Exploring Mental Health Outcomes for Low-income Mothers of Children With Special Needs
Implications for Policy and Practice

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Research has indicated that there is a heightened risk for the occurrence of childhood disabilities in single-parent-female-headed households that are living at or below the poverty line. Research also demonstrates increased levels of parenting stress and parenting depression among mothers who have children with special needs. However, very little is currently known about mental health outcomes among women who are poor and raising children with disabilities. To work effectively with these caregivers, human service professionals must utilize multifaceted approaches based on an ecological framework to address the multitude of challenges that these families face. This article draws upon ecological theory and a case study to examine the ways that having a child with special needs impacts women’s emotional well-being and their ability to function in roles they deem appropriate for their children. The case study highlights current policies and the ways in which they may exacerbate caretakers’ mental health issues. It also provides a framework to identify and demonstrate the ways in which an ecological approach is useful in looking outside the individual and the family to understand the processes through which other systems may interact with the family to affect maternal mental health. Finally, specific links are drawn to both policies and practice. Key words: early childhood special education, early intervention, maternal mental health, poverty

POVERTY, CHILDREN WITH SPECIAL NEEDS, AND MATERNAL MENTAL HEALTH

In 2001, 16% of American children—almost 12 million—were living in poverty (Lu, 2003). Poverty impacts children’s health in a myriad of ways. When families do not have enough income, fundamental prerequisites for good health such as adequate shelter are often difficult to obtain. When shelter is inadequate, basic hygiene is more difficult to maintain and infections can be easily contracted and spread. Moreover, the presence of cockroaches, rodents, and other allergens, often found in older, poorly maintained housing (typically the type of housing that is found in lower-income, minority, inner-city households) can aggravate chronic conditions such as asthma.

As a result of these multiple factors, childhood disability is overrepresented among children living in poverty. Using the National Health Interview Survey, Wise, Wampler, Chavkin, and Romero (2002) found that among children whose families were living in poverty, there was a prevalence rate of 21.5% for chronic illness, and among those whose families reported receiving Temporary Assistance to Needy Families (TANF), there was a
prevalence rate of 25.6% for chronic illness (defined here as asthma, mental retardation, cerebral palsy, autism, attention deficit disorder, muscular dystrophy, cystic fibrosis, sickle-cell anemia, diabetes, arthritis, and congenital heart disease). Looking specifically at families receiving welfare, Meyers, Lukemeyer, and Smeeding (1996) found that 21% of the women in a sample of AFDC (Aid To Families With Dependent Children) recipients in California reported having at least one child with a disability or chronic health problem. As a comparison, the American Academy of Pediatrics cites data finding that 12% to 16% of all children have some sort of developmental or behavioral disorder (American Academy of Pediatrics, 2001). Finally, approaching the issue from the perspective of children diagnosed with special needs, data from the National Early Intervention Longitudinal Study show that 42% of children entering early intervention were in families who were receiving some form of public assistance (Hebbeler et al., 2001).

Both living in poverty and having a child with special needs have been found to be associated with negative mental health outcomes in women. Women living in poverty are approximately twice as likely as women from higher income groups to be depressed (Lennon, Blome, & English, 2001), and women who have children with special needs have also been found to demonstrate higher levels of both depression and parenting stress than women with typically developing children (for a review, see Rosman, 2003). Women living in poverty who care for children with special needs often engage in a host of healthcare activities related to their children, and this caretaking is often done in isolation (Lloyd, 2002). Because of this isolation, caregivers often feel high levels of emotional and physical stress. These women often do not have periods of respite and relief that are important to maintaining mental and physical health (Lloyd, 2002).

