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## Child Care and Children With Special Needs: Challenges for Low Income Families [Report]

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Child Care and Children with Special Needs:

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Challenges for Low Income Families



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*Final Report*

# **Child Care and Children with Special Needs: Challenges for Low Income Families**

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*December, 2006*



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Furthermore, the findings from our study reflect the experiences and opinions of the research participants only and the suggested strategies we include in this report are those of the staff at the Cutler Institute who conducted this study. While the Advisory Committee helped us to conceptualize and carry out this study, and individual members provided us with comments on this report, the final conclusions do not necessarily reflect the opinions of the individuals who served on that Committee.

Lastly, please note that when parents are quoted in this report, the quotes are anonymous and when a parent refers to a child, the first name of the child, and sometimes the gender, are changed to protect confidentiality.

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## CHAPTER ONE

# Highlights of Findings

## Introduction

In Maine, an estimated 10.4% of children, or one in ten, has a diagnosed disability and/or chronic health condition; the highest prevalence rate in the country (U.S. Census, 2004). Many more children in Maine have *undiagnosed* conditions that still present significant challenges for their 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 in Maine designed to prevent child care expulsions, an estimated 70% of the calls received from child care providers involve children with *undiagnosed* behavioral problems. Similarly, in our survey of licensed child care providers in Maine, 65% of respondents believed they had cared for a child with special needs who did not have a diagnosis.

This is a growing problem in Maine. Between 1992 and 2005, the total number of children and young adults (ages 6 to 22) in Maine diagnosed with disabilities increased by 30.3% and the number diagnosed with autism increased by a remarkable 3,098% from 46 children ages 6 to 22 to 1,471 statewide. (IDEA Data).<sup>1</sup> Experts cite a range of possible causes for these increases including a greater awareness of childhood disabilities which has led to more diagnoses at younger ages, pollutants in the environment and medical discoveries that have helped many more premature babies survive but with a higher risk of disabilities and chronic health conditions. (Hogan, 2003; Shonkoff, 2000) Child care providers report a growing number of children exhibiting behavioral difficulties, diagnosed and undiagnosed. Thousands of parents of children with special needs across Maine are facing significant challenges maintaining stable employment and balancing work and family. Many of their difficulties are experienced by families of “typical” children but the problems of these parents are ratcheted up because of the special needs of their children.<sup>2</sup>

Our analysis of data from the National Survey of America’s Families (NSAF) shows that *low income* parents of children with special needs are having an even harder time than are higher income parents of children with special needs. Yet the prevalence of special needs among children, as reported by parents in the NSAF, is twice as high for these families as it is for higher income families (See Chapter 6 for more information). Maine is a state which depends heavily on the availability of workers for lower wage employment in the tourism, retail and health fields. The challenges these parents face present significant obstacles to attracting and retaining the workforce Maine’s economy needs. This issue is also significant because if parents are experiencing these child care and work problems, their ability to meet the special needs of their child at an early age, when intervention is most effective, can be diminished. Missing these opportunities will only increase the costs to the state for health care and remediation when these children reach school age.

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<sup>1</sup> This increase is largely due to the number of very young children ages 3 to 8 who have been diagnosed in the last decade and are included in these special education statistics when they become school age.

<sup>2</sup> We use the term “typical children” to refer to children with no special needs, as defined in this study.

This three year study, a project supported by the Child Care Bureau, Administration for Children and Families, U.S. Department of Health and Human Services, examined the challenges faced by low income parents of children with special needs in finding and retaining child care for their child, and balancing work and family. We also looked at the degree to which the early intervention/preschool special education system under the Individuals with Disabilities Education Act (IDEA) is coordinated with child care because difficulties accessing these services can lead to work disruptions for parents.

The strength of this study comes from the triangulation of data from multiple sources in order to examine the very complex cross-systems issues experienced by this population. Very often the real challenges these parents face are not adequately understood when studies are confined to their experiences with only one system such as TANF or child care or early intervention/preschool special education. We gained our richest insights into the experiences of these families when we examined where these systems *intersect* with each other. In fact, when parents were surveyed by phone, several told us that this was the first time anyone had asked them about the “real” issues they faced. Our approach would not have been nearly as effective had we not started with qualitative research interviewing parents and the staff of the agencies, within all three systems, which serve them. These interviews were invaluable not only in producing the “stories behind the numbers” but also in informing the development of our research questions and survey instruments, as well as the secondary analysis of national data, for the quantitative phase of our study.

## **How this Report is Organized**

This report is divided into chapters which describe our methodology and report our findings from each of the data sources used in this mixed-method, exploratory study. This chapter provides the major themes which emerged from our research, a brief description of the overall study methodology and highlights of our major findings from all of these data sources, illustrated by quotes from parents. It also includes a discussion of the policy implications of our findings and suggested strategies. A preliminary report providing the results of our first year interviewing parents of children with special needs, *Parents’ Voices*, was published in April, 2004 and can be downloaded from our web site: <http://www.muskie.usm.maine.edu/specialneeds>.

## **Major Themes**

- **Parents of young children with special needs face significant challenges finding and keeping child care arrangements for their child.**
- **Parents report significant problems with the child care arrangements they have used for their child with special needs, including:<sup>3</sup>**
  - Lack of support from provider
  - Concerns over safety
  - Lack of inclusion of child in the activities of other children

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<sup>3</sup> Parents were asked to report only those work problems that were directly related to the demands of caring for their child with special needs.

- Provider wouldn't administer medications
  - Provider called more often than parents felt was necessary
  - Child Care hours didn't match work hours
  - Too expensive
  - Loss of child care because provider asked parent to remove child from the program
  - Child "aged out" of child care system but because of special needs still needed supervision and there were no other options available.
- **There are significant programmatic and financial barriers to supporting parents of children with special needs so they can work, and balance work and family.**
    - Child care providers report a desire to care for children with special needs but a lack of resources to do so including, in particular, a lack of funding for additional staff to care for the child with special needs and the other children.
    - Lack of coordination between early intervention/preschool special education services under IDEA and the child care system, as well as a shortage of specialists (e.g. OTs, speech therapists), mean that special services often are not delivered in the child's "natural environment" as required by Part C, or in the "least restrictive environment" as required by Part B of IDEA.<sup>4</sup>
      - Lack of on-site delivery of services at the child care program, lack of appropriate transportation options and long distances to service centers in rural areas make it necessary for some parents to leave work to transport their child to special services. Some have had to forgo services altogether because of these difficulties.
      - Even when special services are provided on-site, decisions about the amount and frequency of these services provided under IDEA are determined by the child's therapeutic needs, not the parents' need to work. As a result, services children may need to be successful in the child care setting such as a one-on-one aide or a deaf interpreter, are provided for only part of the day, even though the children are in the child care setting all day. In addition, therapeutic programs provided for children with special needs are often only open part-day or part-week and are closed in the summer causing significant transportation and work issues for families.
- **The combination of all of these problems and the particular demands of caring for a child with special needs often result in employment problems and job instability.**
    - Parents of children with special needs report a range of work problems for reasons related to caring for their child with special needs, including having to change or reduce their hours, turning down job offers or promotions, quitting work other than for normal maternity or family leave and being fired from or fearing the loss of their job.
    - Mothers of children with special needs are less likely to be in the labor force than are mothers of children without special needs.
    - Mothers of children with special needs have less job stability (weeks worked in last year and number of consecutive months with current employer) than do mothers of children without special needs.

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<sup>4</sup> Part C of IDEA provides early intervention services to children ages 0 to 3 who are developmentally delayed or who have conditions likely to lead to developmental delays. Section 619 of Part B of IDEA provides preschool special education services to children with disabilities ages 3 to 5. In Maine, both programs are administered by Child Development Services (CDS) under the Maine Department of Education.

- *Low income* mothers of children with special needs have less job stability than do higher income mothers of children with special needs.
- *Single* mothers of children with special needs have less job stability than married mothers of children with special needs.
- **Families of children with special needs face more economic difficulties (poverty, food and rent insecurity, lack of health insurance) than do families of children without special needs.**
- **Certain types of disabilities have a greater impact on the number of child care and work problems than others.**
  - Parents with children with multiple diagnoses with a behavioral component (e.g. autism with a seizure disorder) reported the greatest number of child care and work problems, followed by parents of children with purely behavioral problems, parents of children with only physical disabilities and, lastly, parents of children with speech/language problems.
  - Employed mothers of children with disabilities are no less likely to work full-time (as opposed to part-time) than are mothers of children without special needs. However, mothers of children with health conditions or behavioral problems are actually *more* likely to be working full-time than are mothers of children without special needs.<sup>5</sup>
  - Mothers of children who reported that their child was in poor health had less job stability than those who reported that their child had a disability or behavioral problem.
- **Having a child with multiple special needs or having more than one child with special needs significantly increases the likelihood of employment difficulties and job instability.**

## Summary of Study Methodology

A full description of each of the methodologies used in this study is included in the other chapters of this report. These methodologies are also summarized in the table below and described briefly here.

- **Focus groups and individual in-depth interviews** with low income (below 225% of the federal poverty level) parents with at least one child age six or under with special needs. These were conducted in three communities in Maine (Bath/Brunswick, Lewiston/Auburn and Presque Isle) and in Connecticut (Waterbury, Manchester and Norwich).<sup>6</sup> We also did

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<sup>5</sup> We speculate that the data regarding levels of employment (full-time vs. part-time) may reflect the particular importance to these families of obtaining the health insurance that often goes with a full-time job in order to meet the special needs of their children.

<sup>6</sup> At the end of the first year of our study, we concluded that we needed to confine our research to Maine for two reasons. First, we could make a significant contribution to existing knowledge if we looked in greater depth at these issues, especially as they manifest themselves in rural communities. Second, the complexities of these cross systems issues and recruitment challenges would have made it difficult to conduct our study effectively in both states within available resources.

interviews with parents in Portland (N= 41).<sup>7</sup>

- **A field study** consisting of in-depth interviews with TANF caseworkers and case workers at the multi-barrier agencies which help TANF families overcome barriers to employment, physical, occupational and speech therapists, child care providers, staff at Child Care Plus ME which provide assistance to child care providers in serving children with special needs, and staff at the child care resource and referral agencies (called RDCs in Maine) in three communities in Maine: Presque Isle, Lewiston/Auburn and Portland (N=66).
- **A statewide survey of a random sample of licensed child care providers** in Maine to examine the issues they face serving children with special needs (N=179).
- **A statewide survey of parents of children with diagnosed special needs** across the income spectrum in Maine. Parents responded to a mailing sent to 4,000 families receiving services from Child Development Services (CDS)<sup>8</sup> and 2,200 families enrolled in Maine Care (Title V and the Katie Beckett Waiver eligibility groups) (N=441).<sup>9</sup>
- **An analysis of data from families with children participating in the National Survey of America's Families (NSAF).** This analysis allowed us to compare work patterns of families with and without a child with special needs and among different types of special needs. In order to generate sample sizes large enough to reliably investigate relationships between child special needs and parental employment outcomes, data were extracted from all three waves (1997, 1999 and 2002) of the NSAF and merged to create a pooled sample of primary caregivers and their children. The pooled sample consists of 81,841 caregivers who are either the biological parent to the child or step or adoptive parent who answered questions about 104,556 children under the age of 18. Eleven percent (N=8,914) of these families reported having a child with a mental or physical disability and 5.2 % (N=4,240) reported having a child in poor health. Among the sampled children ages 6 to 17, 7 % (N=4,713) are reported by their parent to have behavioral or emotional problems.<sup>10</sup>

## Definition of Special Needs

For our research in Maine, special needs were defined broadly for purposes of selecting and analyzing the study population. Since the focus of our study was on the child care and work challenges of low income families with children with special needs, we selected our study population and categorized the special needs of the children by how the condition(s) reported by parents would affect the care of the child and the other children in the child care setting. We asked parents about the diagnoses of the children and also whether there was a behavioral component that went along with the diagnosis and whether the child required daily medication and/or medical procedures. We came up with the following categories for purposes of our analysis: Non-behavioral, Behavioral,

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<sup>7</sup> In quoting parents for this report we have changed names, and in some cases the gender of the child, in order to protect confidentiality.

<sup>8</sup> CDS is Maine's program to administer the Part C Early Intervention and Part B Section 619 Preschool Special Education programs under the Individuals with Disabilities Education Act (IDEA).

<sup>9</sup> Maine Care is Maine's expanded Medicaid Program. Children with a special health care need or a disability severe enough to qualify, can be enrolled in Maine Care regardless of income through the Katie Beckett Waiver program. The Title V category for Maine Care are those children who are enrolled in Maine Care and who are also eligible for the Title V Maternal and Child Health Program because they have special health care needs.

<sup>10</sup> In the NSAF, questions about behavioral/emotional problems were only asked about children ages 6 to 17.



Multiple Diagnoses with a Behavioral Component (e.g. autism and a seizure disorder) and Speech/Language Only. These categories, and the decisions about which category to place specific diagnoses in, were reviewed and approved by two pediatricians with extensive experience caring for children with special needs who advised us in this study.

For our analysis of the NSAF data, special needs were grouped by the answers to a series of questions asked of parents in the NSAF to determine if their child had a disability or emotional/behavioral problem as well as questions relating to the child's health status. Questions about behavioral problems were only asked about children ages 6 to 17. These produced the following categories for purposes of our analysis: Disability, Health Problem and for children ages 6 to 17, Behavioral Problem.

The table on p. 1-8 provides a comparison of data sources. In general, the NSAF was a nationally representative sample of families which allowed us to compare families with and without children with special needs. The sample of families with children with special needs was based solely on parental report about the special needs of the child and so is likely to include some children with diagnosed but *milder* special needs as well as children with *undiagnosed* special needs. Our survey sample in Maine, on the other hand, was drawn from state agency lists and so consisted only of children with diagnosed special needs significant enough to qualify for services. Therefore, the impact of the presence of children with special needs on work is likely to be less in the NSAF survey than in our parent survey in Maine.

## **Limitations of the Data**

### ***Qualitative Research***

The findings from our qualitative research are based on interviews and focus groups with parents and service providers who responded to our recruitment efforts and are not necessarily representative of the point of view of the entire population of parents of children with special needs or the providers who serve them. Nevertheless, the findings from this exploratory phase of our study are remarkably similar to the findings of our quantitative research involving a statewide survey of a representative sample of parents of children with special needs receiving services in Maine, our statewide survey of licensed child care providers in Maine and our analysis of data from the National Survey of America's Families (NSAF).

### ***Parent Survey***

Our parent survey, which was conducted by phone, had 441 participants who responded to a mailing sent to 6,200 parents on agency lists whose children were receiving services and/or health insurance coverage because of their special needs. This yielded a sampling error rate of +/- 4.5 percentage points. Since we were not permitted by the state agencies to call the parents on the agency lists directly to make an initial contact, the survey sample consisted of only those parents who called us in response to the mailing we sent. Therefore, there may be an inherent bias if that resulted in parents with more time, more motivation, higher education levels and/or stronger opinions being more likely to respond.

### *Analysis of the NSAF*

The NSAF was a survey conducted on a nationally representative sample of families, including those with children with special needs. The NSAF provided a large enough sample of families to enable us to conduct a more comprehensive analysis of some of the issues addressed in this study. The NSAF did not, however, ask the same questions we asked in our parent survey but where the areas of inquiry did overlap, we were able to use the NSAF data to give us some sense of the degree to which our findings in Maine are supported by national data.

## Methods Used

<b>Parent Interviews/Maine and Connecticut<sup>11</sup></b>  (2002)	<b>Field Study/Maine</b>  (2003/2004)	<b>Child Care Provider Survey</b>  (2004)	<b>Parent Survey</b>  (Winter 2004/2005)	<b>Analysis of 1997, 1999 and 2000 Data from National Survey of America's Families (NSAF)</b>  (2005/2006)
<p>41 low income parents (under 225% of poverty) of children ages 0 to 6 with special needs in six communities in Connecticut and Maine.</p> <p>Recruited through co-sponsorship of community grassroots organizations and publicizing study in low income neighborhoods.</p> <p>Special needs broadly defined to include diagnosed and undiagnosed behavioral, physical and mental health problems; however, almost all of the families who responded to our recruitment efforts had children with diagnosed conditions.</p>	<p>66 interviews with child care providers, therapists, TANF caseworkers, multi-barrier agency caseworkers, therapeutic specialists (OT's, speech, etc), and child care R&amp;Rs in three communities in Maine.</p>	<p>Statewide survey of 179 respondents from a random sample of 430 child care providers in Maine drawn from state agency lists of licensed providers.(41.6% response rate).</p>	<p>Statewide survey of 441 respondents who are parents of children ages 0 to 18 with diagnosed special needs, and enrolled on Maine Care, (Katie Beckett and Title V eligibility groups) and CDS caseloads. <sup>12</sup> 61% (267) were parents of children ages 0 to 5.</p> <p>Sample does not include children with undiagnosed health conditions or disabilities/conditions that are too mild to qualify them for Maine Care or CDS services.</p> <p>Categories of special needs for our analysis included Speech/Language Only, Behavioral, Non-behavioral and Multiple Diagnoses with a Behavioral Component.</p>	<p>Analysis of data from the NSAF, a nationally representative sample of 81,841 parents of children ages 0 to 16 and a sub sample of those parents who reported having a child with special needs (diagnosed and undiagnosed). Families represented were of all income levels. Comparisons were made between parents of children with and without special needs and among the types of special needs represented.</p> <p>To obtain a large enough sub sample of parents of children with special needs, the sample was pooled from three waves of data from 1997, 1999 and 2000.</p> <p>Categories of special needs for our analysis were disabilities (8,914), poor health (4,240) and, among children age 6 to 17 only<sup>13</sup>, behavioral problems (4,713).</p>

<sup>11</sup> See footnote # 6.

<sup>12</sup> See footnote #'s 8 & 9.

<sup>13</sup> See footnote # 10.

## Research Questions

Our research questions for our study in Maine were as follows:

- What are the experiences of low income parents of children with special needs in finding and keeping child care and employment and balancing work and family?
- What constellation of supports makes it possible for these parents to work and successfully balance work and family? What are the triggers that cause things to fall apart?
- Is the system of child care subsidies and provider training and support adequate to respond to the need for child care by low-income families with children with special needs?
- What has been the experience of these families in the workplace?
- Does the manner by which early intervention and preschool special education services are delivered reflect the need of parents to maintain employment?
- What is the economic impact on the family?

Our research questions for our secondary analysis of the data from the National Survey of America's Families (NSAF) were as follows:

- Are mothers of children with special needs working less than mothers of “typical” children?
- Are working mothers of children with special needs having greater difficulty retaining jobs than mothers of “typical” children?
- Do some types of special needs have a greater impact on maternal employment than others?
- Are families of children with special needs more likely to be poor and experiencing financial insecurity than families of “typical” children?
- Do *low-income* mothers of children with special needs have more difficulty balancing work and care giving compared to more financially secure mothers with children with special needs?
- Do *single* mothers of children with special needs have more difficulty balancing care giving and work compared to married mothers with children with special needs?

