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Finding a Fit Between Work and Family Life: Support for Working Caregivers

Eileen M. Brennan

Portland State University

Julie M. Rosenzweig

Portland State University

Alice Myrth Ogilvie

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FOCAL POINT

A NATIONAL BULLETIN ON FAMILY SUPPORT & CHILDREN'S MENTAL HEALTH

FINDING A FIT BETWEEN WORK AND FAMILY LIFE

SUPPORT FOR WORKING CAREGIVERS

This issue of *Focal Point* examines the ways in which families with employed caregivers and children with emotional and behavioral disorders manage to meet the demands of employment and family responsibilities. Finding a fit between the demands of work and family life is a struggle for every employed mother and father. For parents whose children have emotional, behavioral, or mental disorders, meeting this challenge can prove extremely stressful, particularly since supportive services are notably lacking. Although Fernandez has estimated that 10% of all employed parents have at least one child with a disability living in their homes, there has been little research on the perceptions of employed parents of children with mental health concerns about the ways in which work and family responsibilities can fit together.

For the past five years, the Research and Training Center for Family Support and Children's Mental Health has conducted a project, Support for Working Caregivers. The researchers studied families with employed caregivers whose children have serious emotional disorders. After examining nearly 400 books and articles, and finding few studies which addressed the balance between work and family, the researchers decided to interview families with children with emotional, mental or behavioral disorders.

Project staff conducted five focus groups of employed parents of children with emotional, behavioral, or mental disorders. These groups explored the perceptions of employed



parents regarding adaptations they made in their work and family life, and the strategies and services they used to achieve a balance between the role of a worker and a parent. This article reports the findings from this study which addressed the strategies and services the parents employed to make these adaptations work in six major domains: employment, child care, education, transportation, financial assistance, and household tasks and management. (See chart, page 4)

The five focus groups were composed of family caregivers who worked more than 30 hours per week and who cared for at least one child with a serious emotional or behavioral disorder. The 41 focus group parents represented a total of 39 families with 106 children, 60 of whom were identified as having serious emotional disorders. Parents were recruited through service provider organizations, parent support groups, family support conferences, and professional contacts. It should be noted that access to services varied widely among focus group members, and was partially dependent on their geo-

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INCLUSIVE CHILD CARE

For parents to balance work and their children's needs is a challenging task. An additional complication for working parents who have children with emotional or behavioral disorders is to find nurturing, appropriate child care. Some of the barriers to locate suitable child care services involve not receiving equal access to child care settings, the limited number of trained caregivers and the cost of care. A parent advocate, Sherry Archer expressed her concern regarding the accessibility of child care for parents of children with special needs, "Because children with emotional, behavioral or mental disorders are frequently viewed as "bad" or "out-of-control," there may not be the impetus for inclusion of these children in child care settings. Also, empathy for the children or family members may not be present compared to families affected by other types of disabilities."

Additionally, a recent survey by Arthur Emlen of the Regional Research Institute shed light on working parents' perceptions of their child care arrangements. Of the 476 employed parents surveyed, 56 of the parents had a child with an emotional or behavioral disorder that required special attention. Also, he found that of the 56 parents with children with disabilities, 41% responded to the statement, "I've had caregivers who quit or let my child go because of behavioral problems" compared to 2.1% of the 420 parents who reported not having children with disabilities.

In another survey of 2,461 low-income parents receiving child care

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SUPPORT FOR WORKING CAREGIVERS CONTINUED

graphic location. Certain states provided more services, and parents who lived in urban areas reported greater access to support than those from rural areas.

Parents reported that they needed to make adjustments in their type and level of **employment**, so that their jobs would be compatible with the demands of caring for a child with a serious emotional disorder. One parent noted, "I would not be looking for a job based upon my capabilities. I would simply look for a flexible, convenient job which would accommodate my hours so that I could only work when my son was in school." Full-time jobs were traded for part-time work, parents switched to employment which had flexible scheduling available, and work aspirations were reduced, with some parents accepting jobs which had fewer demands for time investment and sustained concentration. When faced with the reality that their child's needs dictated their work schedules because of appointments and the child's behavioral problems at school, parents sought out family-friendly employers and occupations.

For some parents, holding paid employment became very difficult, due to the problems they encountered in their attempts to find **child-care**. Since many of the children with serious emotional disorders participated in special education or were mainstreamed into the regular classroom, employed parents were principally concerned with finding child-care before and after school. For most families, child-care centers were not an option due to the children's behavioral difficulties or emotional states. Several parents had enrolled their children in center care, but were soon asked to leave due to their children's behavior problems.