It is clear that poor women who have children with special needs are subject to significant demands. Parents must manage a host of factors, including unexpected expenditures and medical appointments, and continue worries about their children’s future (Meyers, Brady, & Seto, 2000). For families whose budget is already stretched to the limit, these demands can hit especially hard. Lack of money for food, clothing, housing, and medical care leads to stress among family members. For example, a study conducted of 31 low-income women—21 who cared for children with special needs and 10 who did not—found that the caregivers of children with special needs reported higher levels of psychological and physical distress. Depression was most prevalent; however, other manifestations included high blood pressure, migraine headaches, anxiety, ulcers, and drug addiction (Lloyd, 2002).

Scorgie, Wilgosh, and McDonald (1998) conducted an analysis of recent studies on families who cared for children with special needs and found that higher income families had more choices available to assist with their own coping. They also found that higher income families had increased levels of satisfaction in their role as parents. In addition to stress experienced from caring for children, interactions with systems outside of the home had the ability to increase or decrease parental stress and mental health outcomes. This focus on resources and systems outside of the family suggests the importance of ecological theory in examining the lives of women who are poor and have young children with disabilities.

The authors have chosen ecological theory as a framework for this article, as it is systems-based and provides a useful mechanism for exploring various factors in and outside of the home that can impact mental health functioning.

ECOLOGICAL SYSTEMS THEORY

Ecological theory suggests that there are multiple facets both of being poor and having a child with special needs that can be expected to impact maternal mental health and well-being. Ecological theory, as originally posited by Bronfenbrenner (1979), points to
the importance of both relationships within the family as well as the family’s interactions with systems outside of the home. Bronfenbrenner’s theory is explicitly bidirectional, with the environment and individuals concurrently affecting one another (Sontag, 1996). Furthermore, while the family is one important sphere of influence on individual development and outcomes, systems outside of the family also play important roles (Bronfenbrenner’s mesosystem, exosystem, and macrosystem).

Ecological theory has begun to play a role in research examining children with special needs and their families. Glidden (2002) conceptualizes environment as a ladder of influence, with parents directly shaping the microenvironments that their children experience by interacting with their children, as well as choosing and changing the larger macroenvironment. As explained by Sontag (1996), special educators acknowledge the influence of multiple settings and systems on children and recognize the necessity of exploring the multiple contexts that influence children’s development. However, even among those studies that have turned to ecological theory, the meaning and operationalization of environment is still fairly limited. Twenty years ago, Crnic, Friedrich, and Greenberg (1983) argued that “...the family’s coping resources and functioning are likely to be mediated by the ecological systems within which they must interact and be acted upon” (p. 126). In 2001, Hodapp (2001) stressed that the meaning of “environment” needs to be broadened in future research.

**ECOLOGICAL FACTORS THAT HAVE NOT BEEN FULLY EXAMINED IN THE LITERATURE**

Ecological theory suggests that there are a wide range of factors that may influence maternal mental health in families that are poor and have children with special needs that remain largely untapped in the literature. There are multiple processes that still need to be explored and that may be especially salient for families who both have children with special needs and are living in poverty. These factors also bear attention as they can be manipulated by policies and interventions. For the purposes of this article, the authors have chosen to explore family resources, service utilization, and maternal employment.

**Family resources**

Families living in poverty are inherently low on resources across multiple domains, including time, money, and supports (Yoshikawa & Hsueh, 2001). These resources may be even more scarce as a result of the Personal Responsibility and Work Opportunity and Reconciliation Act of 1996. This lack of resources may be especially acute for families raising children with special needs. As Meyers et al. (2000) describe them, these are “expensive children in poor families.” For all families of children with special needs, there are typically demands on the family’s time and resources that may not have been expected and that are not encountered by typical families. For example, families may have to pay for modifications to the home, in-home care, specialized medical equipment, out-of-pocket (i.e., not reimbursed) medical expenses, transportation to and from appointments, babysitting for other siblings while attending treatments for the child, special clothing, food for children on specialized diets, and specialized day care (Hogan & Msall, 2002; Meyers, et al., 2000). For families whose budget is already stretched to the limit, these economic demands may hit especially hard, as these are families for whom “there is relatively little in reserve” (Bernheimer, Weisner, and Lowe, in press).