## Summary of Major Findings

**NOTE:** When we report our national findings from our analysis of the NSAF, we will indicate that. All other findings are from our research in Maine. See the individual chapters on each data source for more information.

## Child Care

The questions we included in our statewide surveys of parents and child care providers in Maine, as well as our qualitative focus groups and interviews, enabled us to examine in depth the child care issues of these families.

### *Access to Child Care and Provider Challenges in Accommodating Special Needs*

Issues of child care access for this population are significant because our data on employment indicates that while mothers of children with special needs participate in the labor force somewhat less than other mothers, those who do work outside the home are at least as likely to work full-time as are other mothers (See section on work later in this chapter). In addition, many of the parents we interviewed who did not work indicated that if appropriate child care was available for their child with special needs, they would take a job outside the home.

- Parents interviewed reported being turned down by child care providers because of the special needs of their child or concluding that there was no child care provider adequately equipped to care for their child.
- Findings from our child care provider survey support what the parents told us about the difficulty of finding child care providers willing to take their child. Approximately one quarter of respondents reported that they could not accommodate children with even *mild* issues of mobility, toileting, mental retardation, seizures or conditions requiring the administration of medications.
- Some parents reported using strategies such as not telling a provider that their child has special needs in order to get their “foot in the door” and then feigning surprise when problems came up with their child.
- This strategy was reported by the child care providers as well. Nearly 36% of the providers who participated in our survey said they had admitted a child to their program and learned later that the child had special needs.

*They wouldn't tell you, "Oh no, we don't take too many special needs." They wouldn't flat out tell you that. Instead, "We don't have any space." If you call back, maybe some of them are transitioning out and they put you on waiting lists and then you never hear back from them. I called say, twenty providers from the list and then I had to start calling outside my general area. It was huge but no matter what when I called day cares nobody would take my son.*

A mother of a child with Prader-Willi Syndrome

*I had found a job immediately when I moved up here. Even just to get started, you know, I couldn't find child care because it was too hard, because nobody wanted to take a child with special needs. He is not hard to take care of anyway, I mean he just sits there and plays with his toys. 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." Then my friend brought her child there. She said, "Yeab, I can have him here." He still goes there. So then I had to work nights because my mother could only watch him at night. Finally I did find child care for him. But it was a month later before I even got that started.*

A mother of a child with developmental delays

- TANF and multi-barrier agency caseworkers reported that it was easier to maintain child care for a child with physical disabilities than for a child with behavioral problems. Once the needs of the child with physical disabilities are accommodated, their needs don't usually change. Children with behavioral problems, on the other hand, have needs that are not as stable. As a result, child care arrangements for these children are more apt to fall apart over time.
- In line with this observation, nearly 75% of the child care providers we surveyed said they found it more difficult to care for children with behavioral issues than to care for children with physical/medical special needs.
- Child care providers report a desire to care for children with special needs but a lack of resources to do so including:
  - Lack of funding for additional staff to care for the child with special needs and the other children
  - Lack of specialized training about child disabilities
  - Lack of funds to provide special equipment to make their program accessible
  - Inadequate reimbursements to cover the additional costs
- When asked to identify the biggest challenges in accommodating children with special needs, most providers cited not having enough staff for necessary supervision (58.5%) followed by disruptions to other children (51.7%), lack of training (44.3%) and difficulties including children with special needs in all activities (23.9%).
- While 21% of respondents to our child care provider survey said they were "very satisfied" with the level of child care subsidy for children *without* special needs, only 6 % were "very satisfied" with the level of subsidy received for children with special needs.

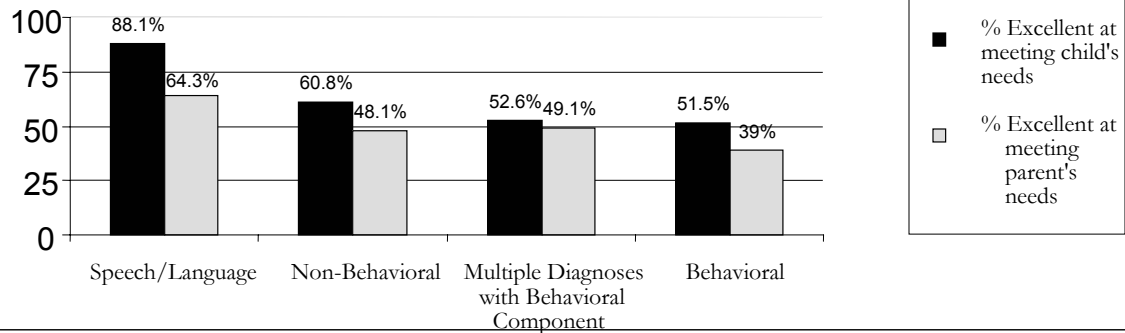
*The problem I seem to have with my son is that his disabilities aren't obvious. He isn't like Down Syndrome so he doesn't have any features. He just seems a lot younger than he is. So I had a real problem putting him in a preschool when he was three. Several day cares wouldn't accept him because he was over three and not potty trained. Even when I said that is part of his special needs. Developmentally he just couldn't do that. You know a disability is a disability. They had so many excuses. Like, "We understand, but our workers can't lift a 45 pound child onto a changing table to change him."*

A mother of a child with developmental delays and a seizure disorder

### ***Parental Satisfaction with Current Child Care Arrangement***

- Parents of children with speech and language difficulties but no other problems were most likely to be satisfied that their child's child care arrangement was meeting their child's needs (81.1%). Parents of children with behavioral problems were the least likely of all the groups to be satisfied (51.5%).

### Percent Satisfied that Current Child Care Arrangement Meets Child's Needs vs. Parent's Needs by Type of Disability (n=277)



Source: Survey of Parents of Children with Special Needs in Maine

### Child Care Problems Now or in the Past

- Parents of children with special needs reported a range of child care problems now or in the past including:
  - Child care hours didn't match work hours (36.1%)
  - Lack of support from provider (30.2%)
  - Lack of inclusion of child in the activities of other children (22.5%)
  - Concerns over safety (22.1%)
  - Too expensive ((19.1%)
  - Child care provider asked parents to remove their child from the program (18.9%)
  - Lack of accessibility (16.7%)
  - Child "aged out" of child care system but still needed supervision because of special needs and there were no other options. (15.5%)
  - Provider wouldn't administer medications (13.7%)
  - Provider called more often than parent felt was necessary (11.4%)

*I don't have child care providers turning me away – they just stick him in the corner. He wasn't as active as the other kids and they would just put him in the corner. He had to go outside for whatever the rule is, at least half an hour or something. They brought him outside and he just sat in the sandbox and the other kids would play. I noticed they would put him in a stroller and strap him down and just leave him there. If I showed up unexpectedly, he would be alone. One day it was his birthday, so I brought in some cupcakes. He was in the corner, like so pitiful. [The mother started crying at this point.] He didn't get any kind of attention, he wasn't part of the general group. He was just there. So I took him out and I changed my shift and worked nights, so I could be home in the daytime until he went to school.*

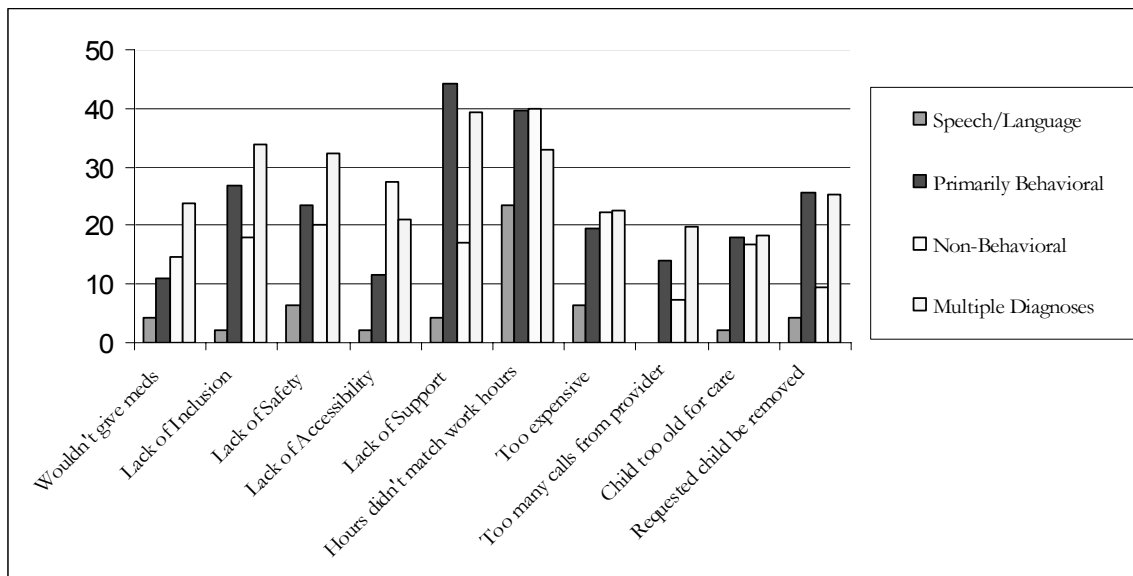
A mother of a child with developmental delays

- Parents of children with behavioral problems only were most likely to report a lack of support from their child care provider (44.2% compared to only 4.3% for children with speech/language problems.)
- Children with multiple diagnoses with a behavioral component and those with behavioral diagnoses experienced significant levels of exclusion from educational or play activities provided to other children (34% and 27% respectively compared to only 2% of children with speech/language problems).
- Almost one-quarter (23.9%) of parents of children with multiple diagnoses with a behavioral component have had problems with providers not administering medications.

*I go in to his child care and I sit him on this big rug with a bucket of toys. When I come back to pick him up he is sitting there in the same spot and nobody is around him – he just sits in the corner the whole time. [The child can't walk.] I just don't think it's fair. So I don't like to leave him there a lot.*

A mother of a child with developmental delays

### Percent of Parent Survey Respondents with the Following Child Care Problems by Type of Disability



Source: Survey of Parents of Children with Special Needs in Maine



## ***Child Care Expulsions***

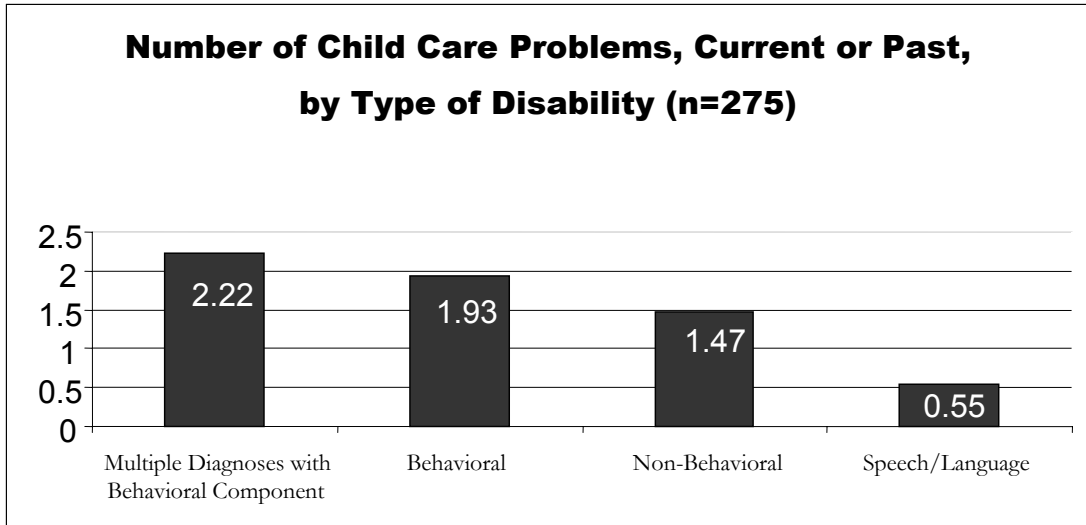
- According to parents and providers alike, child care expulsions are a significant problem for parents of children with special needs.
  - More than one in four parents of children with behavioral problems (25.6%) and parents of children with multiple diagnoses that included a behavioral component (25.4%) reported that their child had been expelled from a child care program.
  - Our survey results only included parents of children with *diagnosed* special needs so the percentage reported may *underestimate* the problem of child care expulsion in Maine. Staff at Child Care Plus ME<sup>14</sup> estimates that about 70% of the calls they receive to help with a child who may be facing expulsion, involve children who have *undiagnosed* behavioral problems.
  - More than one in three (35%) child care providers who participated in our survey said they had asked a child with special needs to leave the child care program. The most frequent reason given was that they felt they couldn't appropriately meet the special needs of the child.

## ***Number of Child Care Problems***

- Parents of children with multiple diagnoses with a behavioral component had the highest number of child care problems followed by behavioral and non-behavioral special needs. Parents with children with speech/language disabilities reported the least number of problems.
- Even after controlling for age of child, family income, and location of residence, having a child with multiple diagnoses with a behavioral component was significantly related to having more child care problems and having a child with speech/language problems was significantly related to having fewer child care problems.

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<sup>14</sup> Child Care Plus ME is a partnership between the University of Maine's Center for Community Inclusion and Disability Studies and the Maine Department of Health and Human Services, Office of Child Care and Head Start. The overall goal of the project is to contribute to the development of a comprehensive system to support the provision of and access to quality early care and education for all Maine's children, particularly those with challenging medical or behavioral needs, and children at risk of being expelled/excluded from child care programs. The project provides staff development, access to mental health consultants, (through training and on-site technical assistance) to child care providers in caring for children with special needs.

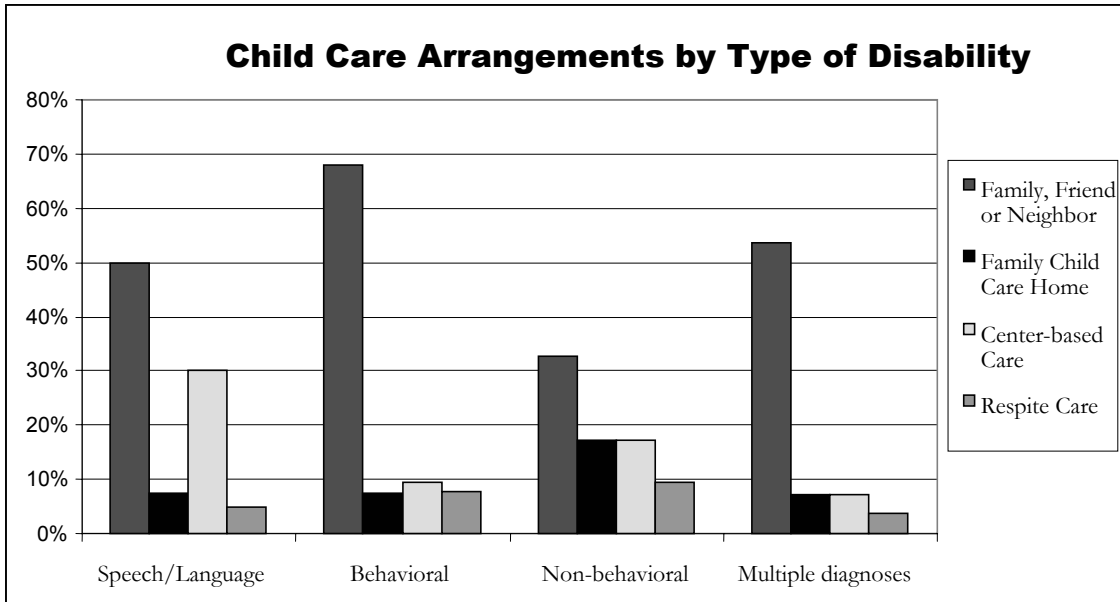


*Source: Survey of Parents of Children with Special Needs in Maine*

### ***Types of Child Care Settings***

In light of the access issues and child care problems experienced by these families, what types of child care arrangements are these families using for their child with special needs? We asked this question of parents and compared these settings by type of disability.

- Only a little over one in ten (11.6%) of the children in our survey used family child care as their primary care arrangement. Because there are so few child care centers in rural areas, difficulties accessing family child care pose real challenges for working parents of children with special needs who live outside of Maine’s cities.
- This limited use of family child care by parents of children with special needs is not surprising. In our child care provider survey, family child care providers working alone reported the greatest difficulty serving children with special needs.
- Although relatively few children with special needs were enrolled in family child care, many of the service providers interviewed in our field study said that children with special needs, particularly those with behavioral issues, fare better in the smaller settings family child care homes provide.



*Source: Survey of parents of children with special needs in Maine*

## *Reliance on Informal Child Care Arrangements to Care for Child*

Parents reported significant problems with the child care they have used for their child with special needs and many reported difficulty accessing and keeping formal, licensed child care arrangements. Yet their children seem to be in some form of child care for about as many hours as children without special needs. Are parents relying on more informal arrangements with family, friends or neighbors to care for their child while they work and are these arrangements stable? Use of informal child care arrangements is a particularly important issue for this population because in these settings, children with special needs are less likely to have the benefit of a structured program with non-disabled peers and they also may be less likely to receive therapeutic services in the child care setting while their parents work. As described later, the lack of on-site services create significant transitional issues for children and work disruptions for parents. We looked at data on use of informal care arrangements and the degree to which this use might vary by disability.

*They just said they couldn't do shots or catheterizations or medications or they told me it would be best to hire a nurse. So it just happens I was lucky that my sister had her hours cut at her job, and my sister knew everything, knows how to give my son a shot, knows how to give my kids their nebulizers, or catheterize and all that kind of stuff. So she does it and she gets paid from child care assistance. But, you know, and that is the whole other mess too, because she is not a certified day care, she only gets so much. It is hard because she is a good person. The one person I would trust my children with, but she doesn't get enough. Where somebody who doesn't even know how to take care of your child gets more money. It's not fair.*

A mother of a child with multiple disabilities and complex medical needs

- Over half (51%) of children with special needs in our survey are cared for by family, friends or neighbors either in their home or in the child's home. This is a higher percentage than is estimated for the population at large in Maine (23%) and is likely due to the difficulties accessing formal child care for children with special needs. (Child Care Advisory Council, 2002)
- Children with behavioral diagnoses, and multiple diagnoses with a behavioral component, are significantly more likely to be cared for by family, friends or neighbors (67.9% and 53.7% respectively) than are children with only speech/language problems (50%) or children with a non-behavioral diagnosis (32.7%).
- In our parent interviews and focus groups, some parents relying on a family member for child care said they did so because they only trusted that family member to meet the special needs of their child. Others used family members because they were unable to find and keep more formal child care arrangements for their child. Still others relied on family members because they needed help getting their children to specialist appointments during work hours or needed the child to be met at the bus stop.
- While some parents expressed satisfaction with these arrangements, others reported that the more intensive care demands of their children led to the family member either neglecting the child's needs or pulling out of the arrangement altogether.
- Some parents who relied on this care received state child care subsidies to pay the family member for the care of their child. Those who praised the family member for doing a good job complained that the state's reimbursement policies meant that the family member was getting a lower rate than formal child care providers. They felt that licensed child care

providers who had either turned down their child or had done an inadequate job of caring for their child shouldn't be eligible for a higher reimbursement than that provided to the family member.

