status was a normal response to extreme external stresses. Taking care of a behaviorally or emotionally disturbed child was by far the most common and overwhelming stressor cited by the mothers. In addition, poverty and past and/or current abuse were cited as reasons for their distress. As one mother put it, "Walk in my shoes for one week. You'll be depressed too" (p. 930).<sup>1</sup>

In addition, many mothers were single and the heads of their households. Interviewees stated that this responsibility left them with little time to do anything but keep the home functioning. Some women expressed resentment of clinical labels of their mental health status, which they thought erroneously suggested that their distress was internally caused and not the inevitable result of their environment. Others believed it would be inappropriate or illogical for them to address their own needs before their child was well.

### Reactions to Being Referred for Mental Health Treatment

Believing in the effectiveness of mental health treatment is essential to engaging and remaining in care.<sup>2,5</sup> However, many of the women in Anderson's study did not believe that

counseling would help them. This was because these women more often than not perceived the reasons for their distress to be external causes. And, as mental health services usually address *internal* issues, this type of treatment was deemed to be irrelevant and therefore unacceptable.

These mothers believed that their distress would be relieved by improvements in their life circumstances, not through counseling or medication: "It was recommended that [I] go get counseling. ... And that, like in itself, ... in no way, shape, or form addresses the situation. I joked with my friend,

*Mothers believed that their distress would be relieved by improvements in their life circumstances, not through counseling or medication.*

I said, you know, that really irritated me. If they really want to make a difference here, throw \$10,000 at me" (p. 935).<sup>1</sup> These women viewed their depression and anxiety as natural responses to a difficult life. These findings offer insight as to why previous research has shown that both socioeconomic disadvantage and higher levels of stress are associated with lower levels of perceived treatment acceptability.<sup>5</sup>

### Perceptions of Mental Health Services

Finally, negative experiences with mental health services while caring for their children also biased mothers against seeking care themselves. Their interactions with their children's therapists led them to believe that the therapists had little credibility and lacked life experience. They also expressed frustration when clinicians did not appear to want their input as to what they believed was best for the child: "Why is it that we're [mothers] relegated to stupid status, you know, when we're the ones who really know what's going on?" (p. 936).<sup>1</sup> A strong, positive relationship between a parent and his or her child's therapist is associated with higher levels of treatment acceptability.<sup>5</sup>

Being a mother has many positive associations for women with mental health conditions. When asked what changes motherhood had brought to their lives, three fourths of a sample of women with various mental health diagnoses named factors that were positive in nature—that being a mother gave them a sense of pride and accomplishment, and caused them to change their habits and behavior for the better. In contrast, just over one third mentioned negative changes associated with being a mother, such as feeling angry and losing free time.<sup>6</sup> The importance and positive associa-

tions these women place on motherhood demonstrate that their relationships with their children are essential components to their well-being. Any perceived threat to this bond would be seen as a barrier to receiving mental health support. The distressed women from Anderson's sample expressed fear of being judged by professionals as inadequate caregivers. The professionals, they believed, had the authority to take their children away, if they were assessed as inadequate caregivers. Thus, many mothers became skeptical of mental health professionals: "I don't tell them [everything] because I don't know what they might try to do. I ain't that stupid" (p.937).<sup>1</sup> A lack of trust between a person and her therapist makes it difficult for them to work together to improve the situation.

### Increasing Treatment Acceptability

Treatment acceptability is an important issue to consider when examining why low-income mothers with mental health concerns are not seeking treatment. There is evidence that these mothers are reluctant to seek care because of a mismatch between their beliefs and those of mental health professionals regarding



the causes of their distress, and their negative perceptions of the usefulness and intentions of mental health service providers. The stories of these mothers suggest that a model of mental health that implies their symptoms of distress are evidence of an illness (and thus internal) may not fit with their perceptions and experiences that their distress is caused by a tough living environment. Additionally, this population needs more reassurance that mental health professionals understand their situations and are committed to helping them get the support and resources they need and not threaten their relationships with their children. Even though Anderson and her colleagues emphasized in their research that many mothers named their child's condition as a source of their own mental health difficulties, other research indicates that motherhood is a positive experience for women with mental health conditions and therefore may be a good strength to focus on during treatment.