Some research has been conducted that specifically addresses the role of resources in predicting outcomes for families who are poor and have children with special needs. For example, Supplemental Security Income benefits, which are offered to individuals in poverty who are older than 65 years, blind, or disabled, have been found to make the difference for families between living above or below the poverty line (Kearney, Grundmann, &
Gallicchio, 1994; Meyers et al., 1996). However, research is not available explicitly linking those resources to maternal mental health and well-being. Furthermore, any research that does consider maternal mental health typically ignores the subgroup of families who have children with special needs. In the Minnesota Family Investment Program, a recent welfare-to-work experiment that embraced the notion of “making work pay,” financial incentives reduced mothers’ risk of depression (Knox, Miller, & Genettian, 2000). However, this intervention did not specifically target or examine outcomes for families in poverty who have children with disabilities (Rosman, 2003).

Service utilization and associated hassles

Another factor that has not been sufficiently explored in the literature is the role of service utilization for families that are living in poverty and have children with special needs. These families live at the intersection of both poverty- and disability-related services and, therefore, may be interacting with an unusually high number of service providers and service systems. McDonald, Poertner, and Pierpont (1999) explored service utilization from an ecological perspective. They counted the number of services used by families of children with serious emotional disorders and found a linear relationship between caregiver stress and total number of services ever used. For families using both disability- and poverty-related services, this may translate to increased stress, simply as a result of the large number of services being accessed. It is fairly easy to imagine that the hassles involved with these interactions may stress mothers to a point where potential benefits are overshadowed by the “transaction costs” involved in obtaining them (Gibson & Weisner, 2002).

Rosman (2003) explored the effect that service-related hassles played in moderating the relationship between service utilization and maternal mental health. She surveyed 80 low-income mothers whose children were receiving early intervention services in Washington, DC, and Montgomery County, Md. Rosman found that the use of poverty-related services (eg, TANF, Food Stamps, Medicaid) served a protective function on maternal levels of child-related stress, but only when the use of those services was accompanied with low levels of hassles. Similarly, the use of child care was associated with lower levels of both child-related and parent-child-interaction-related stress, but only when accompanied with low levels of hassles. These findings suggest the need for increased attention to the hassles that these families encounter on a regular basis and the toll they may be taking on maternal mental health.

Maternal employment

The role of work in the lives of women who are poor and have young children with disabilities has also not been sufficiently studied. Most of the research that does exist explores the impact that the child’s disability status may have on maternal employment status. However, even in this area, there are no clear-cut answers. Some researchers document lower levels of employment for mothers whose children have special needs (Dodson, Manuel, & Bravo, 2002; Meyers, et al., 2000; Skinner, Slattery, Lachicotte, Cherlin, & Burton, 2002). However, others find inconsistent results, possibly due to differences in definition of childhood disability (Lee, Oh, Hartmann, & Gault, 2003). In a recent study using data from the 1996 panel of the Survey of Income and Program Participation, Lee et al. (2003) found that childhood disability had a significant negative impact on maternal work, but not as great an effect as the mother’s own disability status.

There is also a body of research that explores that role of employment on maternal mental health for low-income women, reflecting a trend that suggests that maternal employment may serve a protective function for low-income women (Howard, 2003; Jackson & Huang, 2000; Rosman, 2003). However, this pattern is not typically explored specifically for families who have children with special
needs. A qualitative study by Lloyd (2002) documented that low-income mothers who cared for children with special needs had higher levels of stress associated with employment than low-income mothers who did not have children with special needs. The stress occurred as a result of difficulties in finding appropriate child care, as well as the difficulty of maintaining a consistent work schedule, particularly when children had chronic and unpredictable healthcare needs. While Lloyd (2002) was able to document the reported stress that caretakers of special needs children faced, the sample size was small and limited to a specific geographic location. In addition, the study was exploratory so that one was not able to “measure” the differences between the 2 groups of women and their reported experiences.