It was not surprising then, that many parents attempted to supervise their children using nuclear family members. In families with two adult caregivers, work schedules were often arranged so that one parent could



provide child-care after school. For single parents, or families with rigid work schedules, child-care was sometimes provided by siblings backed up by parents who responded in emergencies. A single parent remarked, "I have a problem with having my son cared for. Mostly my teenage daughter takes care of him after school and definitely on the weekends. I work every single weekend; sometimes I work seven, eight or nine days before I get a day off. I have to do this in order to support four kids. I can't afford to pay someone to watch a special needs kid. Everyone I sent him to (cares for him), one time only, and they won't do it again. It is too much. It is hard to find people that understand the child's disorder. It is very important that they understand the disorder before they try and take care of a kid with those disorders."

Other parents discussed carrying pagers or cell phones so that they could be contacted in a crisis. Extended family members on a regular basis rarely gave care.

Because of limited options, parents sought child-care assistance from providers willing to come to the child's home. Often hired care providers were not trained to handle children with serious emotional disorders and so parents had to spend time training them. Child-care workers who could nurture children with

emotional disorders were a rare and expensive resource, and they set their own conditions for employment. A parent commented on her child-care conditions and lack of respite time, "Because it was impossible for a one-on-one adult to handle this little girl, we also had a day care provider to take her from after school until 5:00 pm. For an entire year, the only time that I was away from her was when I was at work because the behavior was so bizarre. We could only find one day care person, and the worker said she would absolutely not take her for more than that hour and a half of time." Few families had satisfactory respite care or school holiday and vacation coverage. Another parent added, "Summer is a very critical time for a parent who works and has children with disabilities because there is no school. They have an additional six hours on hand, and you really have to work and shift with your spouse. Otherwise, you get financially ruined."

A third area of service provision which parents extensively discussed was **education** for their children. Although school personnel provided the principal source of supervision and education, parents expressed the following concerns regarding educators: they were not informed about their child's disorder; nor were they responsive to their children's special needs, and educators had stressful relationships with family members. Parents noted that they spent hours away from work in school meetings because staff did not know how to handle their children. One parent in particular said, "For my daughter who does most of the acting out, the crises...always happened at school. So for me it meant rearranging my work schedule and making the time to meet with schoolteachers, principals and counselors. Sometimes there would be six to eight professional in the room trying to figure out what to do with this child and setting up a new IEP. So I had to drop things and be able to work with the school people

SUPPORT FOR WORKING PARENTS OF CHILDREN WITH SERIOUS EMOTIONAL DISORDERS: A WORKING MODEL FOR INTERVENTIONS

PROBLEM STATEMENT: Although as many as 5–10% of employed parents care for a child who has a severe emotional disorder, and who is under the age of 18, there are inadequate resources available to maintain a satisfactory balance between work and family responsibilities. Most notable, resources for child care are lacking.

GOAL: To promote satisfactory work and family life and to ensure that employed parents are able to access and afford adequate and sufficient child care and family support resources and services.

OBJECTIVES	INPUTS	INTERVENTIONS	OUTCOMES
<p>CHILD CARE To ensure that supervision of children with serious emotional disorders is available and adequate</p>	<ul style="list-style-type: none"> Information on children's specific conditions Adequate pool of child care providers Financial subsidies for child care 	<ul style="list-style-type: none"> Training of care providers by parent groups Resource and referral lists of trained providers Individualized care plans for each family and child with serious emotional disorders Funding distributed for child care subsidies 	<ul style="list-style-type: none"> Adequate, affordable care is available for children with serious emotional disorders Care is of high quality and individualized to meet the children's needs and those of their parents.
<p>PARENT EMPLOYMENT To make available satisfactory and satisfying employment for parents of children with serious emotional disorders.</p>	<ul style="list-style-type: none"> Family-friendly employers and work sites Flexible and adequate benefits packages Flexibility built into work schedules 	<ul style="list-style-type: none"> Education of employers and co-workers about the needs of families with children having serious emotional disorders Personal or employment counseling for parents of children with serious emotional disorders 	<ul style="list-style-type: none"> Parents satisfied with their employment Income needs of families met.
<p>SCHOOLS To foster positive, appropriate and responsive educational experiences for children and employed parents.</p>	<ul style="list-style-type: none"> Training of school staff on child-specific conditions Staff and structure in schools to manage behavioral crises 	<ul style="list-style-type: none"> Training of school personnel on practical aspects of children's disorders Establishment of school crisis management teams to deal with emotional or behavioral crises of children 	<ul style="list-style-type: none"> Better educational experiences for children with serious emotional disorders Fewer interruptions of parents at the workplace for child management issues
<p>TRANSPORTATION To make adequate, safe, and accessible transportation available to meet needs of children and working parents.</p>	<ul style="list-style-type: none"> Adequate pool of providers of transportation for child- and family-specific needs 	<ul style="list-style-type: none"> Training of providers for work with children having emotional disorders Subsidized private transportation as an alternative to public conveyances 	<ul style="list-style-type: none"> Children with emotional disorders are safely transported to school and activities Parents spend fewer hours in transportation per week.
<p>FINANCIAL RESOURCES To secure adequate financial resources and employment benefits to provide for child and family needs</p>	<ul style="list-style-type: none"> Adequate and affordable insurance Entitlement programs which subsidize child care and supportive services for families having children with serious emotional disorders 	<ul style="list-style-type: none"> Training of human resource personnel of public and private sector on family needs Advocacy for legislation for financial supports. Advocacy for changes in child care tax law 	<ul style="list-style-type: none"> Parents can afford quality child care experiences and mental health treatment Parents have incentives to remain employed
<p>HOUSEHOLD TASKS AND MANAGEMENT Ensure satisfactory household management and accomplishment of homemaking tasks.</p>	<ul style="list-style-type: none"> Family members' efforts to accomplish housekeeping tasks Paid help to complete specific tasks 	<ul style="list-style-type: none"> Individualized care plans for household management Training and funding for household services providers 	<ul style="list-style-type: none"> Families live in less stressful and more comfortable surroundings Parents can take on a more extensive work schedule