Engaging mothers to address their own mental health needs requires a sympathetic understanding of their perceptions of the problems that underlie their distress. Grote and her colleagues developed a program specifically designed to engage and retain depressed women who are economically disadvantaged.<sup>4</sup> Using a combination of ethnographic and motivational interviewing, their

program aims to elicit and resolve a woman's reluctance towards coming into treatment. This involves taking into account the client's understanding of and explanation for her depression, which entails gathering information on social problems and chronic stress. Additionally, counselors in this program are instructed to consider clients' personal and cultural resources that have helped them cope thus far. Preliminary results have demonstrated higher levels of client engagement and retention when compared to standard treatments.

Working with both mother and child together may send the message that the counselor cares about all family members equally and wants to help preserve the family—not destroy it, as some clients may fear. When working with low-income mothers, focusing on finding sources of support to alleviate external stressors can be an important first step in the therapeutic relationship. This approach also conveys the understanding that many of the sources of their stress are externally based. This would ultimately enhance the therapeutic alliance between mental health service providers and low-income mothers. By working together to lessen the burdens these women face every day, it is possible that the family situation would become less stressful, and both the mother and child would remain in a treatment setting that felt relevant,

fair, and acceptable to the family.

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## Author

L. Kris Gowen is Co-Editor of *Focal Point* and a Research Associate at the Research and Training Center on Family Support and Children's Mental Health at Portland State University.

## A Daughter... and a Mom

**M**y name is Felicia. I'm 22 years old and work for the Tri-county health services department in Maine. I also go to college and hope to major in either social work or criminal justice. I'm engaged and the mother of an 8-month-old boy. I love to sing and have been in several plays at the community theater.

I grew up with a single parent, my mom, who struggled with alcoholism and probably the after-effects of childhood sexual abuse. She was a prostitute, and hooked up with a military guy in a one night stand. The result was me.

By age 5, I was sexually abused by three men. I never had a good relationship with men before my fiancée and that was definitely because of my mom—seeing men abuse and mistreat her and her letting them do all that. Because she was a prostitute,



if men didn't like what she gave, they wouldn't pay her or they would beat her. My grandfather abused me, and I think he abused her too. He was an angry guy, and I wonder if he passed that characteristic onto her. She had

drunken rages and abused me; she would beat someone if she couldn't find a drink. I think some of that could have been avoided if she had been more mentally stable. My mom needed all sorts of support, but no one was ever there for her. I can't help but think that if she had had a chance with foster care, she wouldn't have been the way she was.

While I lived with my mom, I remember my dad coming to visit me every once in a while and giving me presents. Then, when I was 7, I went to live with my dad. I don't really remember much about living with him, but it was more stable. He had a job and a good place to live. But that only lasted for about a year.

Then one day my mom called and said that she wanted me to come home. She promised she was done drinking and that my step dad wasn't

going to be around. She had just had a baby and wanted me to meet my new stepsister. I went back—but the whole thing was a trap. My mom stayed home for about a week when I first returned, and then she started to just leave us alone. She left me to take care of the baby by myself. She would come back every once in a while to give us food or money but would just leave again. So I was pretty much by myself.

I tried to keep going to school even though I had to take care of the baby. I would ask my neighbors if they could watch her when I wanted to go to school. I would say my mom had to leave early for work and make up excuses, but I think they knew what was really going on. Apparently—I didn't know this until later—the police were outside my house undercover for a while. The step father wasn't supposed to be around me, but he was coming in and out of the house and they saw that. They also saw that I was being left alone a lot. So, eventually the police came in and took me into foster care.

I lived with the same foster family for almost 10 years—until I graduated from high school. For me, it was a second chance at life. It was like being baptized. I didn't start making real connections until a few years into foster care, and after a few years of counseling. I was very angry and couldn't trust people. I mean, if you can't trust the person who birthed you, who can you trust? I would beat on people just like my mom. But I was lucky and had a lot of support that got me through some really rough times. My third-grade math teacher got me into singing—she encouraged me to audition for the elementary school choir and I got in and just kept on going. Then and now, theater is a great source of support. I have had all these people in my life that really cared—my foster family, counselor, teachers, my music instructors—they have been everything to me. They provided positive support by telling me that I was a good person. They gave me the positive reinforcement that I was lacking in my past life. My mom didn't have

any of that. I sometimes think about what could have happened to me if it weren't for them. I would be like my mom.