CASE STUDY

The following case study will be used to help explore some of the aforementioned issues. The family depicted in the case study is a composite of various families that participated in a qualitative study that examined the transition from welfare to work for low-income women who cared for children with special needs (Lloyd, 2002). The women who participated in the study were purposely sampled. That is, they were selected on the basis of the fact that they could provide insight into navigating welfare-to-work requirements while simultaneously caring for a child with special needs. The study also targeted caretakers on TANF who did not care for children with special needs. This is especially important to note, as the comparison group allowed the researcher to understand the differences in the lives of low-income women who cared for children with special needs and those who did not. Thus, the distinction in sampling allows the case study to be presented in a manner that provides a snapshot of the contextual issues that a “typical” low-income urban caretaker who is attempting to meet TANF requirements and care for a child with special needs faces on a day-to-day basis.

The Darden family

Family structure

Deborah Darden is a 29-year-old never married mother of two: Davon, age 8, and David, age 4. Both children have the same father, Michael Jones. Although they never married, he was actively involved with the family until David was born. Ms Darden feels that once the father became aware that David had multiple health problems, he could not handle the stress and made a decision to “leave his children.” Ms Darden’s mother lives in the area and she is able to help out occasionally with the children’s care. Ms Darden wishes her mother could do more, but she is in “poor health” and she does not want to “put a strain on her.”

Education and employment status

Ms Darden is a high school graduate and is currently employed part-time as a home health aid. Her job offers some flexibility with respect to work hours, because she works for individual clients in their homes.

Children’s health and school status

By all reports, Davon has no significant physical health issues; however, his mother feels that he is suffering emotionally because she spends an inordinate amount of time caring for David. David has been diagnosed with asthma, attention deficit disorder, a behavioral disorder, developmental delays, encopresis, seizures, and a speech impairment. He attends a center-based early childhood special education program. His teachers describe him as combative, noncompliant, difficult to keep on task, and unmotivated.

Child care

Both children are eligible for free daycare through welfare-to-work vouchers. Ms Darden takes advantage of this benefit, and the children participate in after-school daycare programs. Unfortunately, the daycare voucher that is provided by the state does not cover the costs of caring for a child with special
needs. In order for David to receive daycare while Ms Darden is at work, she pays an additional $250 per month.

**Community resources**

Ms Darden is connected to a welfare-to-work program. She has a great relationship with her case manager, and the agency has been helpful in assisting her develop a resume and locates childcare. In addition, her case manager has provided referrals for employment, money for transportation, and emergency food. At one time, Ms Darden was actively involved in the Agency’s training program; however, she had to stop attending because she was missing too many days. She feels supported by her welfare-to-work case manager; however, she does not feel supported by her caseworker in the welfare office. She states that the people at the welfare office are “nasty” and that they really do not want to “see you succeed.” She reports having to make numerous visits to the welfare office to submit paperwork that “they already have.”

**Housing**

The family’s apartment is subsidized by the Department of Housing and Urban Development. It is located in a high-crime area, and the unit is cramped, with minimal light, peeling paint, and leaky ceilings. There is also evidence of roaches and mice. The family lives near a bus line, which enables them to travel to the children’s schools, the welfare-to-work office, church, grocery stores, the laundromat, and David’s medical appointments.

**Income**

Deborah is typical of many low-income mothers in that she uses a combination of earnings from work and welfare to make ends meet. Her income includes monies from her part-time job, a public assistance grant, food stamps, and Supplemental Security Income. Her expenses include, but are not limited to, subsidized rent, utilities (gas, electric), a landline phone and a cell phone, transportation, groceries, daycare, clothing, and laundry. Typically, her expenses exceed her income.

**Social supports**

Ms Darden’s mother is able to assist occasionally with visits to David’s school to change his diapers. Ms Darden feels supported by her welfare-to-work case manager and has a strong connection with a community church, although she does not attend regularly.