## Coordination of Special Services with Child Care

Since the focus of our study was on the child care and work experiences of parents of children with special needs, it was also important to examine the way in which special services (e.g. OT, speech/language therapy) are delivered to children in Maine as this can have a significant impact on parents' ability to work and still meet the special needs of their child.

- There are significant programmatic and financial barriers to effective coordination across systems to enable parents of children with special needs to work and balance work and family.
  - Over 90% of children ages 0 to 5 were reported by their parents to be receiving special services (e.g. O.T., Speech/language therapy). Despite the requirement under IDEA for services to be delivered in the child's "natural environment" or, for preschoolers, in the "least restrictive environment," almost half of these children received some or all of their services at specialists' offices. While for some families this may have been a preference, our parent and field study interviews indicated that for others, on-site services were desired but for the reasons cited below, were not available. This caused transportation and work problems for the families.
  - Respondents in our child care provider survey were asked how special services were *usually* delivered to the children in their program who received them. Only one third (33.6%) said services were most frequently delivered by specialists coming to their program to provide services.
  - Specialists reported that the ideal mode of delivery of services was a combination of delivery at home and in the child care setting. This serves the need of parents to work but also means that there is at least some contact between the specialists, the child care staff and parents in order to share information to make sure "everyone is on the same page."
  - However, according to the specialists we interviewed, reimbursement levels and policies for early intervention/preschool special education restrict coverage for travel time for specialists and put pressure on specialists to conduct a higher number of sessions per day. This undermines inclusion and makes it more difficult to provide services at the child care site or at the child's home. A shortage of specialists, particularly in rural areas, as well as a high turnover rate, exacerbates these problems. Lack of onsite delivery of services and a lack of transportation options, especially in rural areas, make it necessary for some parents to leave work to transport their child to special services or, in some cases, to forgo special services altogether.

*I was working full time and I would have to tell my boss that I have to leave for a little while and she was really cool about it though. She is like okay do what you got to do and come back. You know, I did that. I was bringing him to OT here, preschool, plus speech and after I bring him to all of those, I have to go back to work. It took me an hour to get focused again. Then I would have to stay overtime because I had to make up my hours I lost.*

A mother of a child with Autism Spectrum Disorder

- Even where transportation is available to transport the child to specialists' offices, some parents and providers report concerns about the safety and reliability of these services, called Regional Transportation Programs, as well as the transitions and long rides for children who are least able to tolerate those stressors. According to interviews with child care providers, reliance on volunteer drivers meant that there was a high turnover of personnel which made some parents uncomfortable about allowing their children to go with the driver. Vans are used for both adults with disabilities and very young children and sometimes no aide is provided to the children. Since the disabilities of the adults can at times result in unusual behaviors, this has caused some children to be fearful. Child care providers also report that these vans are often delayed, causing disruptions in the children's schedules.
- Decisions about the amount and frequency of special services under IDEA is determined by the child's therapeutic needs, not the parents' need to work. As a result, according to parents and child care and service providers:
  - Some children eligible under IDEA are provided a service they need in the child care setting, such as a one-on-one aide or a deaf interpreter, for only part of the day even though they are in child care for a full day. Parents, child care providers and staff at Child Care Plus ME referred to this gap and almost one in five of the child care providers who responded to our survey cited this issue as a barrier to accepting children with special needs.
  - Many therapeutic programs designed to serve solely children with special needs are open for only part of the day or week and are closed during the summer. Children have had to be transported to regular child care programs for the additional hours causing disruptions in their day and long rides from one program to the other. When transportation is not available, parents have to leave work to transport the child. In some cases, parents have even had to choose to put their child in a regular full-day child care program instead of the therapeutic part-day program their child needs because they have to work.

*I found out he was autistic when he was ...about two and a half. It took me like a year to get all of the services. And I couldn't get all of them in one spot. It is frustrating because I have lost many jobs over that, because they couldn't work around my schedule.*

A mother of a child with Autism Spectrum Disorder

*The program our child will be going to— it is the place where they are going to have all of the services on site at one location. It is so wonderful. He is on the waiting list. They do potty training there. I told them that is one of the biggest things I need help on.*

A mother of a child with Autism Spectrum Disorder

*If he was in full time care then CDS would only pay for an aide for my son for three hours a day. But he would be in school longer. But the aide would transition from an educational benefit to a day care benefit. And my question was, well, who is going to pick up the difference because if you are paying an aide \$10 an hour, \$8 an hour, whatever an aide gets paid, then you also have a day care expense of whatever per week, then you have it worked up on an hourly basis then who is going to pick up the difference? It could be very considerable.*

A father of a child with multiple disabilities and complex medical needs

## Work

Because child care problems and a lack of coordination of services can lead to significant work problems, we examined next whether and how the presence of a child with special needs affected parents' employment patterns and work experiences. We did this through our parent survey in Maine and also through analyzing employment data from the NSAF. Because of the nature of the questions asked and the large sample size in the NSAF, we were able to conduct an in-depth study of the labor force patterns of parents of children with special needs. We were also able to compare their labor force patterns with those of parents of children without special needs. Our data from our parent survey provided a sense of the possible reasons behind some of the effects on employment and economic security revealed in the NSAF data.

### *Labor Force Participation*

- Nationally, mothers of children with special needs aged 0 to 5 have a 7 % lower employment rate than do mothers of young children without special needs.<sup>15</sup>
- Among mothers of *older* children age 6 to 17 in the NSAF, the differences in labor force participation between those with children with special needs and those with “typical” children were more pronounced.
  - Mothers of older children with disabilities are 13% less likely to be employed than mothers of children without disabilities.
  - For mothers of older children in poor health, there is an 11.7% lower employment rate than for mothers of children in excellent health.

### *Level of Employment (full-time vs. part-time)*

- Once employed, the NSAF data shows that having a child with special needs does not have the same impact on the *level* of employment (full-time vs. part-time) as on labor force participation. This may reflect the fact that workers often don't have control over the number of hours they have to work so that even if they might prefer to work less they may not have that option.
  - In the NSAF, there was little difference in impact on level of employment among types of special need. Interestingly, the only statistically significant differences were that mothers of children aged 0 to 5 in poor health and mothers of older children with behavior problems actually work slightly *more* hours than mothers of children in excellent health or mothers of children with only positive behaviors. This may reflect the need to work full-time because their child has needs that require significant financial resources, including the health insurance that more often comes with full-time employment.

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<sup>15</sup> For our secondary analysis of the NSAF, we used a sample of female caregivers. They not only represented the great majority of respondents, but studies show that decisions related to employment and caring for children rest predominantly with the mother, even in a two parent family. See our chapter on the NSAF data for more information.

- Unlike the NSAF data, our parent survey in Maine revealed no statistically significant differences in the impact of different special needs on the number of hours worked. This may have been due to the small sample size compared to the NSAF.

### *Work Strategies*

While mothers of children with special needs seem to be participating in the labor force at higher rates and levels than might be expected, these rates alone do not tell the whole story. We further examined the work experiences of this population through our interviews in Maine in which parents revealed some of the work strategies they have had to use to meet the special needs of their child and still maintain their jobs. While some of these are used by parents of “typical” children, the precariousness of these strategies and the stresses experienced as a result, seemed more intense for the families we interviewed. This seems to be supported by the NSAF data on job retention and stability and by the data on work problems in our parent survey.

*I go in to his child care and I sit him on this big rug with a bucket of toys. When I come back to pick him up he is sitting there in the same spot and nobody is around him – he just sits in the corner the whole time. [The child can’t walk.] I just don’t think it’s fair. So I don’t like to leave him there a lot. I try to pick him up every day and bring him with me to my third job – office cleaning. I do that until about 7:00 or 7:30 pm. My employer doesn’t know I take him with me but I have to bring him with me because it is so hard leaving him at that child care.*

A mother of a child with developmental delays

- In our interviews, some parents reported doing split shifts with their spouses so one parent could be at home with their children.
- Other parents worked two or three jobs so their spouse could stay home with their child.
- Some single parents reported working at night so they could stay home with their children during the day and get their children to services.
- Some parents adopted these strategies because they were not able to find child care for their children; others did so because they didn’t think any child care provider could meet the special needs of their children or because they had to transport their children to so many appointments during traditional work hours.
- A number of parents had to bring their children to work either because they didn’t have child care, they were unhappy with the care they had and wanted to limit the hours their children were in care, there were gaps in care because of their work schedules and the limited hours the programs were in operation or there were medical reasons for keeping the children with them. Sometimes this worked out fine and for this the parents were very grateful. Other parents felt the displeasure of their supervisor.



## Work Problems

- Despite these strategies, parents of children with special needs reported experiencing a wide range of work problems. Based on what parents told us in our focus groups and interviews, we included a list of potential work issues related to having a child with special needs in our survey and asked parents if they had experienced them now or in the past *for reasons related to having a child with special needs*.<sup>16</sup> These included:
  - Having to reduce their hours (57.2%)
  - Having to change their hours (44.2%)
  - Quitting work other than for normal maternity or family leave (30.3%)
  - Turning down job offers and promotions (29.4%)
  - Changing jobs (26.9%)
  - Fearing they might lose their job (25.5%)
  - Being fired from their job (5.3%)
- Among parents of children with multiple diagnoses with a behavioral component, more than three quarters have reduced their hours at work (76.2%), more than half have had to change work hours (51.2%), almost half reported having turned down a job offer or promotion (45.2%) and more than one third have changed jobs (38.1%) because of the demands of caring for their child. Almost half have had to quit work altogether (45.2%). These percentages were significantly higher than for parents of children with disabilities that were behavioral or non-behavioral and much higher than for parents of children with only speech/language problems.
- In our survey, more low income parents and parents with lower education levels<sup>17</sup> had lost their job or been fired for reasons related to their child's special needs than had higher income parents and parents with higher educational levels.
- Parents with more education were more likely than parents with less education to have turned down a job or promotion for reasons related to caring for their child with special needs. This may be due to there being more opportunities for promotions for employees earning higher incomes than for low wage earners.

*The only reason my employer didn't fire me was because he knew that the Family Medical Leave Act lets you have 120 days of leave unpaid and I hadn't missed more than that. But he would make all types of comments. I would have to leave work because of my son's seizures. He would call me into his office and say, "What are you going to do?" My feeling is, if you want me to leave, I will leave. If I had a schedule of my son's seizures for the next three months I would give it to you. Sometimes you feel against a wall because, I mean, you want to work.*

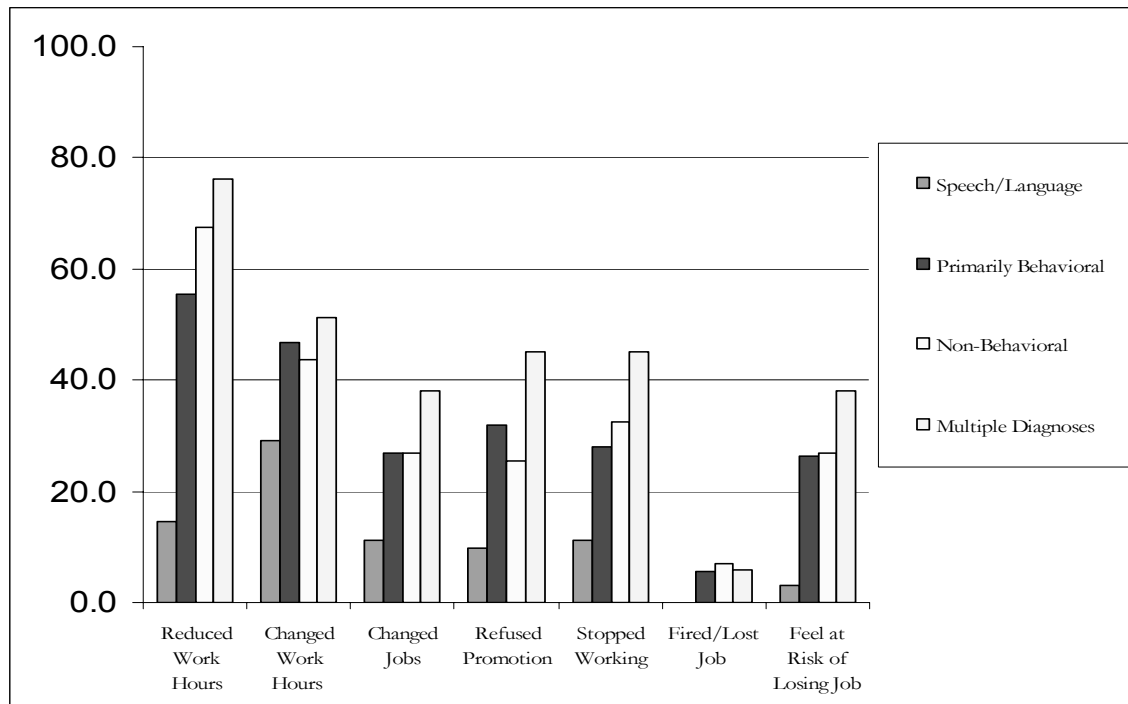
A mother of a child with multiple disabilities and complex medical needs

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<sup>16</sup> In our survey we informed parents that we only wanted them to report work problems that were directly related to having a child with special needs.

<sup>17</sup> Lower educational levels are defined as having less than a four year degree and higher education levels are defined as having a four year degree or higher.

## Percent of Parent Survey Respondents with the Following Work Problems Related to Caring for Their Child with Special Needs



Source: Survey of Parents of Children with Special Needs in Maine

*Being gone from work because of the special needs my son requires, causes me to miss work and it causes me to stay at work longer than I would normally when I am available at work. So it is not a good situation all the way around. I am in an office with so few people. It is really difficult. My supervisor does a lot more than he should for his position. It is because I am not available to him as often as I would be because of my son's situation. You know, you take two weeks off, you take a week off here, you take a couple of days there, that adds up. You have to make up a lot of lost time. Like last night for instance I didn't leave the office until really late. I had to go to Baltimore for two weeks while my son got treated for his seizures from specialists there. I had a deadline and since I needed to go I had to do all the work by staying late. When I'm available I need to work longer hours to accommodate the work I couldn't do when I wasn't there.*

A father of a child with multiple disabilities and complex medical needs

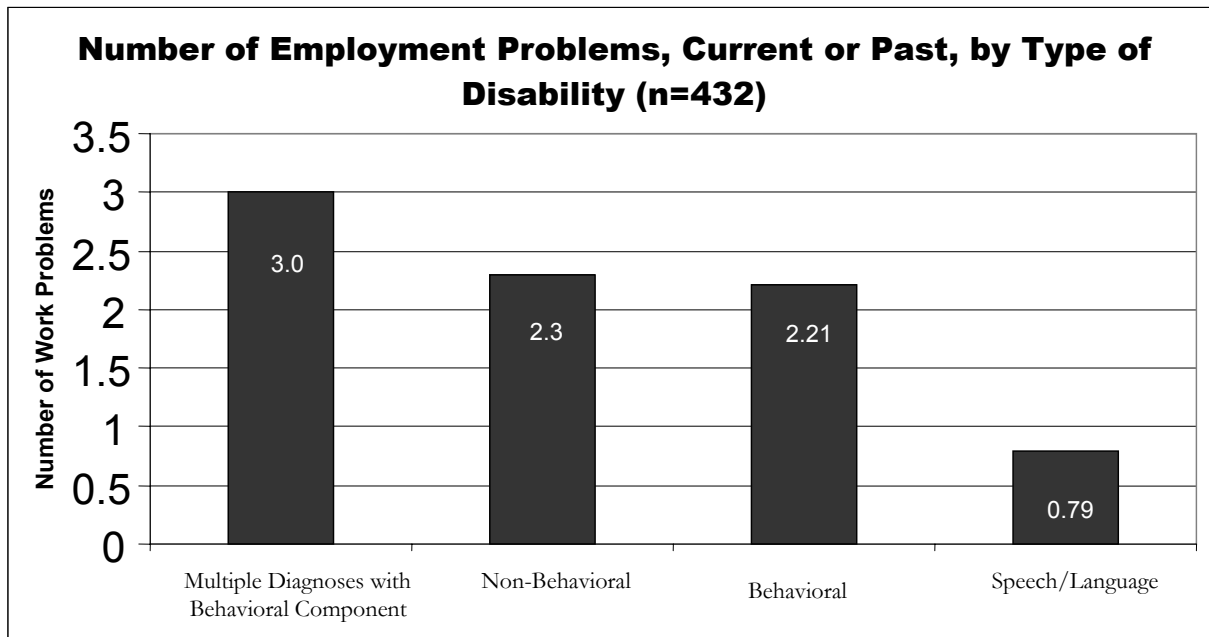
### Number of Work Problems

Just as we did with child care problems, we added up the number of these work problems families reported in our survey to examine whether the number differed by type of special needs or other factors. The range reported was 0 to 7.

- Parents of children with multiple diagnoses with a behavioral component reported they had experienced an average of three of these work problems compared to an average of only 0.79 for parents of children with only speech/language problems.
- Even after controlling for age of child, location of residence and monthly income, having a child with multiple diagnoses with a behavioral component is significantly related to having more work problems while having a child with speech and language issues was related to having fewer work problems.

*I almost lost it because of the job I had which was a factory, forty hours. You have to be there from 7:30 to 4:00. Because of all the appointments I had for my child, I was getting suspensions, one day suspensions. They give you one day, two day, and five day suspensions. After the fifth day, you get another warning and then you are out. And like when I would get the warnings I would have to not do the appointment because I needed to cool off at my job, or guess what? It would be another suspension. After one year, the warnings in your file are voided out so I had to keep track and I used to ask them to schedule the appointments for my child a few months down the road and keep on postponing them so I'd get past that one year and wouldn't get in so much trouble.*

A mother of a child with speech delays



Source: Survey of Parents of Children with Special Needs in Maine

## Work Disruptions

- Many parents in our focus groups and interviews also reported difficulties with their employers because of the disruptions in their work day required to take their children to medical appointments and special services, deal with crises and/or meet with their children's teachers and specialists. Some of these parents reported job losses; others told us about the difficulties making up lost hours even when their employer was understanding about these disruptions.
- More than one third (36.4%) of parents of children with behavioral problems and parents of children with multiple diagnoses with a behavioral component (34.5%) reported being disrupted "often" at work for reasons related to the care of their child with special needs (e.g. making and answering phone calls about their child's special needs, taking their child to appointments for special services and/or medical care, attending meetings related to their child, etc.).
- Parents who said they were disrupted "often" at work reported an average of 3.5 of these disruptions per week.