I had contact with my mom for the first 2 years I was in foster care. Then my mom and I got into an argument and we said we never wanted to see each other again. That was the last time I ever spoke to her. I see her about once a month now just walking around the neighborhood but I haven't talked to her. When I look at her, she looks out of it. She doesn't look well at all. I know she still drinks because I know the people who own the convenience store and they told me she comes in there every day to buy alcohol. Every once in a while, I would think of trying to talk to her, but when I learned she still drinks I changed my mind. My sister was adopted by a former teacher of mine. She lives a half hour away and I see her quite often. She's doing great—she really excels in almost anything she touches.

Now that I am a parent myself, I sometimes fear whether I am a good parent. I worry that other people might not think I am doing a good job. It is something that is always in the back of my mind. I try to remind myself every day that I am going to be a better parent than my mom ever was. I think my foster mom really helped. She was patient with kids and did a lot of activities with them.

We would go outside and play, color, and work with clay. My mom would never do anything with us and so we just sat around and did nothing. But I know the best way to parent is to do a lot of activities with your kids and be patient when your baby is fussy. My baby is a good baby—he is really easy going and relaxed so it's easy to be with him—but sometimes, I freak out when he is fussy and I wonder what I should do. But then we just go on a walk together and I take a deep breath of fresh air and relax. And, with their love and support, I can talk to and work through things with my family and closest friends. My best friend is a social worker, but sometimes I think I should have counseling, and not rely as much on my friends. When I feel parenting anxiety, my coping mechanisms are reaching out for the support of those around me and knowing that my son is relying on me to give him what he needs. That is my therapy! I am working on being patient, knowing that I am OK, and just going through what every other mom goes through.

### Author

**Felicia Brown** is a youth resource specialist for the Thrive Initiative and the Tri-County Mental Health Services in Maine.





## The Mental Health of Rural Grandparents Rearing their Grandchildren

Grandparent-headed households, in which grandparents take on the surrogate parental role for their grandchildren without a parent present, have increased dramatically across the United States. In many of these families, grandparents are not rearing grandchildren by choice or tradition but rather because of family crises that necessitate grandparent intervention.<sup>1</sup> These family crises may have resulted from parental substance abuse, chronic physical or mental health problems, abandonment, death, incarceration, or teen pregnancy.

Grandparents who intervene during a crisis in their families are often unprepared for their new role as primary caregiver of their grandchildren and face considerable challenges. Many grandparents struggle to make the psychic shift (or are ambivalent about making the shift) from the grandparent role to the parent role.<sup>3</sup> Many grandparents are ill-equipped to cope with the socio-emotional, cognitive and behavior problems of grandchildren who have experienced

parental abuse and neglect. Many grandparents find it difficult to navigate the educational, legal, social, and health care systems to meet the needs of their grandchildren. Caregiving grandparents may also struggle with their relationships and maintaining healthy boundaries with the adult children who are unable or unwilling to perform their parental duties. Yet many grandparents remain hopeful that their adult children will “get their act together” and resume parenting, leaving the family system in limbo until parental crises are resolved.

It is not surprising, given the complex, stressful, and often tragic circumstances surrounding grandparent caregiving, that grandparent caregivers experience more symptoms of depression and other negative emotional sequelae than do their noncaregiving counterparts.<sup>5</sup> Grandparent caregivers also experience poorer physical health and more activity limitations than their peers who are not caregivers. However, the toll of taking on the parental role a second time around

and coping with familial crises does not only affect grandparent caregivers. As one might expect, many grandchildren in these family systems must cope with feelings of parental abandonment while also feeling like a burden on their grandparents. Many grandchildren must also deal with past traumas, the uncertainty of their futures, and who will be caring for them.

While most researchers and social workers agree that grandparents are often the preferred caregivers of children in these situations because the children remain within their family systems and are less stigmatized than children placed in foster care, it is critical that social service and other systems of care support grandparent caregiver well-being. As is well-documented in the research literature, when caregivers are functioning well, children often reap significant benefits. When caregivers suffer from depression and other negative emotions, children are at significant risk for many difficulties including ele-

vated stress responses, poor cognitive development, poor affect regulation, and aggression.