**Mother’s health**

Ms Darden expressed that it was extremely difficult for her to care for her children, particularly David, in addition to meeting the demands of her job. She feels like she “never gets a break from caretaking…” and expressed that she often feels like she is on the verge of having a breakdown. She has been diagnosed with depression and sees a therapist who has recommended medication. Ms Darden is resistant to taking the medication even though she stated at one point she “cried for a week straight” and could not get out of bed to change her clothes, much less care for her children. She also has been diagnosed with anemia, asthma, and diabetes.

**Strengths**

The family is tight-knit, and all family members care about each other immensely. Ms Darden has social supports who she feels are reliable, although somewhat limited in their ability to assist with her problems. Ms Darden has a high school education and a good work history. She is interested in obtaining additional education and/or training, and she has good parenting skills.

As the case study and ecomap (Fig 1) illustrate, the needs of the Darden family are varied and complex. It is apparent that there are several systems that affect their lives. Although Deborah Darden and her children are connected to various human service agencies within their community, these agencies generally do not coordinate with each other and often have different expectations regarding Ms Darden’s multiple roles, including mother, worker, and recipient of public assistance. For example, the preschool program has expectations that Ms Darden should be available for
Figure 1. Darden family ecomap.
meetings concerning her child’s care; however, these meetings occur during business hours when Ms Darden is expected to be at work. Because she works with clients in their home, Ms Darden is able to occasionally negotiate her schedule so that she can make medical appointments during the day; however, when this type of negotiation occurs, she often feels obligated to make up the time by doing tasks outside of normal patient care duties, such as grocery shopping and laundry. These tasks are typically time-consuming and her job offers no protection for her when she is engaged in such activities since they do not condone them and are unaware that this negotiation is occurring. In addition, Ms Darden is a part-time employee and is not eligible for benefits such as paid time off and medical insurance.

Problems also develop when systems do not effectively communicate. For example, because the preschool nurse is part-time, she has not been made aware of the treatment that the doctor has recommended for dealing with David’s encopresis. As a result, the center has not been able to actively reinforce the doctor’s treatment recommendations and David is not receiving consistent care. Ms Darden is also expected to interface with multiple systems, and the differing expectations of these agencies and individuals cause great stress. As a result, she becomes easily overwhelmed, and requests like another medical appointment or an unpredictable asthma attack causes her already fragile system to become unbalanced, and her physical and mental health to suffer.

DISCUSSION AND IMPLICATIONS FOR POLICY AND PRACTICE

The Darden case study highlights the 3 main factors that are presented here as being especially relevant to maternal health outcomes for women who are poor and have children with disabilities: resources, hassles, and maternal employment. These factors are vastly understudied, yet they are highly salient in the aforementioned ecological model. Implications for policy and practice, on both micro and macro levels, will be presented for all 3 areas.

Family resources

David is clearly an example of an “expensive child in a poor family.” David’s encopresis means that his mother is constantly washing sheets and pajamas. While Ms Darden’s mother is occasionally available to visit the school to change David’s diapers, this is a weak resource at best, as the grandmother herself is in poor health. The potential benefits of increased resources for Ms Darden’s mental health is suggested by the welfare-to-work interventions cited earlier and is also made clear by Ms Darden herself who said that she often feels on the verge of a breakdown as a result of so many demands on her. Six specific recommendations for increasing this family’s resources are

1. Increased linkages with community resources. Ms Darden could clearly benefit from an influx of additional resources from the community. For example, perhaps David’s preschool could participate in a foster grandparent program, so Ms Darden and her mother would need to go to the school less frequently. David’s service coordinator at school could also help connect them with community resources that provide diapers or help them obtain donated sheets or pajamas. Assistance in this area would help to reduce the amount of laundry that needs to be done on a daily basis in addition to decreasing the amount of time and costs associated with washing clothes.