quite intimately in dealing with her behavior.” Family members reported that they became experts in the Individuals with Disabilities Education Act (Public Law 101-476) and supported others facing challenges in the educational system. When their children’s behavior was disruptive to school programs or the child’s emotional state was not manageable by teachers, parents stated that they were called at work and summoned to school to retrieve their children and deal with the problem. Although several parents spoke of their admiration for school personnel who were well equipped to care for and educate their children, this was the exception. More frequently family members discussed strained relations they had with educators and school administrators, and stated that schools were not set up to deal with employed parents.

Transportation of their children to and from school, appointments, and activities is the fourth area of services perceived as crucial by employed parents. The vast majority of family members reported that they themselves had to provide all transportation for their children with emotional problems. Even though other children with disabilities were transported to school in buses, children with emotional disorders were often excluded from school district buses due to their behavior. One mother expressed her experience; “...my older daughter...managed to get thrown off every bus system she was ever on. I rode the bus with her for a few weeks... and clearly she was a troublemaker. I would be sitting right there beside her and it was still a problem. Transportation problems were a hassle.” When children with serious emotional disorders were allowed on district buses, parents reported that they had to supervise the child’s departures and arrivals home.

Alternative means of transportation to school and activities, such as public transportation and carpools, were not seen as viable options. Therefore, most parents took considerable time out of their workdays to drive their children to school, activi-

ties, or doctor’s appointments.

The fifth domain, **financial assistance** was another area parents’ expressed their concerns. Several family caregivers discussed the inadequacy of their financial arrangements to meet their children’s needs in such areas as mental health treatment, child-care and home services. A few reported that wraparound programs provided financial and material assistance which helped them retain employment and meet their children’s special needs.

Household tasks and management was the sixth domain of concern discussed by the parents. Many employed parents reported that they simply did not have help with household tasks, even though they were employed 40 hours a week or more. This was due to their lack of discretionary funds and their concern about admitting housekeepers into their homes who were unprepared to meet their children’s special needs. However several parents reported that individuals were found who could provide adequate household management services, and emphasized the contributions these workers made to the quality of their family life.

Family members reported very different paths toward achieving fit between the demands of work and family life. Some of the focus group participants settled into a “military routine,” and held to a regimented schedule, which they perceived, worked for their families. Other families achieved fit through viewing their work and family lives as pieces of a complex puzzle. Assistance was hired to reduce work, provide child-care, transportation, and decrease home care demands. Compromises were made in work aspirations, standards for home care, and leisure activities. A parent noted, “I could have worked in international sales because I know different foreign languages, and I unfortunately had to reject this opportunity. I would have accepted the job if I did not have a disabled child. ...I feel that I could not work to my fullest potential intellectually or professionally because I just had to look

for my son’s welfare first.” In addition, several parents stated that the solution to the challenges regarding work, leisure activities and home care were never final since their children’s mental health and developmental changes produced a different set of challenges on a daily basis.

Barriers to achieving a fit were often set up in the communities and organizations within which the employed parents worked. Fragmented services and school systems denied their children certain educational and transportation opportunities because of their emotional or behavioral disorders. Unsympathetic supervisors and co-workers expected employed parents to have their family lives “under control”. Needless to say the work place provided little support.

These findings underscore the need for the development of greater support for families with employed caregivers. More trained child-care providers must be available along with suitable transportation services. Educators must recognize the need for parents to retain employment and provide school crisis teams to care for children when their behavior exceeds recognized classroom limits.

The parents’ responses in the study, Support for Working Caregivers strongly suggest that families and service providers advocate and educate employers regarding the challenges of finding a fit between work and family life for families with children with disabilities. Barriers to employment will come down when employers provide improved benefits in such areas as child care subsidies, flexibility in the use of sick leave, and permit increased flexibility in work schedules.

EILEEN M. BRENNAN, Ph.D., JULIE M. ROSENZWEIG, Ph.D. and A. MYRTH OGILVIE, M.S.W. are faculty research associates for the Research and Training Center and teaching faculty in the Graduate School of Social Work, Portland State University.