In this article, we review our research on grandparent caregiver well-being and examine the stressors related to caregiver depression. Our work takes place in Montana, a rural frontier state with a total population of less than 1,000,000. Between 1990 and 2000, Montana experienced a 54% growth in grandparent-headed households. To date, there are approximately 9,526 children being reared by grandparents in the state, more than 4% of all children in Montana. Many of these children would likely have ended up in the foster care system without grandparent intervention. However, because many grandparents take their grandchildren in to avoid foster care, they are not eligible for many state-based services and fi-

special needs resulting from parental abuse and neglect. In Montana, the average age of grandparent caregivers is about 60 years. Thus, many of the grandparents we have met are retired or nearing retirement and have limited incomes. In our research, we found that grandparent caregivers with less household income have more symptoms of depression than those with more income. Retired grandparent caregivers may return to work to make financial ends meet. Conversely, we have seen employed grandparent caregivers leave their paid jobs in order to meet the needs of their grandchildren. This places an additional burden on the household as now there is less income with more family members to house, feed, and clothe.<sup>4</sup>

The scope and severity of depression may be exacerbated for rural

be challenging and thereby contribute to caregiver mental health problems because rural communities generally lack public transportation and have fewer readily available services for families when compared to those who live in more urban areas. For example, rural areas often lack mental health services, specialized medical care, child care, support groups, and food banks. In recent years, many rural areas have also experienced job loss and significant reductions in population because their economies have suffered in the changing global marketplace. As the population decreases, there are fewer resources and informal networks for families to draw upon in times of need. Many rural communities in the West are also combating a methamphetamine drug problem (in addition to high rates of alcohol abuse) that is impacting families, depleting limited social service resources, and leading to increased criminal activity that rural communities have not previously faced.

### Native American Grandparents

In Montana, Native Americans make up the largest minority group, representing approximately 6% of the population. In our research, we have found that Native American grandparent caregivers have higher levels of depressive symptoms than those of their European American counterparts. In our study of 55 grandparent caregivers, more than 58% of the Native American grandparents were found to have depressive symptoms at a level that suggests clinical concern. Native American grandparents who reported feeling depressed also reported high levels of parenting stress and limited social support. Native American grandparents have traditionally been very involved in raising their grandchildren, particularly the first-born grandchild, and likely derived a sense of pride and pleasure in teaching their grandchildren about their culture, traditions, and language. In contrast, we find that today's Native American grandparents are providing care due to family crises similar to those experienced by their European American counterparts. In



nancial assistance programs offered to support the well-being and healthy functioning of foster care families.

### The Impact of Limited Incomes and Rural Living

The lack of access to support services and financial assistance is a significant issue and a source of great stress for grandparent caregivers in Montana (and in the U.S.), given the financial impact of rearing grandchildren—especially those children with

grandparent caregivers, whose lives are typically characterized by a number of stressful conditions. For example, research on the health of elderly individuals in general suggests that those living in rural areas are at risk of poor mental health, social isolation, and low social network involvement due to limited finances, poor physical health, and transportation challenges, including the high cost of gas and far distances to travel to reach support groups.

Rural living in particular can also

native cultures, elders are respected, revered, and expected to play a role in grandchildren's socialization; however, with the changes in familial roles and cultural and social norms, along with pressures from the majority culture to assimilate, these grandparent caregivers may be experiencing an increased sense of grief and loss.

Depression among Native American grandparent caregivers is complex and must be understood through historical and cultural lenses. Native American grandparent caregiv-

ers may be experiencing depressive symptoms as a result of a complex web of factors including cultural genocide and the legacy of boarding schools where children were taken from their communities and placed in schools often very far from home in order to assimilate them into the majority culture.<sup>2</sup> Anecdotally, we have been told that there is a generation of Native Americans who do not feel a sense of competency or efficacy in their parenting abilities because they were not reared by their biological parents and were not taught the traditional ways of their culture and families of origin. The historical traumas associated with cultural genocide and boarding schools likely remain in the psyches of many Native American people, impacting their psychological well-being. Native American grandparents may also experience great sadness because of the current hardships experienced by their communities and the ways in which their families are affected. For example, in our research, grandparent caregivers lamented about their adult children's struggles with unemployment/underemployment, the lack of educational opportunities, substance abuse, and/or the inability of their children to care for their own offspring.

