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Child Care and Children with Special Needs: Challenges for Low Income Families, 2002-2005

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Child Care and Work Challenges for Maine's Parents of Children with Special Needs Report

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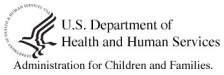

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Child Care and Work Challenges for Maine's Parents of Children with Special Needs

by Helen D. Ward

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Research by the authors with parents, child care providers, and other service providers found that parents of children with special needs face particular challenges trying to maintain stable employment while balancing work and family. These parents have more difficulty finding and keeping child care for children with special needs, and there is a lack of coordination of therapy with child care programs. Since the study was completed, Maine has taken several steps to begin to address these issues.

Carol lives in Maine and is the mother of Jason, a four-year-old boy with autism spectrum disorder. Until recently, the only child care arrangements Carol could find for her son did not offer special services such as speech and occupational therapy (OT) on-site. As a result, Carol lost several jobs because her employers were not willing to accommodate her hectic schedule driving Jason to these services three times a week. Eventually, Carol was able to find a job with a more understanding employer although she still faced challenges at work. In Carol's words, "I was working full-time and I would have to tell my boss that I have to leave for a little while. She is like okay, 'Do what you got to do and come back.' I was bringing him to OT here, preschool, plus speech and after I bring him to all of those, I had to go back to work and stay overtime because I had to make up the hours I lost." For a time, Carol was able to manage this arrangement because her mother was in the area to care for Jason while Carol worked overtime. Eventually, however, her mother moved away. Although Carol enjoyed her job immensely, she was forced to leave the position because no one was available to care for Jason. After suffering a period of financial hardship, Carol was able to enroll Jason in a half-day comprehensive preschool program in her community. Expressing the relief she felt, Carol said, "It is a place where they are going to have all of the services on site, at one location." There would no longer be any need for Carol to leave work to take Jason to his appointments. She felt free to begin looking for a new job, at least for the limited hours that the new preschool is open.

Carol's difficulties balancing the economic needs of her family with the special needs of her son are not unique. In Maine, almost one in ten (9.4 percent) individuals ages five to 20 has a diagnosed disability, the second highest rate in the country (U.S. Census Bureau 2007). Many more children in Maine have *undiagnosed* conditions that present real challenges for parents in finding and keeping child care arrangements, maintaining stable employment, and meeting the special needs of their children. According to staff at Child Care Plus ME, a program designed to prevent child care expulsions, an estimated 70 percent of the calls received from child care providers involve children with undiagnosed behavioral problems (Ward et al. 2006).

Low-income families are especially vulnerable to the work and financial challenges of caring for a child with special needs because they are twice as likely to have a child with special needs as are higher income families (Ward et al. 2006). These low-wage earners are also less likely to have the workplace flexibility that allows them to attend to their child's special needs without jeopardizing their employment (Ross Phillips 2002).

This article presents research we conducted in Maine to examine the complex relationships between child care and work issues for parents of children with special needs. Elsewhere in this issue, Alan Cobo-Lewis writes about the bewildering array of programs and funding streams that families of children with special needs must navigate to access services for their children. While we focus on the child care and work challenges of parents in this population, we echo his call for better coordination of services, specifically as it relates to the difficulties this lack of coordination poses for parents who are attempting to maintain stable employment while meeting the special needs of their child.

We used focus groups and interviews with parents of children with special needs and interviews with child care providers, professionals delivering therapeutic services (e.g., occupational therapists, speech therapists), DHHS caseworkers, and others who serve this population. We also conducted a statewide survey of 189 child care providers and 441 parents of children with special needs, and analyzed data from the National Survey of America's Families (NSAF).

Our findings indicate that thousands of parents of children with special needs across Maine face significant challenges maintaining stable employment and balancing work and family. Most of the difficulties these parents face will seem familiar to any parent. Yet our research indicates that for parents of children with special needs, the intensity and frequency of these

difficulties and the impact they have on their employment is heightened because of the particular demands of their children. Research conducted elsewhere in the country echoes our findings, especially with regard to the particular difficulties faced by parents of children with behavioral special needs (Rosenzweig et al. 2008).

DIFFICULTIES FINDING CHILD CARE FOR CHILDREN WITH SPECIAL NEEDS

Parents of children with special needs face great difficulty finding child care. One parent told us,

> I found a job immediately when I moved up here…. I couldn't find child care because it was too hard, because nobody wanted to take a child with special needs. But I brought him to a day care and I had called every other place and went and drove by it to see what it is like before I brought him. About the tenth one I called, she said, "Sure, bring him over." So I bring him over and she called me two days later and I was supposed to start work on Monday and it was Saturday and she said, "I can't watch your son because it is going to be too difficult for me."