2. Increase knowledge and utilization of respite services. Ms Darden said that she “never gets a break from caretaking.” Both her welfare-to-work case manager and her son’s service coordinator should be able to connect her with respite care services. One resource for locating respite services is the ARCH National Respite Network and Resource Center, http://www.archrespite.org/. This is extremely important as research clearly demonstrates that use of respite care is associated with lower levels of caregiver stress and burnout (Cowen & Reed, 2002).
3. Increase child care subsidies for families of children with special needs to reflect market rates for children with special needs (Rosman, Yoshikawa, & Knitzer, 2002). Ms Darden paid an extra $250 per month above her subsidy for David’s child care. In their focus group study of welfare recipients with children with special needs, LeRoy and Johnson (2002) found that the average hourly rate for specialized care was $4.80 in Michigan, while the subsidy was only $2.95 per hour, regardless of whether or not a child had special needs. As research has consistently shown, financial hardship is a key indicator of poor mental health for individuals in poverty (Chun-Chung Chow, Jaffee, & Snowden, 2003).

4. Education of early intervention specialists. It is obvious from the case study that there are virtually no linkages between early childhood facilities and welfare agencies. Local welfare offices and welfare-to-work programs should be in collaboration with agencies that service children with special needs. Once early childhood workers become familiar with the goals and demands of public assistance offices, they will be in a better position to offer information to mothers or advocate for them to receive exemptions based on the mother’s or child’s physical and/or mental needs.

5. Mental health specialization of early childhood intervention specialists. Most early childhood facilities subscribe to the philosophy that children with special needs are best served when families are functioning at optimal capacity and are able to actively participate in their children’s educational process. Making the family the focus of early childhood care ensures that the development of these children is supported both in and outside of the home. Currently, early childhood agencies are not equipped to address the needs of caretakers who are in need of substantial mental health services.

For low-income mothers who are in need of mental health services, the addition of case-workers who are skilled in the identification and treatment of mental health issues can aid in the early detection of the mental health needs of caretakers. As most developmental literature acknowledges, successful outcomes of children are in a large part dependent on the context that parents are able to create (Ramey, 2002). To date, there are minimal welfare-to-work agencies (Derr, Hill, & Pavetti, 2000) or early childhood agencies that have a systematic approach to screening and assessing mental health needs of low-income women. If early intervention workers can be trained to recognize the symptoms of common mental health issues such as depression, improved family functioning, including better care for children, may be realized.

6. Provision of clinical case management services. Mothers who are identified as needing more support can be assigned a clinical case manager who is trained to work with women who are in need of more support. Issues such as time management, transportation assistance, discharge planning, and navigation of multiple systems can be facilitated by a specially trained clinical case manager who is knowledgeable regarding issues that impact families in poverty and families who care for children with special needs. Emphasis should be on the development of an ongoing relationship with the family. The clinical case manger can also help facilitate discussion among various agencies that work with the family to ensure that all of the systems that impact the family are working collaboratively. Furthermore, any competing or conflicting agency ideologies can be discussed and treatment recommendations made that are satisfactory to all agencies involved in the care of the family unit.

Service utilization and associated hassles

Ms Darden was also very explicit about the level of hassles in her life. Not only is it common sense that hassles are related to mental health but Rosman (2003) begins to suggest an empirical link as well. Hassles can be reduced both within individual systems and between systems. Three specific recommendations for reducing hassles are
1. *Within individual services, ensuring that the steps necessary to obtain or maintain one particular service are not excessively cumbersome.* Ms Darden’s statement that she frequently makes visits to the welfare office to provide paperwork they “already have” demonstrates the importance of making poverty-related services easier to access. The hassles involved with poverty-related services need to be minimized so as not to overshadow the benefits. For example, in their qualitative study of welfare recipients who were part of the Project on Devolution and Urban Change, Clampet-Lundquist, Edin, London, Scott, and Hunter (2003) discuss the differences between the Food Stamp programs in Cleveland and Philadelphia. In Philadelphia, individuals had to provide verification of their eligibility for Food Stamps on a monthly basis, while in Cleveland, this paperwork had to be completed quarterly. They found that this seemingly small difference had very real impacts on the lives of women in their study, with women in Philadelphia reporting frequent problems with the monthly reporting, stemming from both their own difficulties keeping up with the paperwork and from caseworker error.