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In our work we have also exam-

ined how degree of rurality was related to symptoms of depression in grandparent caregivers. Although not a powerful predictor of depression, we did find a relationship between rurality, race, and mental well-being. Most highly rural Native American grandparents experienced higher levels of depressive symptoms than their similarly-situated European American counterparts. Among the European American grandparents, those who lived in the more rural areas had been raising their grandchildren lon-

### Depression: Individual and Family Factors

ger and had less parental stress than those living in less rural areas. Certainly individual and family factors have an impact on depression. We found that the best predictor of grandparent caregivers' depression was grandparental stress. Grandparent caregivers who reported experiencing more stressors in raising their grandchildren had higher depression levels than did their less stressed peers. It is possible that grandparent caregivers felt overwhelmed by the responsibilities of taking care of their grandchildren, especially those on limited incomes. Many children raised by grandparents have experienced significant traumas such as family violence or abandonment. These children come to their grandparents with significant emotional needs, which may place additional burdens on grandparents who are stepping in to provide care in the absence of biological parents. Many grandparents experience fulfillment of being there for their grandchildren during this time of need yet they may also experience emotional stressors of caregiving with few available supports. Support groups where grand-

parent caregivers can meet with other grandparents in similar circumstances can help develop social networks and provide educational opportunities to help alleviate parenting stress.<sup>4</sup>

Many grandparent caregivers struggle with the change in their roles in the family. Prior to parenting a second time around they were able to be grandparents and now they must take on the role of being a fulltime parent again. Grandparents talk about how even what their grandchildren call them—grandma/grandpa or mom/dad—can be distressing. There is a sense of loss of who they were and a loss of how life was supposed to be as they entered their later years. Additionally, there is ambiguity about the roles they are now trying to fulfill. Some grandpar-

ents strive to keep the family roles as they were prior to being a fulltime caregiver hoping that their adult children will get their lives in order and be able to parent again. Other grandparent caregivers see that the family reconfiguration will be long term or even permanent and adapt by becoming mom and dad.<sup>3</sup>

We have found that grandparents who had spent less time caring for their grandchildren showed higher depression levels than did those who had been caregiving for longer periods of time. This most likely is because many grandparents begin rearing their grandchildren during a time of family crisis. It may take months if not years for the family to grapple with the situation and to stabilize in the new family configuration. Additionally, because so many of these arrangements are informal with no court approved custodial arrangements, grandparents and the grandchildren under their care are often unsure about the permanency of the situation. The initial period of custody unknowns may dissipate as time goes by and it becomes clear that the biological parents are not going to come back and reclaim the children. Some grandparent caregivers and biological parents may reach an informal understanding of their respective roles as caregivers and

the family may remedy the emotional fallout resulting from the earlier crises and transitions.<sup>4</sup>

### Supports for Grandparents and their Grandchildren

Given the often tragic circumstances that necessitate grandparent involvement, the difficulties experienced by the children may intensify

rural Native American and European American grandparent caregivers. Grandchildren may also benefit from mental health intervention, given the circumstances by which they came to live with their grandparents such as parental substance abuse, neglect, and domestic violence.

In Montana, the Montana Grandparents Raising Grandchildren Project, sponsored by Montana State Uni-

versity Extension, offers resources for grandparent caregivers. Support groups are offered in numerous areas around the state. Evaluations of these groups indicate that grandparents are finding social support and learning new information on how to adapt to their family situation. MSU Extension also has fact sheets available on topics such as parenting a second time around, depression, grief, and stress to assist grandparent caregivers in their roles. Presentations are offered and an annual conference on issues of concern for grandparent caregivers is provided. These educational resources are designed to assist grandparent caregivers as they take on parenting a

second time around. For information on the project, go to <http://www.montana.edu/wwwhd/grg/grg>.

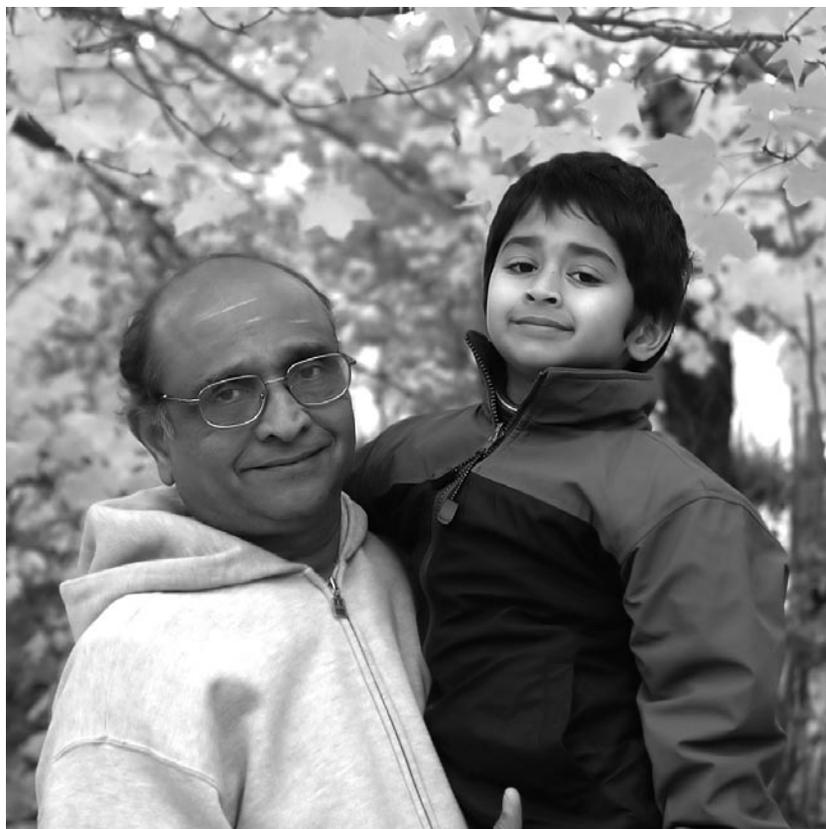
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### Authors