…job stability among parents of children with special needs… is significantly lower than for parents of children without special needs.

Parents whose children have behavioral difficulties face more challenges finding and maintaining child care arrangements than do parents of children with solely physical disabilities or speech/language difficulties. DHHS caseworkers reported that it was easier to find and maintain child care for a child with *physical* disabilities than for a child with behavioral problems. Similarly, about three-quarters (74.8 percent) of the child care providers we surveyed said they found it more difficult to care for children with behavioral problems than children with physical/medical special needs. Interestingly, both parents and providers reported that parents whose children don't appear on first impression to have special needs will enroll their children without telling the provider just to "get their foot in the door." Then when the child has difficulties, the parents feign surprise. Staff from Child Care Plus ME liken children with behavioral difficulties to "canaries in a coal mine" who are the first to show the negative effects of more global issues of quality in a child care setting. Yet with improvements in overall quality, appropriate training and on-site consultation from mental health experts, children with special needs can be integrated successfully into child care programs.

EXPULSION OF CHILDREN WITH SPECIAL NEEDS FROM CHILD CARE

Although Maine is making inclusion efforts for children with special needs, our study found that expulsion from child care is a significant problem. More than one-third of the providers we surveyed (35.2 percent) reported asking a child with special needs to leave their program. Asked what challenges they face in caring for a child with special needs, providers cited lack of staff for necessary supervision (58.5 percent); concerns about disruptions to other children (51.7 percent); lack of training (44.3 percent); and difficulties including children with special needs in program activities (23.9 percent).

Parents reflected many of these concerns. For example,

- Almost one in five (18.9 percent) were asked by a child care provider to remove their child from the program.
- Almost one-quarter (22.5 percent) reported a lack of inclusion of their child with special needs in the activities of the program.
- Almost one-third (30.2 percent) reported a lack of support from the provider regarding their child's special needs.

LACK OF COORDINATION OF THERAPY WITH CHILD CARE PROGRAMS

Even when stable, satisfactory child care is found, our findings demonstrated that the ability of parents of children with special needs to balance work and family is often affected by a lack of coordination between the child care system and the services their children need (e.g., speech therapy, occupational therapy, developmental therapy). The Individuals with Disabilities Education Act (IDEA) provides for early intervention and preschool special education services for children ages zero to five, as well as school-aged children. IDEA contains requirements that emphasize the importance of children receiving these services at home or in a setting where the child interacts with nondisabled peers, rather than in a specialist's office. If services are delivered in the child's natural environment, communication can occur between the specialist and the parent and/or child care provider so that between sessions all of the adults interacting with the child are "on the same page." The child is able to apply what is learned in his or her normal environment instead of having to transfer what is learned in the artificial setting of the specialist's office to those more normal settings. In addition, as Carol's story illustrates, when services are delivered on site, parents have fewer transportation issues during the work day.

However, funding and other constraints, along with the transportation issues inherent in a rural state such as Maine, have hindered full implementation of that model, which is reflected in our findings. Ninety-three percent of children of the parents in our survey were reportedly receiving early intervention or preschool special education and related services under IDEA. Nearly half (42.4 percent of children ages zero to two and 46.8 percent of children ages three to five) were receiving some or all of their services in specialists' offices. Parents indicated all of the settings where their child received services, so some children may have been receiving services only at child care or both at home and at a specialist's office. However, only 22.5 percent of child care providers in our provider survey reported that services were provided at their child care program. This lack of coordination between child care and IDEA early intervention/preschool special education services can cause transportation problems, work disruptions, and difficult transitions for children and families. In some cases, as Carol's story illustrates, despite a desire to work, parents are unable to stay employed. But for many more, employment remains an economic necessity.