*I can never get an appointment for my son that works with my schedule so I either have to go to work and then go home and then go back to work, usually when I have appointments for him or if he's sick. Depending on how sick he is I will take time off from work or I will, you know, switch around with somebody, so I can take the day off and tomorrow I will work all day. Also, his dental appointments always have to be in the morning because he needs the special room separate from the other patients because he screams and fights when he goes. I decided to leave my job and now I am going to school. Last semester I had to withdraw from a couple of classes because we are having a problem with his seizure disorder. They finally got it [his medication] up to a level where it was really controlling his seizures with a couple of different medications and one of the side effects was that he is losing weight. So then my doctor says we'll have to lower the medication but then he will have more seizures. That makes it difficult. So I am back in school and just doing my best day to day. It is hard to juggle everything."*

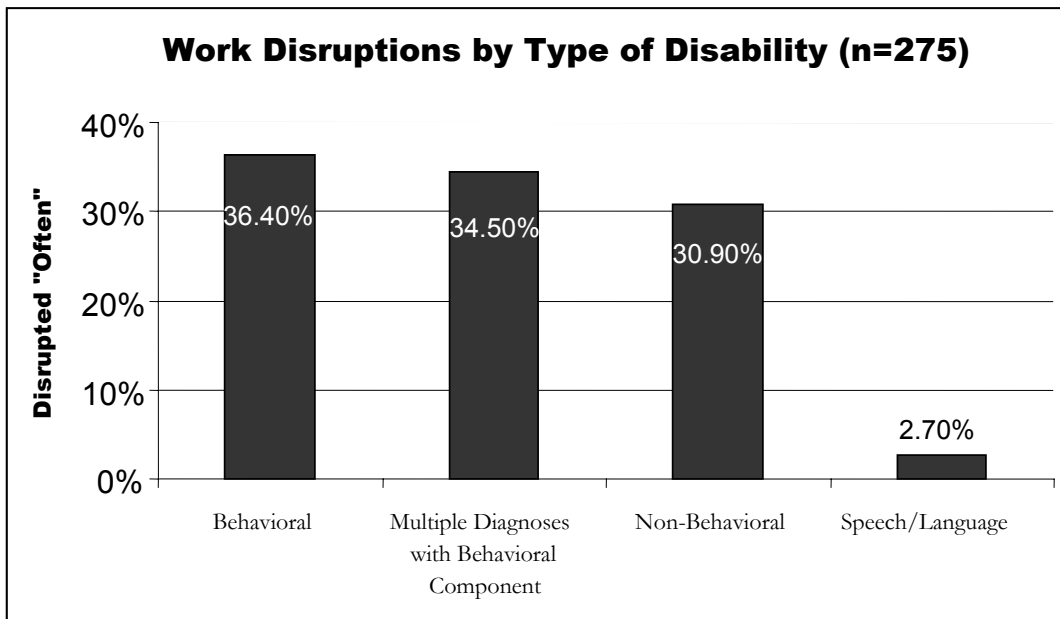
A mother of a child with developmental delays and a seizure disorder

*It was not that I didn't want to work, but that I had a responsibility that I had to make sure that my son's needs were met. He was seeing many specialists and, you know, eye appointments. I had two other kids that in my opinion, got left out a lot of the time because I couldn't get consistent day care for him. I was up at 4:30 every morning and I was working from 6:00 am to 8:00 a.m. and then going back at 3:00 p.m. and working until midnight. But they didn't want to give me a regular schedule. Every week I'd want to say, "Okay, this is what I am going to be working so I can make Ethan's appointments around this." But they just wouldn't do it and I needed to work. I just felt that because of that need to have to work I was, you know, accepting the job even though I was the one in the end that was going to pay dearly for trying. I am not going to neglect my child for a job. I left that job because they wouldn't let me have time off to meet my son's needs. I was working seven days a week and I was a basket case. I ended up getting on Prozac because I couldn't do it anymore. Now I have a more flexible job and my son's in a preschool so it's easier. I work over forty hours and the pay is good and I have benefits so I can't quit.*

A mother of a child with Down Syndrome

*When I was working I was always off the wall, always with doctor's appointments, like twice a week. I will be like, "I can't come in." You know they give you this many chances to get yourself together. I was working second shift. I had my Mom working third shift so I figured by her working third shift she could stay with my daughter. But it didn't work out. My mother was taught how to clean the G-tube and everything. But my daughter, she pulls it out. I mean every day, every night she is pulling the G-tube out. I am rushing her over to the hospital because I couldn't get it back in. It was always a problem when I was working. It closes up and my Mom said, "I can't do it [take care of her] anymore."*

A mother of a child with Cerebral Palsy



Source: Survey of Parents of Children with Special Needs in Maine

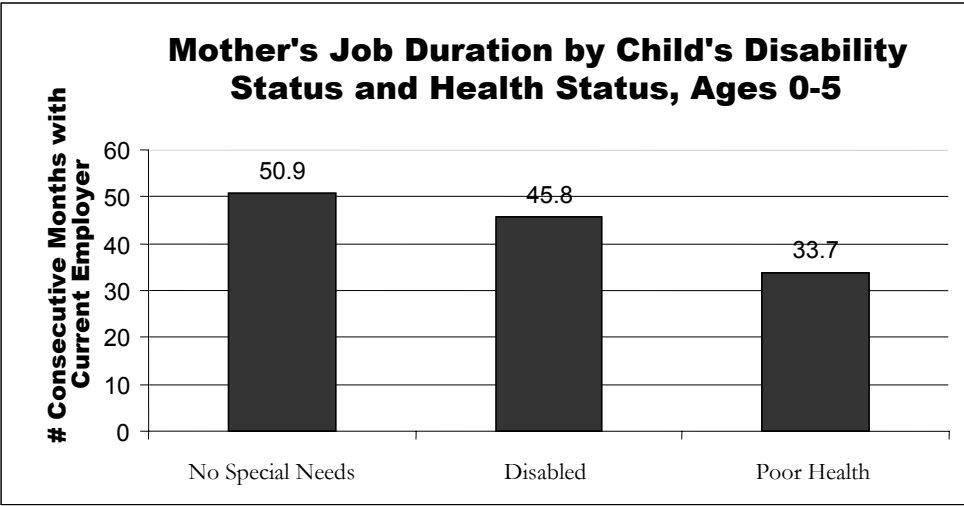
## *Job Stability*

The type of work problems reported by parents in Maine may be behind our findings from the NSAF about the lack of job stability among this population of parents. Despite higher than expected employment rates and levels, mothers of children with special needs surveyed in the NSAF experienced significantly more job instability (as measured by the number of weeks worked in the previous year and the number of consecutive months in their current job) than did mothers of “typical” children. Some types of special needs have a greater impact on maternal employment stability than others.<sup>18</sup> The findings on job stability from the NSAF are as follows:

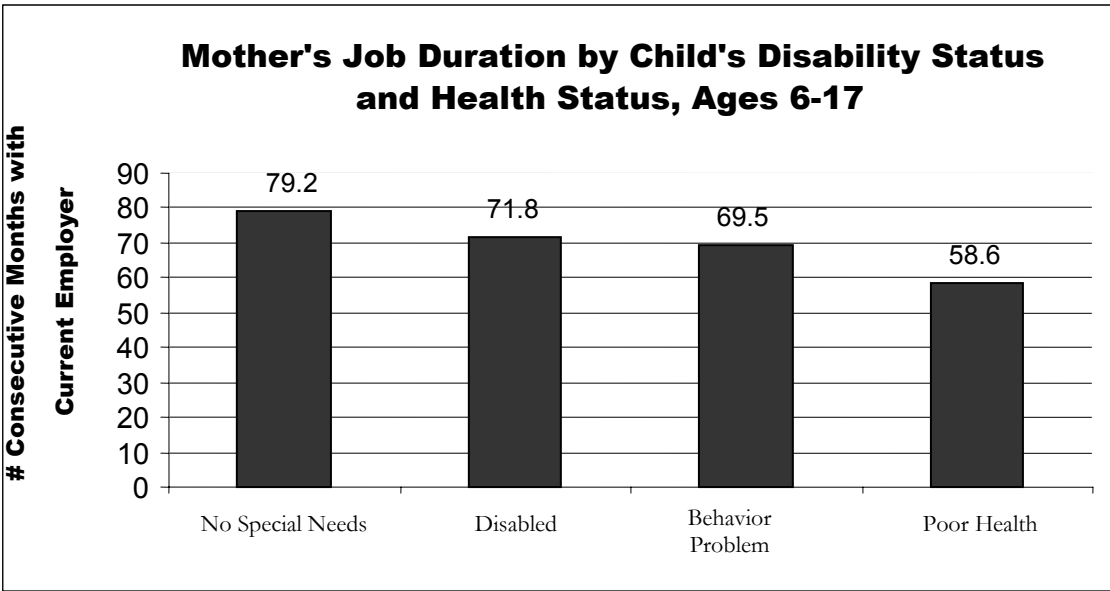
- Mothers of children ages 0 to 5 with health conditions had been in their current jobs an average of 17 months less than mothers of young children with no special needs.
- Mothers of children ages 0 to 5 who are disabled had been in their current jobs an average of five months less than mothers of young children without special needs.
- Among mothers of older children, the impact of having a child with special needs is even greater than for mothers of younger children with special needs.
  - Mothers of older children with health conditions had an average of 20 fewer months in their current job than did mothers of older children with no special needs.
  - Mothers of older children ages 6 to 17 with disabilities had an average of seven fewer months in their current job compared with mothers of children without disabilities.
  - Only mothers of older children in the NSAF were asked about behavior problems. Among these mothers, those with children with severe behavior problems had an average of 10 fewer months in their current jobs than those mothers with older children with no special needs.
- The negative impact of having a child with special needs on the number of weeks worked in the last year was also statistically significant but not as pronounced as the differences in number of months in current job.
- Even after controlling for other factors such as marital status, income and educational level, mothers of children with special needs still had less job stability than did mothers of “typical” children.

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<sup>18</sup> The negative impact of a child’s special needs on the mother’s job retention is potentially more serious than the effect on employment rate. The decision to work or not will depend not only on the caregiving burden and the ability to balance work and family but also on the family’s financial situation and their access to health insurance coverage. Presumably at least part of a mother’s decision to work outside the home is driven by the fact that she needs the income and/or employer-provided health insurance. If the more complicated care giving required by a special needs child makes it more difficult for her to hold on to her job, the family may be exposed to considerable financial insecurity. Moreover, while financial insecurity places all families at risk, families with children with special needs incur even greater health and other costs and are therefore at even greater risk if there is a disruption in earnings or insurance coverage.



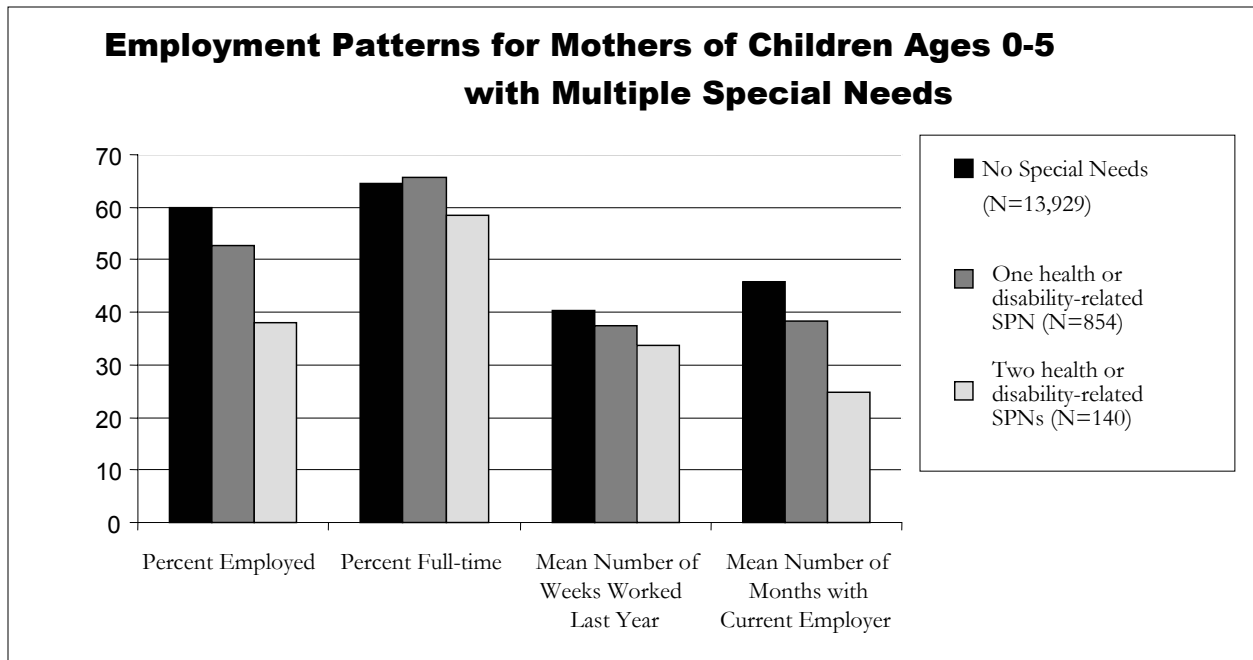
*Source: NSAF*



*Source: NSAF*

***Multiple Special Needs and More than One Child with Special Needs***

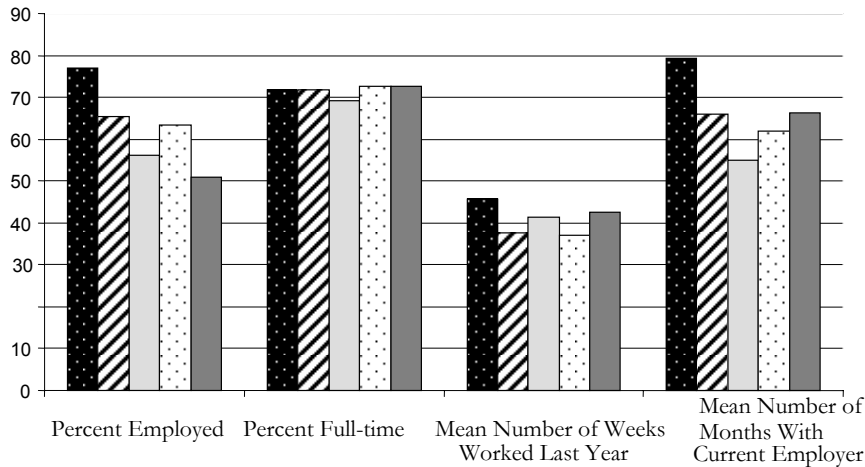
- The more special needs a child has the lower the mother’s rate of employment.
- Similarly, we also find lower maternal employment rates among families who have more than one child with special needs.
- Mothers of children with multiple special needs and mothers with more than one child with special needs have significantly shorter job durations and less continuous employment than mothers with only one child with special needs or mothers whose children have no special needs.



Source: NSAF



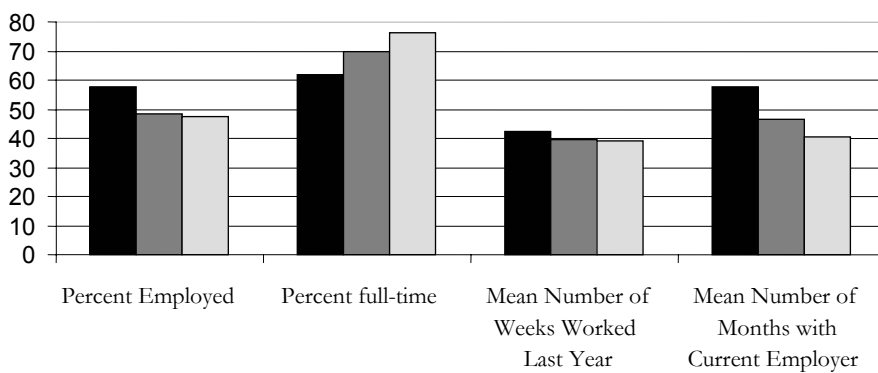
### Employment Patterns for Mothers of Children Ages 6-17 with Multiple Special Needs



- No Special Needs (N=28,993)
- ▨ One health or disability-related special need (N=4,723)
- Two special needs: health condition and a disability (N=457)
- ▤ Two special needs: a health condition or a disability, plus behavior problems (N=1,844)
- Three special needs: health condition, disability and behavior problems (N=335)

Source: NSAF

### Employment Patterns for Families with More than One Child with Special Needs



- Families with child aged 0 to 5 and a child aged 6 to 17 neither who have special needs
- ▨ Child aged 0-5 and child aged 6-17 both with health or disability-related SPNs (N=464)
- Child aged 0-5 with health or disability-related SPN and child 6-17 with a behavior problem (N=194)

Source: NSAF

## Financial Insecurity

Our research in Maine focused on the child care and work problems of families. Because our sample for the parent survey included families across the income spectrum and was comparatively small, we looked to the NSAF to determine, in light of these work problems, whether the presence of a child with special needs had a negative impact on families' economic security. We found that families with children with special needs are significantly less financially secure than are families with children without special needs.<sup>19</sup>

- Nationally, while one quarter (25.0%) of families of children without special needs are poor,<sup>20</sup> more than twice as many (53.3%) of families of children with health conditions, 33.93 % of families with children with disabilities and 35.5% of families of children with behavioral problems are poor. Almost one in two (45.3%) families with children with multiple special needs or with more than one child with special needs are poor. All of these families also experience significantly more rent and food insecurity than do families of children without special needs.
- More than twice as many families with children with health conditions lacked health insurance (35.6%) as families of typical children (15.9%).
- Even after controlling for demographics and socioeconomic status, the presence of a child with special needs has a separate and significant effect on family economic hardship as measured by going without food, the inability to pay rent, mortgage or utility bills, and having no health insurance coverage.