**Sandra J. Bailey** is an associate professor and extension specialist in the Department of Health & Human Development at Montana State University.

**Bethany L. Letiecq** is an assistant professor of Family Science in the Department of Health & Human Development at Montana State University.



the adjustments related to middle aged and older grandparents who are taking on the role of parenting a second time around. Grandparent caregivers could benefit from mental health services, especially in rural areas where mental health professionals are sparse. The high rates of Native American depressive symptoms are cause for concern. These grandparent caregivers may be grappling with numerous emotions—not only those pertaining to rearing their grandchildren due to family crises, but also those related to historical traumas experienced over generations. Dealing with grief and loss would seem an important component of interventions for both

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## Antidepressants in Pregnancy: Weighing the Risks

**A**lthough there has been a renaissance in sensitivity surrounding assessment and treatment of depression during the postpartum period, pregnancy itself (albeit complete with “tolerated” mood swings) is still widely considered a time of good health and emotional stability. Yet pregnancy has not been found to provide any protection against mood disorders. Just as many women become depressed during pregnancy as their non-pregnant peers—about 10 to 15 percent, or one in eight pregnant women. In total, half a million pregnant women each year become depressed in the United States.

For about one-third of the women who become depressed during pregnancy, this episode may be their first; however, many women with a history of recurrent depression decide to discontinue psychotropic medication around the time of conception. These women have a staggering seventy percent chance of relapse, nine out of ten of which occur by the end of the second trimester.<sup>2</sup> The data on the effects of these maternal mood and anxiety disorders on the fetus, newborn, and growing child are accumulating, and cannot be ignored.

While psychotherapy can be an effective treatment for pregnancy and postpartum depression or anxiety, full recovery in pregnancy or postpartum (during lactation) may require medi-

cation. Thus, depression and anxiety during this time offer a continuing conundrum for thoughtful clinicians: to treat with antidepressants or not to treat? And if to treat, for whom, with what, when, and how much? Though still incomplete, the literature provides information for practitioners and patients to carefully, collaboratively, and individually begin to address these questions.

### Risks: Disorders vs. Medications

Clinicians often err on the side of caution in recommending medication during pregnancy, perhaps slightly less so during postpartum. Yet the risks of untreated depression or anxiety on the maternal-fetal, or mother-infant, dyad are significant. Depression and anxiety during pregnancy can contribute to self-injurious or suicidal behavior in the mother, as at any other time. But they also can contribute to the following:<sup>4,6</sup>

- Poor self-care and poor adherence to prenatal care
- Less-than-adequate weight gain, with incumbent risks to fetus/newborn
- Increased risk of tobacco, alcohol, and/or drug use
- Preterm birth, low birth weight

- Higher rates of pre-eclampsia, cesarean section, and neonatal intensive care unit admissions

Lactating women also may avoid medication. But untreated depression and anxiety in the new mother predispose to long-term effects on the infant as well, such as:<sup>4,7,8</sup>

### RISK FACTORS

#### *Predisposing factors for depression and anxiety in pregnancy:*

- Personal history of depression or anxiety
- Marital or relationship stress
- Poor psychosocial supports
- Unwanted pregnancy
- Adverse life events

#### *Increased risk during postpartum:*

- Health problems in the infant
- Depression during pregnancy

- Overactive stress response
- Poorer motor skills, coordination, resiliency, and activity
- Attachment issues
- Heightened anxiety
- Lower cognitive and language abilities
- Behavioral/emotional difficulties and maladaptive social interactions
- Increased risk for conduct problems, suicidal behavior, and other psychiatric sequelae