EMPLOYMENT CHARACTERISTICS OF WORKING PARENTS OF CHILDREN WITH SPECIAL NEEDS

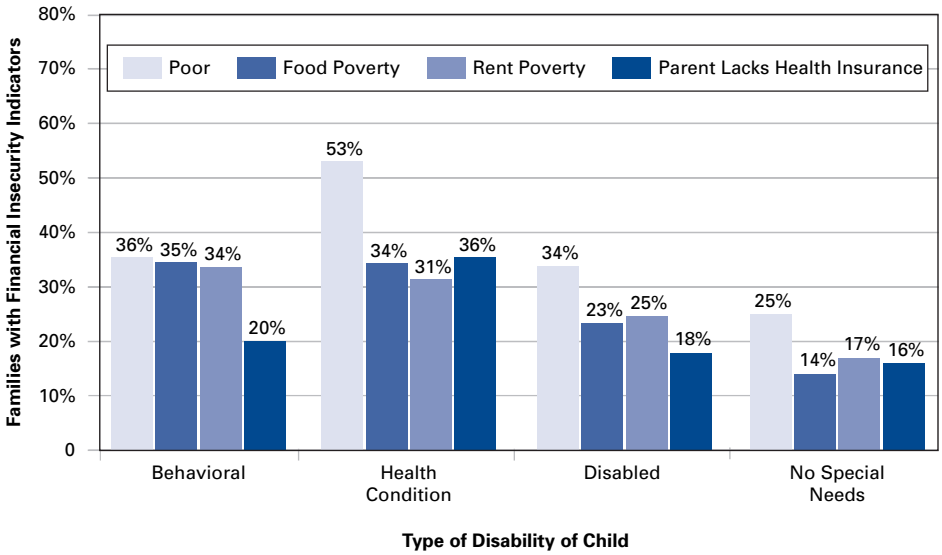
Parents of children with special needs do work, but their employment is unstable, and they find it difficult to move up the career ladder. Our analysis of data from the National Survey of America's Families revealed that a substantial proportion of parents of children with special needs work, and among those who are employed, they are as likely to work full-time as parents of children without special needs. This may be due to economic necessity, the need for the health insurance, and/or the desire for a respite from caring for their child with special needs.

Parents in Maine reported some of the difficult work choices they made related to the demands of meeting the special needs of their children. These included reducing (57.2 percent) or changing (44.2 percent) their work hours, refusing a job offer or promotion (29.4 percent), or quitting their job altogether (30.3 percent).

Given these work difficulties, it's not surprising that despite higher than expected labor force participation rates, job stability among parents of children with special needs, as measured by number of months in the parent's current job, is significantly lower than for parents of children without special needs. Nationally, parents of children with no special needs reported they had been in their current job on average for 79 months; for parents of a child with a behavioral disability it was 70 months; and for those whose child had a health condition, it was 59 months. In part due to this job instability, parents of these children experience more financial insecurity than do parents of children without special needs.

Even after we controlled for other factors (mother's age, race, education, marital status, number of dependent

FIGURE 1: **Percentage of U.S. Families Experiencing Indicators of Financial Insecurity, by Type of Disability of Child**



children) that can influence economic status, financial security for these families remained more precarious than for parents of children without special needs.

INCREASING PARENTAL FINANCIAL STABILITY *AND* MEETING CHILDRENS' NEEDS

Addressing the challenges faced by parents of children with special needs is important both to provide a more stable workforce for Maine's economy and to enhance the long-term outcomes for children with special needs. If parents experience child care and work problems, their ability to access services for their child at an early age (when intervention is most effective) can be diminished.

Meeting the complex needs of these families will require greater public investment and closer collaboration between agencies in order to strengthen the capacity of the early care and education system to serve these children, address gaps in services, and resolve programmatic and policy conflicts. Since we completed our study in 2006, Maine has taken significant steps to address these issues. The state continues to support Child Care Plus ME, a state-university partnership project of the Maine Department of Health and Human Services (DHHS) Early Childhood Division and Children's Behavioral Health and the Center for Community Inclusion and Disabilities Studies (CCIDS) at the University of Maine. The initiative provides information, resources, training, and technical assistance to child care providers to increase access, participation, and retention of children with special needs in child care, to prevent expulsion, and to improve the quality of early care and education.

In 2007, a new program built upon the early childhood mental health consultation to child care provided by Child Care Plus ME—an initiative designed to train community early childhood mental health clinicians to provide child-specific and programmatic consultation to child care programs. Maine also participates in Expanding Inclusive Opportunities, a federally funded initiative to enable states to receive technical assistance in undertaking state team/systems-level collaborative planning to expand inclusive opportunities for young children and their families. This interagency planning process includes the key stakeholders from the early care and education system, the early intervention/preschool special education programs under IDEA, the CCIDS, and parents of children with special needs.

These efforts are in line with many of the broad recommendations included in our final report from the 2006 study:

- Providing greater interagency coordination to meet the complex needs of families of children with special needs.
- Strengthening the capacity to provide inclusive, high-quality child care to children with special needs.
- Delivering services under IDEA (e.g., speech therapy, occupational therapy, physical therapy, developmental therapy, specialized instruction) in a way that supports inclusion and the need of parents to work.

- Making welfare to work policies flexible enough to meet the individual circumstances of families of children with special needs.
- Providing greater flexibility in the workplace to allow parents to maintain employment while still meeting the special needs of their children.

Specific strategies under each of the recommendations listed above are suggested in the final report which can be downloaded from our project Web site (www.muskie.usm.maine.edu/specialneeds). We are encouraged that the voices of parents like Carol are being heard by Maine policymakers, and we hope the difficult interagency work that has begun at the state and local level will ultimately relieve parents' child care and work challenges and help children to gain access to the early intervention services they need to reach their full potential.

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