2. *Create “one-stop shopping” for both disability- and poverty-related services.* Making it possible for families to access multiple services in one location would better facilitate families’ access to multiple services, as well as allowing for different types of services and service providers to communicate with each other. A “one-stop shopping” model to services would mean that families could apply for benefits at early intervention or preschool centers, and program caseworkers for antipoverty programs could be located at centers that provide disability-related services. Examples of these types of approaches already exist in the welfare literature: in Oregon and Kentucky, mental health service providers are colocated in welfare offices; in California, CalWORKS offices house not only welfare caseworkers but also public health nurses who are knowledgeable in parenting and child development (Rosman, McCarthy, & Woolverton, 2001); and in Montgomery County, Ohio, more than 40 agencies, nonprofits and businesses, are all housed in a single job center to provide services related to welfare, health, housing, children, employment, and veterans (Yates, 1998). Richer, Kubo, & Frank (2003) discuss the potential of one-stop centers funded by the Workforce Investment Act of 1998 to provide information about a range of work support programs, as well. Examples also exist that follow the family resource center model. In the Orange County area of North Carolina, the Chapel Hill Training-Outreach Project manages 5 family resource centers. These are central locations in communities that house a variety of programs and services ranging from children’s health services to preschool and literacy programs to services related to domestic issues, such as financial planning, parenting education, and housing assistance (Chapel Hill Training-Outreach Project, Inc., n.d.).

One-stop shopping should also include services for the adult caregiver. While early intervention staff members are competent in addressing the needs of children, the parents’ needs often go unidentified. In order to more effectively support the mental health needs of caregiving low-income women, early childhood specialists must understand the types of challenges that low-income women face. In addition to understanding these needs, workers must be able to refer women out if they are unable to provide services in their own facilities. In light of the fact that the “typical” mother caring for a child with special needs has to interface with multiple systems, and is often overburdened, it makes sense to limit the amount of time and energy spent accessing mental health services. To expedite this process, the co-location of mental health facilities in early intervention agencies would be helpful. A realistic way that this could occur would be for early childhood agencies to collaborate with welfare offices, using welfare-to-work funding to expand their existing systems.
3. Communication and assistance between disability- and poverty-related services. Ms Darden and her family received multiple services, and there are many instances in their story where it is clear that those services were not communicating with each other. For example, the preschool serving David expected Ms Darden to be able to attend meetings at times when her welfare-to-work case manager expected her to be at work. As Rosman et al. (2002) explain, possible strategies for improving communication and collaboration include sharing records between poverty-related service providers and early intervention/special education systems (with parental consent) (Rosman & Knitzer, 2001; Rosman et al., 2001); allowing families to have one service plan that would incorporate goals from multiple systems (Rosman et al., 2001; Woolverton, McCarthy, Schibanoff, & Schulzinger, 2000); and putting systems in place for representatives of the multiple agencies that serve families on TANF to communicate on a regular basis (Derr et al., 2000).