On the other hand, risks of Selective Serotonin Reuptake Inhibitor antidepressants (SSRIs) during pregnancy or postpartum are much harder to quantify. SSRIs are one of the most studied medications in pregnancy, and are the most studied medication in lactation. Yet randomized controlled trials are nearly impossible to conduct for ethical reasons. No significant rates of miscarriage or major malformations have been associated with several thousand SSRI exposures in pregnancy, and neurobehavioral development appears to be normal throughout early childhood. In other words, as opposed to children of mothers with untreated illness, children of mothers treated with antidepressants in pregnancy seem to fare as well as those of mothers who had no mood disorders.

There have been scattered reports of various negative birth outcomes or “neonatal adaptation syndromes/NAS” with SSRI use. These include: transient respiratory and/or metabolic problems, slightly lower gestational age, and lower Apgar scores. Yet rarely, if ever, is medical intervention required, and it is quite possible that NAS may be a reflection of pre-existing maternal illness and not a consequence of SSRI use at all.<sup>5</sup>

During postpartum, Hendrick et al.<sup>3</sup> found that exposure to SSRIs through breast milk did not affect infant weight gain, while maternal depression lasting two months or more did adversely impact weight. Berle et al.<sup>1</sup> found SSRI drug levels in nursing infants were low or virtually undetectable. These studies are reassuring for practitioners and their postpartum patients who take SSRIs and choose to breastfeed.

On balance, while the risks of

untreated antenatal or postpartum depression/anxiety are clear and significant to both mother and fetus (and young child), the risks of SSRI treatment are less clear but appear to be fewer in number than those associated with the mother’s untreated depression. Overall, the growing literature supports SSRI treatment during pregnancy and postpartum in cases where the benefits outweigh the risks. In fact, recovery of maternal mental health may be the single most effective preventive measure we have for the current and future mental health of the unborn, the newborn, and the growing child.



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## Author

**Diane Solomon** is a psychiatric nurse practitioner and certified nurse-midwife with a private practice specializing in women’s mental health.



## Identifying Depression in Mothers to Support Young Children

**M**any children are affected by maternal depression because depression is the most common mental health disorder affecting women during their child-bearing years. Approximately 15% of U.S. women experience depression each year, with even higher rates among highly stressed groups such as low-income women. When a mother is depressed, it can affect her child's health and development in many ways that extend from pregnancy throughout the life of the child. Children of depressed mothers are more likely than other children to develop early and lifelong emotional, behavioral, and adaptive difficulties. Although depression is readily identifiable and treatable, the majority of depressed pregnant and young mothers do not receive treatment. Encouraging higher levels of screening of, and treatment and support for, depression in mothers will benefit both mothers and their children.

### Starting Life with a Depressed Mother

Infants whose mothers are de-

pressed during pregnancy are likely to develop internal systems that react to events differently than other infants. Research shows that they are more reactive to stressors, as demonstrated by biological signs such as increased heart rates, and they are more likely to have poor health and problems in early development, which in turn affect later adjustment.<sup>6</sup>

These changes may explain the results of a large community-based study in England that found that children exposed to higher levels of maternal anxiety and depression during the prenatal period were more likely to have behavioral and emotional problems at age four, even after taking into consideration factors such as income, problems during pregnancy, and exposure to the mother's anxiety and depression during childhood.<sup>10</sup> This does not mean that infants of mothers who have mild to moderate levels of distress during pregnancy develop problems. In fact, it appears that when mothers have manageable stress during pregnancy, their children have slightly more advanced motor development at age two.<sup>4</sup>

### Toddlers and Young Children

Young children of depressed mothers are more likely to exhibit difficulties with regulating and managing their emotions, developing a secure attachment, and language development, compared to children of non-depressed mothers.<sup>1</sup> As they enter school, many children of depressed mothers display difficulties, including negative self-concept, disruptive or withdrawn behavior, attention problems, cognitive deficits, impaired social behaviors, and reduced academic achievement.<sup>5,7</sup> As they move into adolescence, their risk of developing a mental disorder increases.