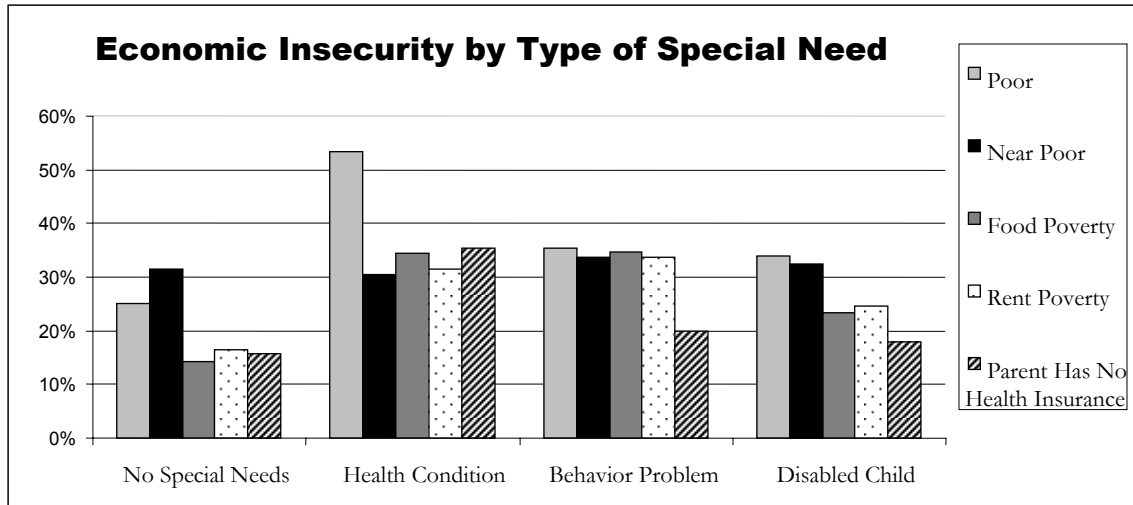
*I have a car that I am making payments on and without the car I can't bring him to his appointments. I don't have enough money for a cab, you know. That is pretty expensive if you think about it. ...I am still struggling with my car and all of my bills, because for the last month I have been struggling trying to work [without child care].*

A mother of a child with a cleft lip and palate

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<sup>19</sup> The interplay between income level, prevalence of disabilities, employment problems and having a child with special needs is complex. The NSAF is a cross sectional study and therefore does not provide the longitudinal data needed to determine which came first: the child with special needs or poverty and financial distress. This question was also beyond the scope of our statewide parent survey. However, considering that our data shows that parents of children with special needs encounter more employment difficulties and less job stability than do parents of typical children, even after controlling for other factors that could affect employment, we can assume that at least some of the economic distress is caused by the presence of a child with special needs.

<sup>20</sup> Family income below 150% of the federal poverty level.



Source: NSAF

## Policy Implications and Suggested Strategies

From the findings of our qualitative and quantitative research, we have identified a number of overarching concerns from a policy perspective that we believe need to be addressed to better meet the needs of these families. We have also listed some strategies that might be considered by policymakers and employers for addressing each of these concerns.

- ***Greater interagency coordination to meet the complex needs of families of children with special needs***

A central policy concern that emerges from our findings is the need for all of the agencies, and programs within agencies, that serve these families to collaborate on the best ways to provide the supports necessary to enable parents to work and still meet the special needs of their children. The interagency conflicts in missions, policies and service delivery we describe in this report need to be resolved so parents can access the special services and quality early care and education programs their children need without compromising their ability to work to support their families.

- ***Strengthen the capacity to provide inclusive, high quality child care to children with special needs.***

Parents of children with special needs report significant difficulty accessing child care. Even when parents are able to find child care, many report significant problems with the care provided to their children including lack of understanding of special needs by providers and a lack of inclusion. Child care providers express a desire to accept children with special needs but a lack of resources and training to do so. And, research has shown that early care and education programs that support inclusion of children with special needs with their non-disabled peers tend to

provide higher quality care for *all* children (Frank Porter Graham, 2001). Our findings point to the need to strengthen the *capacity* of our child care system to serve this vulnerable population of children and families. Maine should consider “braiding”<sup>21</sup> state and federal funding from a variety of sources (e.g. CCDF, Medicaid, IDEA, SSI, Title V Maternal and Child Health, Public Pre-K funding, Head Start), as well as allocating additional funding where needed, to provide comprehensive, affordable, quality early care and education settings across the child care system where children with special needs can attend with their non-disabled peers and receive the interventions and support they need.

### *Some strategies to consider*

- **Expanding the services provided by Child Care Plus ME:** Making the services currently offered by Child Care Plus ME (training and on-site technical assistance to child care providers) accessible to more providers and children.
- **Greater access to mental health consultants to help providers care for children with behavioral issues:** Currently, Child Care Plus ME and Head Start programs provide some access to these experts but access could be expanded so that *every* child care provider is able to obtain the help of knowledgeable professionals in caring for children with behavioral difficulties. Child Care Plus ME has been piloting some cross-training efforts between mental health providers and child care providers so that they can understand each other’s roles and mental health services can be better integrated into the child care setting. These efforts could be expanded.
- **Establishing more degree programs for providers in preschool education for children with special needs:** Funding could also be provided for more degree programs in preschool education for children with special needs, such as the program at University of Maine at Farmington, so as to eventually expand the capacity of the ECE system to accept more children with special needs.
- **Creating family child care hubs or networks to support the inclusion of children with special needs:** Family child care homes are a particularly important source of care for children in rural areas where center-based care is less available. Many of the service providers we spoke to felt that for some children with special needs the smaller settings offered by family child care providers were more appropriate. One strategy worth exploring might be the creation of family child care hubs or networks to support the care of children with special needs. Funding for these hubs could address staffing needs, provide for specialized training, renovations to make homes handicap accessible and the sharing of mental health consultants and itinerant specialists (speech and developmental therapists, OTs, PTs) who could rotate among the homes delivering services on-site.
- **Providing higher levels of subsidy for children with special needs and allowing more families to receive assistance:** Additional funding could be provided to increase the number of families of children with special needs who receive child care subsidies and to increase the *level* of financial support to providers, including family, friends and neighbors, who take children with special needs. We recognize that a modest increase in subsidy may not make a substantial difference in expanding capacity but it could be considered as a part of a larger effort that would include the other strategies we have listed in this report. The state might also consider placing a condition on providers who

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<sup>21</sup> “Braiding” is a term used to refer to combining different funding streams to address a need while still adhering to the regulations and reporting requirements of each of the funding sources.

receive the additional subsidy that they allow regular observations from Child Care Plus ME staff, as well as a promise to meet certain requirements for specialized training.

- **Providing access to child care for children with special needs over age twelve who still need supervision:** Although our study focused primarily on child care for children with special needs ages 0 to 5, we note here that a significant number of parents of older children in our survey said they had lost child care when their child became too old to be enrolled, even though they still needed supervision while their parent worked because of their special needs. Maine does provide child care subsidies to children over the age of twelve under these circumstances, but steps may be needed to expand the *capacity* of the system to meet these needs through collaborative planning with other programs serving older children with special needs.

- ***Special services need to be delivered in a way that supports inclusion and the need of parents to work.***

As discussed earlier, a concern expressed by many of the parents in our study was the degree to which their work was disrupted when the special services their children needed (OT, speech, PT, etc.) were delivered at a site other than the child care setting. Parents were worried about the difficult transitions their children experienced traveling to specialists' offices and the group activities they missed by leaving the child care program. Specialists complained that it was difficult to travel to child care programs because of a lack of adequate reimbursement for their travel time.<sup>22</sup>

### ***Some strategies to consider***

- **Review and reform reimbursement policies** where they undermine delivery of services in the child's natural environment/least restrictive environment in order to support inclusion and avoid difficult transitions for children and work disruptions for parents.
- **Greater interagency collaboration on how services are delivered:** Under IDEA, a child's IFSP/IEP team first makes decisions about the special services needed by the child, and appropriate under the Act, and then decides on the setting/schedule for those services in compliance with IDEA requirements and the family's individual circumstances.<sup>23</sup> If other agencies were brought in at that time to come up with a plan that is responsive to the employment and other needs of the family, as well as the needs of the child, work disruptions and transitional issues for children might be reduced.
- **Education and training for specialists on how to integrate services into classroom activities to avoid "pull-outs":** Child care providers and staff of Child Care Plus Me told us that often when children do receive services on-site, they miss out on group activities because the specialist pulls them out of the classroom to deliver the services. In their view, these "pullouts" undermine inclusion, make it more difficult for the child to apply what he or she learns to the classroom setting and create difficult transitions for

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<sup>22</sup> Addressing this concern will be especially important in light of the fact that this requirement was strengthened when IDEA was reauthorized in 2004. In light of these new requirements, CDS is currently working toward using more inclusive settings.

<sup>23</sup> The Individualized Family Services Plan (IFSP) is the plan of services used under Part C of IDEA for children ages 0 to 3. The Individualized Education Plan (IEP) is the plan of services used under Part B of IDEA for preschool and school-aged children.

the child. Pullouts also mean that the specialist misses opportunities to observe the child interacting with other children and provide on-site coaching to the provider in supporting the child's needs. Education through higher education degree programs and ongoing in-service training could address this problem by teaching specialists ways in which services can be integrated into the classroom. In addition, classroom teachers can be trained about why this integration is important so they are able and willing to accommodate the specialist in using these strategies.

- **Development of programs to address the shortage of specialists (Speech/Language, OT, PT) in Maine:** Parents and providers report a shortage of specialists in Maine, particularly in rural areas, which, they say, has led to delays in services and contributed to the problem of lack of inclusion. A loan forgiveness program might be considered for Maine students being trained for these specialties in exchange for their practicing in the state for a requisite number of years.
- **Providing coverage for additional hours of classroom support:** According to the providers we interviewed, currently, a child who needs a one-on-one aide or other supports during the time he or she is in child care may only be able to get a few hours covered through IDEA even though the child needs to be there all day because the parents work. The funding sources used by the state to close these gaps in support services are restricted, meaning that the extended services (beyond what IDEA will provide) can only be provided to children whose family income is low enough to qualify. In the short-term, higher income families whose children need these extended services, could be helped if additional resources were allocated to close these gaps. Ultimately, however, integrating children into the overall structure of a child care program supports inclusion more effectively than using an aide from an outside agency who is assigned only to that child. Over the long term, if the capacity of the ECE system to provide inclusive care to *all* children was strengthened as discussed earlier, perhaps some of these classroom supports, such as a one-on-one aide, might not be needed.
- **Reviewing transportation policies regarding the services provided to very young children with special needs:** Our research revealed significant concerns regarding the availability and appropriateness of transportation programs such as Regional Transportation Services for young children with special needs. If the IDEA early intervention/preschool special education and the early care and education systems were integrated in the ways described above, there would be less need for special transportation for children whose services are not delivered at one location. However, as long as there remains a need to transport children, transportation policies should be reviewed, and additional training and resources provided, to make these services safe and appropriate for young children.
- **Addressing transportation issues in rural communities:** In many rural areas, even these Regional Transportation Services are not available and parents report significant work disruptions to transport their child to specialists' offices. Particular attention needs to be paid to reimbursing specialists for their travel time in rural areas so they can provide services on-site, reduce transitions for children and enable parents to maintain employment.
- ***Welfare to work policies need to be flexible enough to meet the individual circumstances of families of children with special needs.***

Our research revealed a need for low income families of children with special needs to be served in a holistic way in which decisions regarding work and services are based on the individual

circumstances of the family and the type and severity of the child's special needs. The Deficit Reduction Act of 2005 reauthorized the Temporary Assistance for Needy Families Program (TANF), originally enacted in 1996. The new program imposes stricter requirements on states for the work participation rates they must meet, increases the number of hours recipients must work and narrows the range of permissible work activities to meet those new requirements. Specific provisions were included to address the circumstances of recipients caring for a disabled family member. Even under these new regulations, states are still provided with enough latitude to enable them to create a seamless system in which the individual needs of the family can still be addressed.

### *Some strategies to consider*

- **Individualized work requirements:** The new regulations remove from the work participation requirements recipients who are caring for a disabled family member who is not in school full-time. While this benefits parents of younger children, it rests on the assumption that the child care and work challenges of parents of children with special needs disappear when the child reaches school age. To the contrary, our research showed that the work challenges of parents of children with special needs do not ease significantly when their child reaches school age. Federal law gives states the discretion to develop their own definition of “disability” for the purposes of determining whether a family will be included in the work participation requirements. Defining “disability” broadly to include the full spectrum of special needs that our research showed made employment difficult, providing flexibility in what is considered full-time school attendance, and allocating state dollars in cases where federal funding cannot be used, would help provide a more flexible, individualized approach to serving these families.
- **Supporting parents who want to work even if they aren't required to be employed under the program.** Many parents who participated in our study expressed a strong desire to work as a respite from their care giving responsibilities, a source of personal satisfaction and because they needed the income. Even if they do not fall under the work requirements, if they volunteer to work, they should be supported in that endeavor for however many hours they are able to be employed while still meeting the special needs of their child. In those cases, interagency collaboration to synchronize the Individualized Family Service Plan (IFSP) under IDEA with the Individual Responsibility Plan under TANF, could help parents meet the special needs of their child *and* the economic needs of their families. Helping parents find child care for their child, providing child care assistance and delivering special services on-site, might lessen the stresses for these voluntary work participants, in balancing work and family.
- **Cross Training of Agency Staff:** One way to raise awareness and promote better interagency collaboration might be to provide joint training opportunities for TANF caseworkers and early intervention/preschool special education case managers. This training could increase awareness of the challenges faced by low income families with children with special needs and the ways in which agency staff can help provide the coordinated supports needed to enable these parents to be employed and still meet the needs of their children.

- ***Greater flexibility in the workplace***

As discussed earlier, our analysis of data from the NSAF demonstrated that the work problems of parents of children with special needs, particularly those with children with behavioral needs, were significant. While their rates of participation in the labor force approach those of parents of children without special needs, their job *stability*, as measured by the number of months in their current job, is significantly weaker. The parents who participated in our parent survey reported issues at work such as the need to reduce hours, turning down promotions and job offers and being fired or fearing the loss of their job because of the demands of their child's special needs. While most of the suggested strategies included in this report are focused on reforms in government programs and policies which affect this population, working with employers to raise their sensitivity to the challenges of this population of families may be equally important. A group of organizations, including *Family Voices*, *Massachusetts General Hospital*, *the Health and Disability Working Group* and *New England SERVE*, has joined together in an effort to address these work issues. Their publications offer suggestions on what employers can do to provide for a more supportive workplace (Family Voices, 2004) and we include here those addressing the need for workplace flexibility.

***Some strategies to consider***

- **Encourage open, flexible work environments**
  - Offer training on the challenges of employees with children with special needs and what can be done to help them for middle managers and the executives who set workplace policies.
  - Develop policies that allow emergency time off, trading of shifts, flexible hours, job sharing, opportunities to work from home, etc.
  - Implement “paid time off banks” if employees prefer it where instead of having separate sick and vacation times, they have a pool of both that they can use flexibly as needs arise.
  - Allow employees to use sick time to care for their child.
  - Provide time off to meet with the child's school or specialists and medical providers.
  - Provide a way for employees of children with special needs to support each other through support groups and other means.
  - Establish an employee group of parents of children with special needs. These groups can be represented on company-wide diversity councils that meet with company executives and can have input on the setting of workplace policies.
- **Provide stable work schedules:** This is not an area included in the recommendations of *Family Voices* but it is an issue that emerged from our interviews with parents who were employed in low wage jobs. Some of these parents worked for employers who changed their work hours with little advance notice. While this practice causes disruptions for all employees with children, it posed particular challenges for the parents of children with special needs. These parents reported that they have to schedule many medical and other appointments for their child around their work schedules and face difficulty trading favors with family or friends to cover sudden changes in the hours their children need to be watched because of their child's special needs. For employees with these special circumstances, it might be helpful for employers to try, wherever



possible, to provide set work schedules, or at least provide more advance notice of changes in those schedules.

## Conclusion

In this mixed method, exploratory study, we have examined the complex interplay between child care and work issues for low income families with children with special needs. Our research shows a significant lack of access to child care for children with special needs. Even when children are admitted, however, parents reported significant child care problems including a lack of understanding about special needs on the part of the provider, child care expulsions and a lack of inclusion of children in activities with their non-disabled peers. These concerns are sometimes significant enough to cause parents to remove their child and either come up with more informal, alternative arrangements, or quit work altogether.

Even when stable, satisfactory child care arrangements are found, the ability of many parents to work, and balance work and family, is affected by a lack of coordination between the child care system and the other special services their children need. This can cause transportation problems, work disruptions and difficult transitions for children and their parents. For some families, these issues mean that despite a desire to work, they are unable to stay employed. But for many more, employment remains an economic necessity.

Our research found that a substantial proportion of parents of children with special needs do work and that among those who are employed, they are generally as likely to work full-time as are parents of children without special needs. Without understanding how meeting the needs of a child with special needs affects work, one would conclude from this data that the system is doing an adequate job supporting parents' employment. However, a significant number of parents reported a different story of work problems and disruptions and difficult choices between meeting their child's special needs and keeping their jobs. And, findings from our analysis of data from the NSAF show that while labor force *participation* approaches that of parents of children without special needs, job *stability* is significantly weaker than for parents of typical children.

Ultimately, the NSAF data shows that even after controlling for other factors that can influence such issues, financial security among these families, as measured by income, lack of health insurance and inability to pay for food, rent and utilities, is more precarious than for parents of children without special needs.

Meeting the complex needs of these families will require greater public investment and closer collaboration between agencies so that the capacity of the early care and education system to serve these children can be strengthened, gaps in services can be addressed and conflicts in policy resolved. We hope that the findings and strategies included in this report will help inform policy makers as they work to improve the well being of this vulnerable population of children and families.

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## CHAPTER TWO

# Parent Interviews and Focus Groups

## Methodology

During the first year of our three year study, we conducted focus groups and in-depth, semi-structured interviews with parents and guardians of children with special needs. These were held between May 20<sup>th</sup> and November 13<sup>th</sup>, 2002 in the following communities:

- Lewiston/Auburn, Maine (urban)
- Presque Isle, Maine (rural northern)
- Bath/Brunswick, Maine (coastal)
- Waterbury, Connecticut (urban)
- Manchester, Connecticut (urban/suburban)
- Norwich, Connecticut (rural)

A preliminary report providing the results of these interviews, *Parents' Voices*, was published in April, 2004. Here we provide the highlights from that report. The full report can be downloaded from our web site: <http://www.muskie.usm.maine.edu/specialneeds>.

At the end of the first year of our study, we concluded that we needed to confine our research to Maine for two reasons. First, we could make a significant contribution to existing knowledge if we looked in greater depth at these issues, especially as they manifest themselves in rural communities. Second, the complexities of these cross systems issues and the difficulty recruiting this hard-to-reach population would make it difficult to conduct our study effectively in both states within available resources. Thus, this is the only data source that includes data from Connecticut as well as Maine.

### *Co-sponsorship in the Communities*

We were concerned that potential participants might not be as willing to participate in focus groups if they were sponsored by an entity unfamiliar to them. Instead, we approached community sponsors – organizations which had a strong rapport with community members – to assist us in recruiting and to allow us to use their name on the flyers we posted. Community groups also provided us with invaluable local knowledge concerning everything from site selection, recruitment and available populations to details such as transportation and child care.