Maternal employment

Ms Darden was somewhat fortunate in that she was able to create, to some extent, her own flexible work schedule. However, because this flexibility was not condoned by her employer, she had no protection for herself. For Ms Darden, it was a constant juggling act between her children’s needs and her employment that was mandated by her welfare-to-work program. This is in keeping with Chase-Lansdale’s (1998) concerns about the potential negative effect of employment when it is not entered voluntarily. Three specific recommendations for improving the role of work in the lives of poor women with children with special needs are

1. For families receiving welfare, create broader definitions of work, as well as broader definitions of and application of exemptions. Without adequate supports for employment, physical and mental health problems are exacerbated and can lead to ineffective care of children (Lloyd, 2002). For families who are attempting to meet welfare work requirements, this may mean creating broader definitions of what qualifies as employment, such as allowing caregiving to substitute for work. Many states do allow caregiving as an alternative to work, although research has documented that mothers are often unaware that the option exists (Lloyd, 2002). This type of model recognizes that helping families to maintain their carefully constructed routines and balances will help to reduce both parental stress and family levels of risk. One example of a program model that challenges traditional notions of what qualifies as work and instead meets the women “where they are” is Project Match, a program that began in the Cabrini-Green housing project in Chicago. In Project Match, a “step up” model is used in which women move through a ladder of economic independence, from things as basic as volunteering in their child’s Head Start classroom all the way up to work. This model provides women with attainable goals and a clear course to follow (Herr, Halpern, & Majeske, 1995; for more information, see http://www.pmatch.org). Finally, lengthening the amount of time that women are eligible to receive TANF or stopping the TANF clock for women who are performing caretaking duties are also sensitive and viable options that welfare-to-work agencies can employ.

While, as of 1999, 26 states offered exemptions to women “caring for a disabled household member” (State Policy Documentation Project, 2000), many women and their case workers are not aware that these exemptions exist. When they do know that exemptions are available, they are not clear regarding the types of conditions that enable them to qualify (Lloyd, 2002). In addition, because of the disconnect between public assistance application sites and training sites, coordination of exemptions, that is, who is eligible and how exemptions are documented, is inconsistent at best.

2. More education for employers concerning the specific needs of families who have children with special needs. Because low-income women are typically employed in jobs
that do not allow for much autonomy, it is important that employers receive training regarding the inordinate number of demands women face when living in poverty and caring for a child with special needs. Chronic health conditions and disabilities have unique presentations based on the individual, and a cookie cutter, one-size-fits-all approach will prove to be ineffective for those who are juggling the demands of work and caretaking. Linkages between welfare-to-work training sites, agencies that employ women who participate in these programs, and medical facilities is one way to establish ongoing dialogue regarding the individualized needs of these women and their children.

Collaborative models that are geared toward employer education and the development of proactive versus reactive responses to the needs of families with special needs can help identify some of the overarching issues that families face. In addition, these collaborations will allow for advance planning when emergencies do occur.

3. The creation of more flexible employment that is supported. Lastly, considerations such as those identified by Bernheimer, Weisner, and Lowe (in press) and Lloyd (2002) point to the importance of making allowances for basic needs like time to make telephone calls, leave for activities like attendance at meetings outside of work such as school conferences, and the ability to attend medical and welfare appointments. Policies that allow education and/or training or a reduction of work hours may also provide mothers with the flexibility they need to meet their children’s unique demands (Frieden, 2003; Rosman et al., 2002).

CONCLUSION

As this article demonstrates, very little is currently known about the day-to-day needs of low-income caregivers of children with special needs and the way that a mother’s mental health is affected by and impacts children’s development. These families are not typically the focus of research in either the disability field or the poverty field. However, a better, more sophisticated understanding of the way that families develop and sustain caregiving in conjunction with the demands of the living in poverty is critical if mothers are to be competent and skilled partners in their children’s care.

When making assessments, interventions, and/or developing policies, one must understand the functioning of all of the systems that a family must interact with on an everyday basis. Each system has its own line of authority, norms, rules and expectations. This article begins to examine the ways in which systems that have not previously been studied may be playing an important role in determining mental health outcomes for women who are poor and have young children with disabilities. It is vital that exploration of these systems continue, that is, how they help families, how their policies and practices can be improved, and how they can best serve to help—not hurt—families that are living with the confounding challenges of poverty and children with special needs.

REFERENCES


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