Efforts to reduce the negative influence of having a mother with depression highlight the importance of parent-child interactions and the quality of the family environment, because children's development occurs within the family context. Not surprisingly, when mothers are depressed, they are much less available, warm, and responsive to their children than mothers who are not depressed. Their families often have

higher rates of conflict and stress, less consistent discipline, and less secure attachments than families without a depressed mother.<sup>3</sup>

Importantly, mothers with depression are very concerned about the effects of their problems on their children and want to ensure that their children grow up to be mentally healthy and happy. Helping mothers through their own difficulties and preventing the legacy of depression from one generation to the next is a complex task that needs to become a major public health priority. Increased public awareness and significant changes in the health care system are also critical to the successful prevention of similar problems in children. The three basic steps outlined below represent an appropriate and feasible response to this important public health challenge.

### Three Basic Steps

First, routine screening of mothers is imperative and consistent with the 2002 US Preventative Services Task Force recommendations to routinely screen all adults in medical care for depression. Although many obstetricians and pediatricians believe that they have a role in the identification and referral of mothers who are depressed, a lack of training and time are often cited as major barriers to screening. In addition to the low rates of screening by medical professionals, mothers also report barriers to discussing depression with their providers. Mothers identify feelings of mistrust or fear of judgment as concerns, particularly immigrant women and women in racial/ethnic minority populations.<sup>8,9</sup> Additional training for providers and increased public awareness and education campaigns, including those directed towards reducing stigma, may help reduce these barriers to screening for and discussing a mother's feelings of depression during her medical visits.

When a mother is identified as having a high level of depressive symptoms, a plan must be in place that provides doctors and nurses with clear guidance about where to refer her for treatment, how to ensure that

the referral is completed, and how to communicate with the mental health provider to ensure coordinated care. Improved practice collaborations (supported by policy development) among obstetricians, pediatricians, and mental health providers, will likely facilitate the referral process.

Second, because engaging depressed individuals in treatment is challenging, developing strategies to overcome barriers to success is critical. Both medication and psychotherapy are effective in treating depression for the majority of women. Because many pregnant and/or nursing mothers and their doctors choose not to use medication, it is critical that evidence-based psychotherapy treatments, such as cognitive behavioral therapy and interpersonal therapy, are readily available and affordable in their communities. Psychotherapy may offer benefits beyond medication, for example, by helping increase skills to manage highly stressful situations.

Third, even when a mother with depression receives treatment, her children should also receive supports for healthy development. Fortunately, there are several promising and efficacious interventions available to strengthen the family and parenting relationships affected by maternal depression. One effective intervention program that focuses on the interactions that occur between the mother and child, the Toddler-Parent Psychotherapy Program,<sup>2,11</sup> appears to have several positive effects, including improvement in the attachment relationship between the mother and child. Other successful evidence-based preventive interventions are available for school-age children and adolescents. Depending on the ages of the children involved, these programs may target the quality of the parent-child relationship, consistency of discipline, coping, and children's understanding that they are not to blame and cannot fix their mother's depression. However, despite their existence, these programs are not widely available. Efforts should be made to publicize and promote their adoption. In addition, cultural adaptations may be needed to ensure that families

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We invite our audience to submit letters and comments:

Janet S. Walker and L. Kris Gowen,  
Editors:  
[janetw@pdx.edu](mailto:janetw@pdx.edu); [gowen@pdx.edu](mailto:gowen@pdx.edu)

Publications Coordinators:  
[rtcpubs@pdx.edu](mailto:rtcpubs@pdx.edu)

of different socioeconomic and cultural backgrounds benefit from these programs that are designed to help the child and parent, and the family as a whole.

Though parents' health is critical for the health, health care, and development of their children, parental health receives almost no attention in



public policy. A scientifically grounded model of family health is needed to guide policies and programs and support the development and dissemination of interventions to reduce the impact of parental depression and other disorders on children. Conversations at the local, state, and federal levels are necessary to build consensus on the ways the U.S. health care and other systems can ensure access to services designed to identify and treat parents with depression or other illnesses. This will help children avoid some of the risks associated with maternal depression, the effects of which can last a lifetime.

*Author's Note:* This article is focused on maternal depression due to the high prevalence and attention given to this issue in prior research, but recognizes that similarly negative outcomes occur and similar interventions are needed when a father is depressed.

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## Authors

**Carrie Mills** is Research Associate at the Johns Hopkins University Bloomberg School of Public Health in Baltimore, MD.

**Anne Riley** is Professor in the Department of Population, Family and Reproductive Health at the Johns Hopkins University Bloomberg School of Public Health in Baltimore, MD.

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