<b>Focus Group Sponsors</b>	
<b>Community</b>	<b>Sponsor</b>
Manchester	Family Development Center
Norwich	City of Norwich Children First Initiative
Waterbury	Family Services of Greater Waterbury, Inc.
Lewiston/Auburn	Healthy Families Androscoggin
Presque Isle	Aroostook County Action Program (ACAP)
Bath/Brunswick	Family Focus

### ***Recruitment and Selection Criteria***

We knew that recruitment of parents would be challenging given the criteria we were using for their selection and the fact that these were families who were likely to have even more demands on their time than families whose children did not have special needs. Participants (parents/guardians) needed to have at least one child under the age of 7 with special needs. They also needed to have an income below 225% of the federal poverty level (at the time, \$32,900 per year for a family of three). By targeting this income level, we intended to reach people currently on TANF, as well as those who had recently left TANF, had been off of TANF for some time or who had never been on TANF. This group would also include parents whose children were on SSI. We hoped that by using a diversity of recruitment strategies we would also be able to include a wide variety of type and severity of special needs, diagnosed and undiagnosed. We defined special needs very broadly to include any disability or medical condition that might pose a potential barrier to access to child care or have an impact on the care of the child and the other children in the child care setting.

Our focus was on child care and work but in order to understand fully how having a child with special needs affects those issues, we also wanted to include nonworking parents whose children were or were not in some form of child care arrangement. In order to reach this diverse group of families, we made presentations before community groups, posted flyers at churches, laundromats, community centers, libraries, supermarkets, soup kitchens, bus stations, naval bases, community health centers, and other gathering places in the six communities we chose. In addition, flyers were also sent home in elementary school children's backpacks, mailed to all child care centers in the chosen communities, and mailed to statewide organizations working on behalf of, and serving, families with children with special needs. We also placed ads in newspapers in both states and on Spanish and English radio stations in Connecticut.

The language used in the flyers advertising the focus groups was made as neutral as possible. It was important that we acknowledged that the parents were the experts and we were simply interested in hearing about their experiences. We also advertised that cash stipends would be paid to participants to encourage participation. A toll-free phone number was used and in the communities in Connecticut with significant Spanish speaking populations, the flyers were posted in English and in Spanish. We also arranged for our toll free phone number to be answered in both languages.

### ***Screening and Registration***

Those who responded to the recruitment materials were screened to be sure they met our income requirements and had a child with special needs of the appropriate age. All participants filled out a

registration form collecting data on their demographics and employment as well as details on the child's special needs, child care, and early intervention arrangements.

### ***Focus Group Sessions***

The number of people in each of our groups ranged from four to twelve; the meetings lasted around two hours. Each session was tape recorded and a note-taker and observer were the only non-participants in the room. Child care, food, transportation and a stipend were provided to ensure the comfort of participants as well as to encourage their attendance. Sessions also were held in familiar settings, such as community centers, child care centers, and YMCAs.

The pilot focus group was conducted on May 20th, 2002 in Manchester, Connecticut.

All focus groups were facilitated by Linda Rich, an experienced facilitator. A protocol was used to ensure that questions were asked in a similar way and in a similar sequence.

<b>Focus Groups</b>	
<b>Community</b>	<b>Number of Groups Held</b>
Manchester	2
Norwich	1
Waterbury	1
Lewiston/Auburn	2
Presque Isle	1
<b>Total Number of Focus Groups</b>	<b>7</b>

### ***In-Depth Interviews***

Due to the busy lives and schedules of the families we were trying to recruit, getting enough parents together for a focus group proved more difficult than we had anticipated despite our extensive and varied recruitment efforts. Therefore, we decided to also conduct in-depth interviews. Our research staff served as interviewers—one person served as an interviewer and one as an observer at each interview. We used a protocol to enable us to ask questions in a uniform, neutral, and unbiased way. Interviewees were screened and registered. Interviews were held in comfortable, neutral locations, as they were for the focus group sessions. One of our bilingual field workers in Connecticut conducted an interview in Spanish and translated it into English. In quoting parents for this report, we have changed names, and in some cases, the gender of the child, to protect confidentiality.

<b>In-depth Interviews</b>	
<b>Community</b>	<b>Number of Interviews Held</b>
Manchester	5
Norwich	1
Waterbury	1
Lewiston/Auburn	6
Presque Isle	4
Bath/Brunswick	3
Portland	2
<b>Total Number of Interviews</b>	<b>22</b>

### *Data Analysis*

Focus groups and interviews were audio taped and transcribed. As previously mentioned, a note taker also attended each focus group session in order to assist the transcribers in identifying when each participant spoke. The information gathered in the focus groups and interviews was entered into NVivo, a software program for code-based qualitative analysis.

### *Limitations of our Data*

It is important to note that this information is based on interviews and focus groups involving forty-one families who were not randomly selected but who responded to broad-based recruitment efforts at the grassroots level. While the issues identified and the opinions expressed were remarkably similar across the focus groups and interviews, these opinions and experiences may not be representative of the larger population.

## **Profile of Focus Group Participants**

n=41 (CT=21, ME=20)

The following are data gathered from registration forms filled out by parents before the focus groups and in-depth interviews. Included in our analysis of the findings from these sessions is an in-depth interview with one parent for whom registration data was not available.

### *Demographics*

- Average age of parent/guardian is 32
- 51% (21) have a spouse or partner
- Average of 3.6 people per household

- 80% (33)Caucasian, 12% (5)African-American, 7%(3)Hispanic/Latina
- Average number of children is 2.1
- Average age of child with special needs is 4 years old
- 56% (23) have some college or a college degree; 31%(13) are high school graduates; 8% (3) have completed less than high school
- Average annual income of \$18,176 (range = \$4,356 to \$32,900 per year)

### ***Special Needs of Child***

Several parents had more than one child with special needs. However, during the focus group discussions, parents were asked to focus their comments on their *child under age 7 with the most severe special needs*. These children were almost evenly split between those with primarily behavioral issues (56%, 23 children) and those with primarily physical issues (43%, 18 children).

Many children had multiple special needs. The most frequently reported disabilities included: ADHD, Down syndrome, autism, asthma, mental retardation, speech and language issues, epilepsy, seizure disorders and developmental delays. Post-traumatic Stress Disorder (PTSD), Pervasive Developmental Disorder/Not Otherwise Specified (PDD/NOS), Fetal Alcohol Syndrome (FAS), Muscular Dystrophy, Oppositional Defiant Disorder, visual and hearing impairments, paralysis, cleft lip and palate, Spina Bifida, Cerebral Palsy and Prader-Willi syndrome were also represented.

- 58% (23) of children require regular medication
- 11% (4) of children are wheelchair-bound

The following information reflects the family situation at the time of the focus groups and interviews.

### ***Child Care for Child with Special Needs***

- 68% (28) have their child with special needs in care outside the home
- Types of care primarily used for these children (n=25):
  - 24% (6) in their home
  - 20% (5) in school (3 children in nursery school and 1 child each in elementary and after school care)
  - 20% (5) in therapeutic child care
  - 16% (4) in provider's home
  - 12% (3) in Head Start
  - 8% (2) in child care centers
- Average # of hours in child care: approx. 28 hours a week
- Average payment for child care was \$83 per week.



## **Work**

- 56% (23) of participants work outside the home
- 45% (14) of those employed work full time
- 33% (7) work 2<sup>nd</sup> shift or nights
- 68% (13) of those with any benefits have no sick days
- 93% (13) of the 14 spouses or partners who are employed work full time outside the home. Of those:
  - 50% (6) work 2<sup>nd</sup> shift or nights
  - 33% (4) have no sick days

## **Income/Public Benefit Programs**

- 41% (17) are on TANF or receiving some type of assistance (Food stamps, etc.)
- 57% (21) receive SSI
- 31% (11) receive child care assistance

## **Findings**

### **Child Care**

#### ***Difficulty Finding Care***

Parents reported being turned down by child care providers because of the special needs of their children, being asked to take their children out of a child care program or concluding that there was no child care provider equipped to adequately care for their children. One parent said she didn't tell potential child care providers about her child's special needs until their child was accepted into the program. Even then, if asked, she didn't admit to any diagnosis for fear of losing her care arrangement.

*I always worked, right up to when my twins were born. But I had to stop working because of my son. I guess some day cares accept certain kids, but they wouldn't accept him, maybe because of the fracturing, maybe they don't want to feel the blame or maybe because he has to be catheterized they would have to have a nurse do that. Most day cares don't have a nurse... Birth to Three said I wouldn't be able to find child care. They wanted me to stay home. I didn't work for five years and it was hard. I struggled every week.*

A mother of a child with multiple disabilities and complex medical needs

*What I need is a day care that would meet her needs, which is really hard to find. Toward the end of the school year, my daughter was asked to leave the after care program. I couldn't find anybody after that. Right now she only has a play therapist. She has had her for almost a year now, but she got kicked out of a day care because she wasn't listening and too rough with the younger children, she was too bossy, so she couldn't stay at the day care and that was really hard.*

A mother of a child with AD/HD and Post Traumatic Stress Disorder

*I can't find child care..... or an after school program. Nobody will take her, because she flips out. I didn't say anything about her special needs. She is in a program where I didn't let them know. So she has had only one outbreak and all I said was I will talk to her when I get home. I didn't say, "O.K. this is normal for her" because I need the child care. Because otherwise they wouldn't have accepted her.*

A mother of a child with Oppositional Defiant Disorder

### ***Care by Family Members***

A number of parents used relatives to provide child care but for many, these arrangements were short-lived. Parents had concerns about how well their relatives were meeting their children's needs, or there were tensions between the parents and the relatives.

*When I work weekends sometimes my daughter watches my son. It is not a very healthy thing. She wants him to just sit there while she is on the phone or something but he is not going to do that. Pretty much she is not a good babysitter. But if it is a bad situation and there is nobody else I will use her. His aunt used to watch him for awhile and she was the worst babysitter I had. All she did was literally watch him.*

A mother of a child with developmental delays

*We were using my parents but since she has gotten a little worse she is more apt to have a [respiratory] situation happen quicker and it is kind of unnerving. My mom tries to treat her like a normal baby and she can't. Like for instance she was playing with her just the other night and the baby was kind of gurgling and then she just stopped and she was staring and you couldn't hear anything. My mom says, "Oh look, she is staring at me." My dad goes, "No, she is choking." My dad caught onto it, but my mom didn't and she was the one holding her. It is just unnerving to leave them when you know you are the one that knows how to do everything.*

A mother of a child with muscular dystrophy

## ***Toilet Training, Medication and Medical Issues***

Toilet training was an issue for many parents because their children with developmental delays were not able to be toilet trained at the typical age. These parents told us that many child care programs wouldn't take children if they are not toilet trained. Some programs accepted these children but parents complained that they wouldn't change their children regularly. Others were praised for doing a great job helping parents to potty train their children with special needs.

*The problem I seem to have with my son is that his disabilities aren't obvious. So I had a real problem putting him in a preschool when he was three. Several day cares wouldn't accept him because he was over three and not potty trained, even when I said that is part of his special needs. Developmentally he just couldn't do that. A disability is a disability. They had so many excuses, like, "We understand, but our workers can't lift a 45 pound child onto a changing table to change him."*

A mother of a child with developmental delays and a seizure disorder

*They don't change her. We are trying to do the potty thing. She goes to school from 11 am to 3:15 pm. She doesn't know how to go, we are still going through that process. So when she gets home she is all soaked – she is wet and red. It is bad. They knew she was not toilet trained when they accepted her.*

A mother of a child with speech delays

Parents whose children needed daily medications or medical procedures found it particularly hard to find stable child care arrangements.

*He takes medication, that was another thing when you are looking for someone or places to help you. I learned when I first came to Connecticut there are only two providers in the area who are what they call medication licensed. My son is on nineteen pills a day and has been on them for over three years. The minute you tell providers he takes prescription medication there is no one allowed to give medication to the child.*

A mother of a child with multiple disabilities and complex medical needs

*The provider did not administer medication. If he had any medication that he needed, then I would have to come there and give it to him. I would just like to see that! I would have said to my boss, "I have got to drive up to Manchester to give my kids medication and then come back down here, is that O.K. with you?"*

A mother of a child with developmental delays

## ***Lack of Inclusion***

Many parents using regular child care reported that their children with special needs were often isolated from activities and interaction with other children.

*I don't have child care providers turning me away – they just stick him in the corner. He wasn't as active as the other kids and they would just put him in the corner. He had to go outside for whatever the rule is, at least half an hour or something. They brought him outside and he just sat in the sandbox and the other kids would play. I noticed they would put him in a stroller and strap him down and just leave him there. If they knew that the Birth to Three person was coming, they'd put him in the circle with the others. But if they weren't expecting us or if I showed up unexpectedly, he would be alone. One day it was his birthday, so I brought in some cupcakes. He was in the corner, like so pitiful. [The mother started crying at this point.] He didn't get any kind of attention, he wasn't part of the general group. He was just there. So I took him out and I changed my shift and worked nights, so I could be home in the daytime until he went to school.*

A mother of a child with developmental delays

## ***Communication with Child Care Providers***

When asked about their communication with their child care providers, some parents said they were very satisfied with this aspect of care and others wished the communication was more frequent and more informative. This seemed to be a key factor in parents' satisfaction, partly because parents wanted help with how to handle their children at home so there was consistency between home and child care, and partly because they wanted to keep track of whether their children's special needs were being met and whether they were making progress. Parents seemed particularly concerned that their providers be knowledgeable about their children's disability.

*We communicate every day. They tell me how my grandson did, I tell them how he did the night before, if he didn't sleep. When he is really tired, he is more active. So I write them and tell them he didn't sleep well, expect maybe a hard day. They will tell me if he has a good day or a bad day, we write every day.*

A grandmother/guardian of a child with Autism Spectrum Disorder

*I am working full time now and there is no way for me to go to the school to find out how my son is doing. I think I should have a letter sent home at least once a week, or whatever, just to inform me how he is doing. Because it is special needs and I feel that it is all on me. I have to make a phone call while I'm at work.*

A mother of a child with learning disabilities, AD/HD and asthma

## *Delivery of Special Services/Transportation Issues*

Some parents of children in regular child care programs spoke of the difficulties when special services their children needed [OT, PT, speech, etc.] were not provided on site. Some were able to have their children transported to their specialists' offices although this was not always seen as good for the child. Others had to be available to transport their children themselves and this adversely affected their employment. This was a particular problem in rural areas where parents had to transport their children long distances for their appointments.

*I was working full time and I would have to tell my boss that I have to leave for a little while and she was really cool about it, 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 have to go back to work. It took me an hour to get focused again. Then I would have to stay overtime because I had to make up my hours I lost.*

A mother of a child with Autism Spectrum Disorder

*I just started a job, not even three months, and I had to go back to my boss. The job begins at 8:30 am. But my son has a special bus that picks him up with a nurse. He is the last child that is going to be picked up which means that he is going to be picked up at 9:30 a.m. meaning that I am going to be late every day to work. He is going to be dropped off home before all of the other kids because he has a special nurse, which means that he will be home by 2:30 and what am I going to do? On Mondays and Tuesdays, I put him on the bus. I have someone who helps me on Wednesdays, I have someone who helps me on Fridays, I work on Saturdays. I have to be at my job and not take breaks in the morning so I can take a twenty minute break in the afternoon and drive over and pick up my friend so that I can drop her at my house so that she can be there when the bus arrives. I am so lucky I found this employer but how long is he going to keep up with me doing this? Business is business.*

A mother of a child with multiple disabilities and complex medical needs

## ***Comprehensive Programs***

Several parents whose children were in Head Start expressed a high level of satisfaction about the knowledge Head Start teachers had about disabilities, the communication with parents and the comprehensiveness of the services provided to their children.

Those parents whose children were in specialized programs specifically for children with special needs, or integrated programs for children with and without special needs were also happy with the comprehensive services their children were receiving.

*The Head Start program is so good and everybody that works there, they are involved. If they can't do it because it is something the parent should do, they give each and every tool. They say, "O.K., this is what you do, because most of them are parents. They are great. It was hard getting him in that program. But now that he is there, it is a full day program and I was concerned because I thought that when he went to the four year old group he was only going to be half a day so that then, I would have to cut down my hours at my job because to find someone to baby sit and to understand what he is talking about is real hard. I spoke to one of the advocates and they said that this year, for the first time, the kids in the three year old all day program are going to move to a four year old Head Start all day program. So that worked out perfect. He is either the first one or the second one at Head Start in the morning. I mean he loves going there so I don't even feel guilty. There are some kids that dread going to day care, but even when we drive by, "Oh, am I going to school?" I am like, "No, not today." He is receiving Head Start, they give him speech therapy once a week because that is what they determined it had to be at the PPT. That Head Start program is so good and everybody that works there, they are involved.*

A mother of a child with speech delays

*I love Head Start. They take him out. They help each of the kids and they do a lot of things. They go on numerous field trips. They get to learn about everything.*

A mother of a child with learning disabilities

*The program our child will be going to— it is the place where they are going to have all of the services on site at one location. It is so wonderful. He is on the waiting list. They do potty training there. I told them that is one of the biggest things I need help on.*

A mother of a child with Autism Spectrum Disorder

*I had a choice after Birth to Three; they gave me a choice of going to a program only for children with special needs or an integrated program.<sup>24</sup> Talking to my doctors and therapists everybody felt the other one would benefit her more and that is why I went that way. Everyone felt my daughter would probably do better with interacting. They feel she understands everything; she just can't get it back out. So getting in with healthier kids, she thinks she is one of them. She kind of forgets. This is her second year there and she loves it. I mean she doesn't, she is trached and g-tubed, and she doesn't do much, but interacting with the kids she loves it. They all come over to her and make her feel like a princess. She thinks it is the greatest. The other kids are so nice. My daughter is in a wheelchair. I was a little nervous but they have been helpful to her and they have been nice to her. And she is to them. She has touched them. She's been a saint.*

A mother of a child with Cerebral Palsy

### ***Limited Hours of Care***

Because early intervention and preschool special education programs are focused on the special needs of the child and not on the needs of the parents for child care while they work, parents say that the hours often don't mesh, leaving them with gaps in care to fill on their own. This is true when programs for special needs children offer only part-time care or don't operate during the summer and when a service a child needs in the child care setting, such as a one-on-one aide or deaf interpreter, is only provided for part of the time the child is in care. This kind of specialized service is governed by what the team required under IDEA decides is needed educationally by the child, not what the family may need in order to work.

*My son, he is in a triangle. Because he is only going to be in school for this amount of time and then I have got to figure out whether or not he can be dropped at a day care and how that is going to work. You know, it would be so much simpler if they just made it a full day and I know where he is at all day and he is benefiting from it more than he would be benefiting from a day care. You know, he would be with day care kids that would be three and four years younger than he is. What is that going to do? That is going to do absolutely nothing for him, nothing.*

A mother of a child with AD/HD

*If he was in full time care then CDS would only pay for an aide for my son for three hours a day. But he would be in school longer. But the aide would transition from an educational benefit to a day care benefit. And my question was, well, who is going to pick up the difference because if you are paying an aide \$10 an hour, \$8 an hour whatever an aide gets paid, then you also have a day care expense of whatever per week, then you have it worked up on an hourly basis then who is going to pick up the difference. It could be very considerable.*

A father of a child with multiple disabilities and complex medical needs

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<sup>24</sup> Birth to Three is the name of Connecticut's program of early intervention services for children ages 0 to 3 under Part C of IDEA.

## Work

Parents reported an array of work issues which affected their economic well being; problems caused by the difficulty finding child care appropriate for their children, the lack of full-day coverage offered by therapeutic programs for children with special needs, the job of managing and coordinating services for their children and/or the particular demands of their children's special needs.

### *Work Disruptions*

Many parents spoke of difficulties with their employers because of the disruptions in their work day required to take their children to medical appointments and special services, deal with crises or meet with their children's teachers and specialists. Some of these parents reported job losses; others told us about the difficulties making up lost hours even when their employer was understanding about these disruptions.

*Being gone from work because of the special needs my son requires, causes me to miss work and it causes me to stay at work longer than I would normally when I am available at work. So it is not a good situation all the way around. I am in an office with so few people. It is really difficult. You know, you take two weeks off, you take a week off here, you take a couple of days there, that adds up. You have to make up a lot of lost time. Like last night for instance I didn't leave the office until really late. I had to go to Baltimore for two weeks while my son got treated for his seizures from specialists there. I had a deadline and since I needed to go I had to do all the work by staying late. When I'm available I need to work longer hours to accommodate the work I couldn't do when I wasn't there.*

A father of a child with multiple disabilities and complex medical needs

*The only reason my employer didn't fire me was because he knew that the Family Medical Leave Act lets you have 120 days of leave unpaid and I hadn't missed more than that. But he would make all types of comments. I would have to leave work because of my son's seizures. He would call me into his office and say, "What are you going to do?" My feeling is, if you want me to leave, I will leave. If I had a schedule of my son's seizures for the next three months I would give it to you. Sometimes you feel against a wall because, I mean you want to work.*

A mother of a child with multiple disabilities and complex medical needs

*I just finished school. I almost didn't finish because of the day care. They were calling me and they were telling me my son ran out of the classroom or he did this or that and can you come here and get him?" "All right, I'll come and get him." Good thing my school, you know, was with me on that. Otherwise, I would not have gotten enough credits because I was leaving early all the time.*

A mother of a child with AD/HD



## Work Strategies

Some parents did split shifts with their spouses so one could be at home with their children. Other parents reported staying home while their spouse took two and three jobs to support the family. Still others worked at night so they could stay home with their children during the day. This meant that they were up most of the night working and then spent their days taking care of their children and dealing with sometimes very challenging behaviors. Some parents adopted these strategies because they were not able to find child care for their children; others did so because they didn't think any child care provider could meet the special needs of their children or because they had to transport their children to so many appointments during traditional work hours.

*My wife and I work different shifts because of who is going to watch the kids. She works double shifts on the weekends. I work full-time plus part-time at another place. She is a nurse. I come home from work, she goes to work. She does double shifts Saturday and Sunday and we still have no money. We never have any time with each other and it is hard.*

A father of a child with AD/HD

*I had trouble finding child care that worked for him. He moved around three or four day cares until he started to go to school for four hours a day. That was crazy, by the time he got on the bus it was time to take him off. Once he started school, I went to the night shift so I could stay with him in the days. So I got very little sleep at night. I came home and I had to stay awake or half hanging off a chair until it was time for him to get ready for school. Then he would be off to school for like three hours, so by the time you got him on the bus, it would be time to get him off of it. You know, if I would go back to sleep, I was sure I wouldn't hear the bus.*

A mother of a child with developmental delays

A number of parents had to bring their children to work either because they didn't have child care, they were unhappy with the care they had and wanted to limit the hours their children were in care, there were gaps in care because of their work schedules or there were medical reasons for keeping the children with them. Sometimes this worked out fine and for this the parents were very grateful. Other parents felt the displeasure of their supervisor.

*I go in to his child care and I sit him on this big rug with a bucket of toys. When I come back to pick him up he is sitting there in the same spot and nobody is around him – he just sits in the corner the whole time. [The child can't walk.] If I go there during the summertime all of the other kids are outside, he is left inside alone. He is the only person in there besides another person watching him. All the other kids are outside. I just don't think it's fair. So I don't like to leave him there a lot. I try to pick him up every day and bring him with me to my third job – office cleaning. I do that until about 7:00 or 7:30 pm. My employer doesn't know I take him with me but I have to bring him with me because it is so hard leaving him at that child care.*

A mother of a child with developmental delays

*My wife would drop the kids off at my office. It wasn't too bad during the first six months. I would go in at 6:30 am and work until 4:00 pm when she would leave the kids. Then I would take them home. Towards the end of the year it got a little rough. My supervisor, you know, would sort of bite his lip as I was leaving to take the kids home when he knew he was going to be there until eight. But then there were times when I would keep the kids there until 5 or 5:30. Both of my kids seemed to do o.k. but it is really not a proper environment for them.*

A father of a child with multiple disabilities and complex medical needs

### ***Unpredictable Hours***

Some parents complained that their hours were unpredictable. Because they got such short notice of when they were expected to work, it was hard to schedule their child's appointments at times when they wouldn't interfere with their employment. This caused problems with their employer.

*It was not that I didn't want to work, but that I had a responsibility that I had to make sure that my son's needs were met. He was seeing many specialists. I had two other kids that, in my opinion, got left out a lot of the time because I couldn't get consistent day care for him. I was up at 4:30 every morning and I was working from 6:00 am to 8:00 a.m. and then going back at 3:00 p.m. and working until midnight. But they didn't want to give me a regular schedule. Every week I'd want to say, "Okay, this is what I am going to be working so I can make Ethan's appointments around this." But they just wouldn't do it and I needed to work. I just felt that because of that need to have to work I was, you know, accepting the job even though I was the one in the end that was going to pay dearly for trying. I am not going to neglect my child for a job. I left that job because they wouldn't let me have time off to meet my son's needs. I was working seven days a week and I was a basket case. I ended up getting on Prozac because I couldn't do it anymore. Now I have a more flexible job and my son's in a preschool so it's easier. I work over forty hours and the pay is good and I have benefits so I can't quit.*

A mother of a child with Down Syndrome

### ***Inability to Work***

Many parents, particularly of children with the most severe special needs, said they were unable to work at all because of the demands of meeting their children's needs.

*I had to stop working when my grandson was eighteen months old, right around when everything changed. Before that he had a few words but then he just stopped talking. He couldn't handle me being gone all day. He would just have the worst nights. When I got home it would be awful, just awful. He would just bounce off the walls and cry and he couldn't tell his child care provider anything. They never knew what he wanted, why he was crying, all he did was cry and scream. So I couldn't bring him to a day care like that. I was missing so much time too because he was sick all the time with upper respiratory problems. Last winter he had pneumonia five times. Then he was going through the evaluation to figure out what was wrong. And then there was the sleep problem – he was never a good sleeper but it got a lot worse. I would end up getting an hour or two of sleep every night and then go to work and, you know, be up all day and then all night with him and I was just losing my mind. All I did was cry. He would sit there and cry, I would sit there and cry, that is all we did.*

A grandmother/guardian of a child with Autism Spectrum Disorder

*Without a nurse in my home I can't do anything. I owned a business for six years. Then my daughter came along and I was never there. There were other people running my business and the money started to be missing. The place started to go down hill so I thought before it kills us I am going to sell it. Then I went to work at the hospital and I was getting phone calls. My Mom would take care of my daughter. She would call, "She has a temperature of 103." She just doesn't know what to do. So finally, the last straw was the trach came out and she is trying to breathe. So all of a sudden I am riding home - it's a forty minute drive - because my daughter's trach fell out – they had to find someone to come in and replace me. I worked 7 PM to 7 AM because she is asleep most of that time. But you never know when the time will come. My mother said, "I can't do this. I am 60 plus years old and this is going to kill me. I can't." So then they had to put me on medical leave. Well, you can only stay on it for so long and then they say, "Is the situation going to get better?" I can't say that it is or is not. With my luck, it is wonderful for two months and the day I go to work it will happen again. I had to finally leave, I had to give my resignation because I couldn't promise that I would go back and be able to be there and that is what they were asking. So now I sit home unemployed, because of my children. I think about what happened. I think about how like three years ago I was sitting pretty. Now, but to measure it all out, I would rather be with my daughter. So you make the sacrifice. But the sacrifice is rather awful.*

A mother of a child with Cerebral Palsy

## ***Work Overload***

While some parents reported that they were unable to work at all, economic necessity forced others to work longer hours than they thought were healthy for their families. Because they were in low wage jobs, many had to put in more than forty hours to earn enough money to provide for their children and this only added to the worries they had about their children with special needs.

*I'm working an average of sixty hours a week now. And on a good day it takes between 35 and 40 minutes to get from my house to work. I don't know, I guess, I hope that somewhere down the line, I hope my employer feels the need to pay me more money so I don't have to spend so much time at work but that is not a realistic hope.*

A mother of a child with developmental delays

*When I go to work my daughter holds my leg, she will cry, "I don't want you to go to work. I try to take some vacation off – I request it off. I take two or three weekends off during the year and then I take one full week. I would like to work forty hours a week instead of sixty. Maybe if I could make more money it would lessen the burden. I think that has a lot to do with things. I am not making enough. I would like my work hours to be less and get the same amount of money. I want more time with the children, maybe help my daughter get through it. To help her and I want some more days just to myself.*

A mother of a child with Oppositional Defiant Disorder

## ***Welfare to Work***

Of the few parents we spoke with who were receiving TANF, several voiced concerns over being urged to return to work despite the fact that they could not find appropriate child care for their children with special needs. Some have children who have such unpredictable illnesses that they are not even able to attend the orientation meetings conducted by the state agency that administers TANF. They expressed concern about what type of work record they would have if they go to work and end up with frequent absences or tardiness because of their children's special needs. Parents described frustration with the choices they are faced with in either losing their assistance or leaving their children in what they believed to be less than adequate care. One parent did express appreciation for her caseworker's understanding of her situation and the difference it made for her.

*When you are a single parent, you don't have any other options. Okay, this is my option. I either put her in this daycare because it is the only one [even though I don't think it meets her needs] or I go off state aid, have no funds and get my kids taken away because their needs aren't being met. Which they are not being met anyway. You know what I'm saying? But it's like, oh well, what do you do? There are so many Catch-22s I want to just scream from the top of the roof, "Help me!"*

A mother of a child with asthma and a seizure disorder

*I didn't really want TANF, [but] I also didn't plan on him being born early either. I was working until the day I went into labor. [My ASPIRE caseworker] is giving me a hard time right now because they want me to go back to work. They say that I can go back to work but his doctor says that I can't because he doesn't want him in daycare. If he is around somebody for two seconds, it doesn't matter what they have, at the end of the night he will have it. [My caseworker says,] "Don't you have a family member or something?" My mom works from seven o'clock in the morning until close to seven at night. My sister has two kids and is going to school part time. I have a deadline by the end of November to take the aptitude test. I have set it up twice and he ended up getting sick. He could be fine and then sick in an instant. They just don't get it, they just don't care. I would like to be going back to work or school, but I also don't want to leave him with just anybody and end up getting sick. I don't want to get a job and have him getting sick or going to the hospital and me having to take off all the time or getting fired because every time he gets sick, I have to leave. It's not that simple.*

A mother of a child with Pulmonary Stenosis

*ASPIRE has been great working with me and giving me leeway as far as how many hours and really counting a lot of stuff that I do at the group home for me, like counseling hours.*

A mother of a child with AD/HD and Post Traumatic Stress Disorder

*I used to have three jobs. Financially, I would have been better off working than staying home and getting TANF. But I couldn't. I couldn't find quality day care. I had been home with him for a year. Then with ASPIRE, I had gotten a job and relied on a private sitter who didn't meet his needs. I was unsatisfied with the care he was given.*

A mother of a child with Down Syndrome

## Issues that Compound Work/Family Challenges

While our primary focus in this study was on parents' experiences with child care and balancing work and family, other issues arose in our focus groups and interviews which are important to report because they too impact on parents' ability to work and meet the needs of their children.

### *Financial Issues*

While lost wages due to a lack of available child care or work disruptions is the most obvious financial impact of having children with special needs, parents described other examples of hardship. Unique medical needs and special services not covered by insurance were common sources of out-of-pocket expenses. The need for transportation to services and even to out of state facilities was another. A number of parents expressed concern for the future when they are unable to save now for retirement for themselves and anticipate only mounting bills for their children's special needs.

*At two and a half she also got diagnosed with scoliosis and we have to see a specialist in [another state] and he does not accept our [State CHIP] insurance. So we have a lot of out of pocket expenses we have to pay. Even if we get SSI, it doesn't cover....because I don't work full time and it's a strain just with my husband's income. The little I earn helps to supplement, along with SSI, the doctor's visits and the surgeries that she has to have and the specialized things that she needs.*

A mother of a child with Prader-Willi Syndrome

*You really need to have a wheelchair accessible van and you have to buy a new one because they don't want to convert an old van and conversion is \$5,000. Who is going to pay for that? Insurance won't cover it because it's a convenience item.*

A father of a child with multiple disabilities and complex medical needs

*I have a car that I am making payments on and without the car I can't bring him to his appointments. I don't have enough money for a cab, you know. That is pretty expensive if you think about it....I am still struggling with my car and all of my bills, because for the last month I have been struggling trying to work [without child care].*

A mother of a child with a cleft lip and palate

## *Coordination of Services*

Children with special needs often have to see a variety of therapists and specialists. However, many parents indicated that the services were not always well-coordinated. Some parents noted that they were uncomfortable being relied on as the liaisons among the various specialists and wished that the specialists would confer with each other. Parents reported that when they had to act as their children's case manager, the work involved was a significant drain on their time. The parents that expressed that their children's specialists were in contact with each other were generally satisfied with the situation.

*I think that if all of the resources were in place, if the resources are out there... 95 percent of the people that are in my position [with a child with special needs] wouldn't have any real differences to deal with in their family, you know.*

A mother of a child with asthma and a seizure disorder

*They [therapeutic services] are not coordinated at all. It was understood that when he had a case manager that the case manager was to see that his needs got met and according to his schedule and what was convenient or not convenient, but in the best interest of my son. Whether that meant that he had PT at eight o'clock in the morning because that is when he works the best then, that should have happened. Not at four o'clock in the afternoon or two o'clock when he is needing a nap. It didn't benefit him. ... because of the transportation thing, they had him go to OT at 10, got out of there at 11, went from that place to PT at 11:15, and then tried to have that session and meanwhile he is hungry, he wants lunch, but nobody cared, because they needed to get their time in. He didn't function.*

A mother of a child with Down Syndrome

While many parents expressed frustration with the lack of coordination of services, others expressed satisfaction with the therapeutic services their children received.

*I think they [speech and occupational therapists] have done wonderful. They have done an excellent job with my grandchild. It has been under a year and a half and my grandchild's speech has just taken off. They are really wonderful. ... They have done a wonderful job. My grandchild has come very far.*

A grandmother/guardian of a child with Autism Spectrum Disorder

*CDS helped me out a lot. They got everything going for me. I was trying to get him into it [developmental therapy at home] right now before he goes to [a therapeutic program for children with special needs] in November.*

A mother of a child with Autism Spectrum Disorder

*I think as far as my daughter goes, we have been very blessed. I don't know if it is because we were willing to work with the speech therapist's schedule in that she just works Saturday mornings and, you know, I don't mind getting up early, because my child is awake anyway. But to me, it is worth it. I will do whatever it is that I have to do, so that my daughter can get the services that she needs. She is my daughter and I love her and I want her to have the best that she can have.*

A mother of a child with Down Syndrome

### ***Shortages and Turnover of Specialists***

Some parents, particularly those living in rural areas, reported difficulties in finding and retaining specialists, therapists, and individuals in the medical community to work with their children. Not only did parents have difficulties finding specialists, they also said that they lacked options if the specialist or therapist was not meeting the needs of their children.

*We could try to get a nurse in from a home health nurse agency, which we had before. But the nursing shortage in Maine is just crazy right now and we would be put on a waiting list. Then when we do get somebody in you need to, my fiancé and I feel like we need to train her for a few weeks before we are comfortable leaving them alone. Then you have nurses that will say, "Sure, I will take care of a baby." And then they come in and they see her and they kind of get a little uneasy about it. You train them for a month and then they turn and say, "Well, I don't really feel comfortable." So you have to deal with that. We almost feel like that is more of a headache at this point than trying to take care of stuff ourselves. It has kind of taken a toll on our intimate life, but it works, I guess. It would be great if Maine provided some of the stuff that Boston Children's Hospital does. But there are only two neurologists in the State, whereas down there they have a whole neurology floor. So it is an issue, we just don't have that stuff and you hate to go there.*

A mother of a child with Muscular Dystrophy

*The OT therapist seems to be more negative. "This is what your child is doing wrong and she is not doing this." Although I understand that it is important to point those things out, I think I respond more to positive reinforcement. Then the other thing is, my child is fussy when the occupational therapist is here. She doesn't want the therapist to touch her and she is not good at manipulating. Also two of the appointments that we had with the therapist, we went to CDS. So my child was out of her environment, it was cold, she didn't feel well. It was just bad timing. ... I actually asked her caseworker [for a different therapist]. I said "Is there anybody else?" She said, "Well, really that therapist is the only one working with babies right now." She said, "Why don't you give it another try and see if it gets better." It has gotten better, but it is still not optimal.*

A mother of a child with Down Syndrome



## ***Difficulty Obtaining a Diagnosis***

A number of parents of children with behavioral problems expressed frustration at how long it took them to obtain a diagnosis so their children could begin receiving services. This was a particular problem in rural areas. Some parents cited a shortage of specialists while others felt that their regular pediatrician didn't take their concerns seriously enough.

*I was telling all of the counselors and psychiatrists and what have you at the mental health clinic and they were like, there is nothing wrong with your kids. I am like, excuse me, I know there is something wrong because I see them every day. I am with them 24 hours a day, 7 days a week....they'd take them in, do the intake and put them on a waiting list. Six months later I still had no services. So again I take them in, they do another intake and they get on a waiting list. Well, I'm just now receiving services so it has been over two years. ...I got fed up with it, after fighting, fighting and fighting and taking him there every three to six months...Its hard enough being a single parent and now I have two children with special needs instead of one.*

A mother of two children with AD/HD and Post Traumatic Stress Disorder

*They told me he was just....they had a million reasons, the doctor always had a reason. It wasn't anything, there wasn't anything wrong with him, I was just nervous. I've already raised three children, I wasn't nervous....He's just active, oh all kids go through this at his age, they don't sleep. No, no, no! Not eight months, nine months they don't sleep. This isn't just a little no-sleep period, this is no sleep!*

A grandmother/guardian of a child with Autism Spectrum Disorder

## ***Accessibility Issues for Children with Physical Special Needs***

Parents of children with physical special needs described the challenges faced because of the lack of accessibility in their homes and vehicles. Some of these parents expressed their need for adaptive equipment and the frustration of having homes which are accessible for physically disabled adults, but not for physically disabled children.

*I asked my social services worker about a ramp, like to be able to get in the house, to be able to just wheel my son in the house instead of having to carry him. She said she would check into that, but [I've heard] nothing.*

A mother of a child with developmental delays

*I don't bring her out by myself anyway. Right now, we are having transportation issues with her, because she is 30 inches, she is very long for her age, and she is not supported through the chest and her neck area. So we can't find a car seat that will adapt to her needs right now. But we are in the process of getting one custom made.*

A mother of a child with Muscular Dystrophy

## Impact on Families

Parents' descriptions of their experiences with child care and balancing work and family were often accompanied by tears. The sheer scope of what they had to juggle on any given day showed in their words and emotions. Yet most also spoke about the joys of raising their children, the lessons the experience has taught them and the positive impact their children have had on their own personal development and that of the other members of their family.

### Caregiver Stress

Many parents reported high levels of stress caused by a convergence of issues. Some were dealing with severe medical emergencies on a frequent basis; others struggled with balancing medications or complex behavioral issues. Coordinating multiple weekly appointments with a variety of specialists was common. Many said they functioned on very little sleep while balancing the needs of their other children and work schedules. Parents seemed to be burdened with frightening “what ifs?” and worries about their child's future along with their everyday concerns as they went through their day. This seemed to be taking a toll on the parents' well-being and their ability to successfully balance work and family.

*I admit it. There are times he gets me so stressed out, I don't know if I can do this. After I calm down, I am like, how could I think that, you know? At the time, it feels like, “Oh my God, I can't do this.” It's hard having a kid with special needs. I mean it is a lot of stress, a lot of stress.*

A mother of a child with Autism Spectrum Disorder

*She went into respiratory distress, she had a spell of apnea for almost four minutes, so it was crazy, but I had to take care of it because [the ambulance] wasn't fast enough...they, of course, freaked out coming into the house and seeing a baby in respiratory distress. I have to stop them before they go and perform a tracheotomy and say, “No, no, wait a minute. She has got muscular dystrophy. She is supposed to be toneless like this.” It is hard because I'm scared that, what if I am not home and her dad is taking care of her? Sometimes he is rather quiet and what if he doesn't speak up and they just go ahead and do what they think is necessary?*

A mother of a child with Muscular Dystrophy

*My children, my two healthy children, there are times they think it would be great to pick up and go, but not without a nurse for my daughter we can't go. So there are a lot of opportunities missed for my healthy kids because of things that can't be met for my daughter.*

A mother of a child with cerebral palsy

## ***Extended Family can be a Help or a Source of Tension and Hurt***

Parents fortunate enough to have family nearby described the benefits of having someone they could rely on and trust for occasional child care, carpooling or just listening. Having extended family nearby was not always a benefit to parents, however. For some parents, fear and a lack of understanding about their children's special needs among extended family members resulted in tensions and hurt feelings.

*[My mother] is two blocks down so she helps a lot. Sometimes they go camping and they take them [the kids] for the weekend. When they come back home on Sunday, "Oh our children we love them, bring them back!" It is such a breather. Or even for an hour or two, just bring the children over, you know, just so they can come over and play for a while, whatever. It helps out a lot, a lot.*

A mother of a child with speech delays

*Well with my family it does something, because I feel that they should be more understanding. Sometimes when he is in the hospital, they give me a hard time about watching my other kids so I can go spend time with him in the hospital. I get really mad about that. Like I said, they don't understand, you don't know what's going to happen tomorrow, your child could get hit by a car and something could be wrong with him for the rest of his life. Then maybe you would understand how I feel. But as a mom, you know, it is hard for me to bring all of the kids into the hospital, if one of them has a cold, you can't like, it is like hospitals have got all of these rules. So my dad, when he is in the hospital, my dad helps me out a lot. He doesn't really show his feelings and stuff like that, but he has a soft spot for my son.*

A mother of a child with multiple disabilities and complex medical needs

*All of the family readily assumes, they will readily take care of our child without special needs, but they are kind of hands off, well they are hands off on our child with special needs. They are not really interested in helping and even when they do they don't want to take them both.*

A father of a child with multiple disabilities and complex medical needs

*Well, everybody loves my son, but when it comes to push and shove, can we get a break from him, can you watch him? "Bye, bye. Nope." You know, they like us to go visit them, but when we ask them to watch him they tend to say, "No, no, no."*

A mother of a child with Autism Spectrum Disorder

## ***A Lack of Understanding in the Community***

Many parents described the anger, pain and frustration they felt when they encountered insensitivity to their children's special needs in their interactions with members of the community, from fellow shoppers at the grocery store to nurses and teachers. They felt they were being judged a poor parent because of their children's behavior and a general lack of awareness of their children's disability. Others felt they had been wrongfully accused of abusing their children or feared that this would happen each time they took their children out into the public.

*I just get sick of people asking me, "What's wrong with him?" He is fine. It is just frustrating as a parent that you need to explain. Sometimes he will act up in the store and people will be looking at me like, you know they want to say something but they don't. I feel like saying, "What's the matter, you've never seen an autistic kid before?" You know, I want to say that but I don't want to lash out. Then they will say, "OK, there is something wrong with the mother, too!" You can't take your special needs child in the store, going grocery shopping without getting dirty looks. To me that is a big issue. There is a problem there.*

A mother of a child with Autism Spectrum Disorder

*I went to a grocery store and my child would be flipping out and one day I had to literally pick her up and leave and the security guard came out after me. He said he was going to call the police. I told him she has Oppositional Defiant Disorder and there is nothing you can do. He said, "Well, I'm going to call the cops." In the meantime, I brought her out to the car like you are supposed to do; take them out of the situation and then let her throw a fit. I had her in the car and she wasn't going anywhere. She was calming down. So by the time the cop got there, he just said, "Go home." [I am explaining myself to people] all of the time.*

A mother of a child with Oppositional Defiant Disorder

## ***The Stresses of Navigating the System***

Most of the parents we spoke to reported navigating an intricate web of agencies and organizations in order to receive the specialized medical care, child care, special services and income support required to help their children. Parents told us of frustration with miscommunication, bureaucratic red tape and a general misunderstanding of their situation, the children's special needs, or of the other agencies involved. Parents were left to spend their time trying to tie everything together, coordinate efforts or explain themselves again and again to ensure their children received the necessary services and support. Keeping up with paperwork and the rounds of appointments and phone calls added up to a large time commitment, straining their already tight schedules. In order to be a successful advocate, parents also indicated that it was critical to know their rights before and that, in and of itself, was a time consuming task. Some parents reported that an individual – a family member, therapist, doctor or friend – provided them with the help and support they needed to advocate for their child. They were deeply grateful to these individuals.

*I've got to do what I've got to do. My mother said if they didn't give us the services, then we were going to call the state representative. These children need to be blessed with parents that will do everything and go that extra mile because this is what they need. If we would stop every time we got our door closed, our kids would be home and not getting the services they need because there are so many doors slamming. I need to know where every piece of paper is, I feel better [referring to thick folder]. I am more on top of things because I can say, "Her last IFSP, that is right here." I can go pull it out or, "What did the Down clinic say about it? Oh, it's right here."*

A mother of a child with Down Syndrome

*When I was in another city, I had a nurse that came in who could watch my son when he wasn't in school or was sick and couldn't go to school. I asked her about that up here and she said we don't have that up here. It is like she doesn't look into it. When I found the professional home nursing, she called me and said, "Oh, where did you find them?" I told her, "I looked in the phone book!"*

A mother of a child with developmental delays

### ***Strains on Family Relationships***

Parents described the impact on their relationships of balancing work and caring for their children with special needs. Odd hours worked due to a lack of child care, a fearfulness about the responsibility of caring for children with sometimes life-threatening illnesses, frustrations over advocating for their children's services and the day to day stresses of caring for sometimes challenging behaviors seemed to take their toll on marriages and partnerships for many of the parents.

*For a year [my wife] worked nights [because we couldn't find child care]; in at 4 pm and got off at midnight and boy, that was not good. That was absolutely horrible. Any little thing that wasn't just so in the beginning of the week, you spent an entire week thinking, "She doesn't care about me, I don't care about her." This would go on for a whole week. Things escalate, of course.*

A father of a child with ADD, Post Traumatic Stress Disorder and Auditory Processing Deficit Disorder

*There are times when having a child with special needs can bring people together, in my case it worked the opposite. My son's father walked away from us. It was difficult, it was hard because it was only me. I don't know, everybody thinks different, but being a mom of a special needs child, I just put everything next, my son comes first before anything else.*

A mother of a child with multiple disabilities and complex medical needs

## *Learning Lessons and Reaping Rewards*

Despite the challenges of caring for children with special needs, many parents also described the joys and learning opportunities that these children bring to their families. Several said they have learned important life lessons: to take nothing for granted and to appreciate the little things. A number of parents said that the experience strengthened their relationships with their spouse or partner. Those with other children reported that they have become more caring and understanding of differences as a result of having siblings with special needs.

*He is just the greatest. I always say he is like my angel. He was sent here for a purpose and he has made me a better person. I love all my kids the same but he is the one that pushes me every day. No matter what he is going through, he has a smile on his face. He has taught me that there is just so much more to see than to always be angry or grumpy or miserable. He has made me a happier person and every day I just wake up and I see him and I say, "You are my sunshine." It gets me through each day.*

A mother of a child with multiple disabilities and complex medical needs

*[Having a child with special needs] has made us stronger, a lot stronger.*

A mother of a child with Autism Spectrum Disorder

*The simple things that he sits down and looks at and acknowledges. Because he is seeing stuff that nobody else sees. But that is so good in a way because it makes us slow down and stop a little bit in the world. It teaches us a lot.*

A mother of a child with speech delays



## CHAPTER THREE

# Field Study

## Methodology

The field study, focusing on the child care, TANF/Employment and early intervention/preschool special education systems, was conducted in three communities in Maine: the Presque Isle area, Portland, and Lewiston/Auburn. All of these communities were chosen because they represent the central service centers for families in those regions of the state.

This institutional ethnography, conducted in 2003 and 2004, used interviews to investigate the organizational and institutional processes which affect these families and to gain perspective on the issues raised by parents in the Year One focus groups. The investigation consisted of:

### *Interviews/Site Visits with Service Providers/Case Workers*

A total of 66 interviews were conducted with:

- Child care providers (Family Child Care, Center-based, Head Start, and therapeutic providers were included from each community)
- TANF/ASPIRE caseworkers
- Multi-barrier agency caseworkers
- Resource Development Center directors
- Therapists (speech, occupational, and physical)
- Department of Human Services supervisors
- Center for Community Inclusion specialists who staff Child Care Plus ME, an effort to provide support to child care providers to prevent expulsions of children.

All interviews were semi-structured. Each was conducted by two trained interviewers and were tape recorded. Notes were transcribed according to a common template and analyzed by the research team.

In addition to the interviews, three additional parent interviews were conducted in Portland as this community was not included in our Year One research.



## Findings

### Child Care

*With few exceptions, interviewees across systems and across geographical areas of the state spoke of a lack of child care for children with special needs.*

- Most interviewees said that placing children with special needs in centers, though difficult, was still easier than accessing family child care homes. Yet many interviewees felt that the smaller size of family child care homes was better for many children with special needs, particularly those who have behavioral issues. Some Head Start programs, which were unable to accommodate a child's special needs, reported seeking a family child care home as an alternative, because they felt that setting, with its smaller size, would be more appropriate for the child. ASPIRE/multi-barrier caseworkers seeking alternative arrangements for children who had been asked to leave a child care center, reported that placing the child in a family child care home proved to be a more stable arrangement, especially for children with behavioral issues. They also reported that many parents of children with special needs expressed a preference for family child care because they felt their children would get more attention. Yet these caseworkers were concerned that many family child care providers had little general training in developmental milestones for typical children, much less specialized training in caring for children with disabilities.
- Several service providers wished that group size and staff-child ratios could be changed so that centers could serve more children with special needs. They reported that centers providing child care mostly to low-income families are filled to capacity and can't afford to limit class size and survive economically. One Child Care Plus ME staff person said that sometimes her program will pay for a slot at a center to enable the program to lower their staff/child ratio so they can work with a child with behavioral issues.
- Family child care providers reported a range of obstacles to taking children with special needs, including the difficulties of providing sufficient care when the provider worked alone, not having the funding to provide the special equipment needed to accommodate children with physical special needs, lack of on-site assistance to help them deal with challenging behaviors and a lack of accessible training opportunities to learn about special needs.
- Interestingly, the family child care providers interviewed who did care for children with special needs evidenced more of an investment in keeping the child than center-based providers, perhaps because the provider was more likely to have had the child since infancy.
- Maine's Child Care Resource and Referral agencies reported difficulties with arranging for funding to cover the cost of accommodations for children with physical disabilities. They were unclear where providers went at the state agency for help with this – they described it as a “mysterious process” where funds for the equipment (e.g. a ramp) is for the child, not the program so if the child leaves the program, the equipment goes with the child.
- A number of service providers said they felt that many parents of children with special needs didn't work because they believed no one else could care for their child. Some TANF/ASPIRE caseworkers said they believed parents were using that as an excuse not to work. Others said that when a child is thrown out of a child care program, often the parents blame the child and are sure that because of the child's problems, they can't work. It doesn't

occur to them that there might be another child care provider out there who would be a better match for their child. One RDC staff member cited cases in which parents were under the erroneous impression that all providers required children to be toilet trained by age three and they concluded that because their child wasn't toilet trained they couldn't work. They weren't aware that programs like Head Start had no such requirement. Some service providers said they understood the difficulties parents face but wish they could convince and reassure parents that with the proper supports they could work and have their child's needs met in a child care setting.

- One RDC staff person said that the bigger issue in rural areas for low income parents of children with special needs is not finding and keeping a child care provider for their child with special needs, but being able to afford the care and being able to transport their child to services during the work day.
- A number of service providers believed that programs like Head Start that integrated children with special needs with their non-disabled peers, had staff trained in special needs and provided comprehensive services on site, provided families with the best arrangements for enabling them to work. Yet some providers reported significant waiting lists for Early Head Start and Head Start in Maine.

***Access issues were particularly problematic in rural areas but once a child was accepted into a program in a rural community, expulsion was thought to be less frequent.***

- Some ASPIRE/multi-barrier caseworkers reported that it was harder to find child care for children with special needs in rural areas than in more urban parts of Maine. They cited the following reasons:
  - there are so few child care options to begin with in rural communities,
  - there is such a heavy reliance on family child care providers who, because they work alone, may be less willing to accept these children; and
  - in a small community where everyone knows everyone, word gets around among providers that a parent looking for a child care placement has a child who has “problem” behaviors.
- Other service providers said they believe that once a child with special needs is enrolled in a child care program in a rural area (whether a center or a family child care home) they are less likely to be expelled than in urban communities. They speculated that child care providers in small rural communities are more likely to know the family well and that everyone is aware of how few other options are available for that family in the area.

***Parents employ strategies to gain entry into a child care program when they are afraid their child will be rejected because of his or her special needs.***

- Staff at the RDCs attempt to assist families with children with special needs in locating child care. Because of the ADA requirements, they are not able to ask providers whether they take children with special needs but they do keep track of which providers answer yes to a question about having had experience taking children with special needs. Several staff reported, however, that parents often don't tell potential providers that their child has special needs partly because of stigma and partly because they want to “get their foot in the door.”

- RDC staff report that most of the calls they receive involving children with special needs are not initial calls seeking child care but calls from parents or providers about a child being expelled from a program. They call Child Care Plus ME to assist the provider in those cases. One staff person told of a child who had bounced around from one program to another. He had had a different provider every year for seven years. She said they probably get two calls a month about children who are about to be expelled from a program.

***With few exceptions, all interviewees said that children with behavioral issues were harder to place and maintain in child care than children with primarily physical disabilities.***

- ASPIRE caseworkers reported that accessing child care for children with disabilities that were primarily physical required some initial effort but that once the child was accommodated, child care remained stable for most of these children. However, children with behavioral issues were more likely to have changing needs and issues – a child care arrangement that worked in the fall might not work in the spring. As a result, child care for these children was more likely to fall apart.
- An estimated 95% of calls received at Child Care Plus ME are from providers needing help handling a child and 70% involved children with behavioral issues but no formal diagnosis. About half of the calls are urgent – the provider is about to expel the child. Child Care Plus ME staff find that more often than not, when they go to the provider’s site, the child’s issues are the result of global quality issues affecting all of the children and a lack of knowledge about child development by the provider. One Child Care Plus ME staff person described the kids with special needs as “canaries in a coal mine.” Another said the biggest issues she encounters when she provides technical assistance to providers are high ratios of children to staff and “chaos control.”
- Child care providers, RDCs and multi-barrier agencies who had used the services of Child Care Plus ME were very enthusiastic and wished that there was more funding to expand their availability. A number of child care providers were unaware of the services offered by Child Care Plus ME, but staff at Child Care Plus ME felt that with current resources, they wouldn’t be able to keep up with the demand if they were better known. The needs of providers for help in dealing with behavioral issues is so great that Child Care Plus ME’s original vision to provide support to the RDCs so that they could provide the on-site assistance has not yet been fulfilled. Instead they have been in a reactive mode attempting to keep up with the requests. Currently, they are embarking on a new approach, choosing centers with high levels of quality and training staff to care for children with special needs so that they can in turn mentor other providers.
- Some child care providers attributed the increasing problems of behavioral issues in the child care setting to the fact that children were in child care for so many hours. They felt that children were being labeled unnecessarily. One director serving a low income population said that many parents had no choice but to leave their child in care from 6:30 AM to 5 PM and she felt that that was too long to be in a group of ten children. She added that some parents are forced to take second jobs to make ends meet which means that their children go to a second child care arrangement after leaving her center. One of the Child Care Plus ME staff referred to a typical weekday for these children as an “all day cocktail party.”

## **Coordination between IDEA and the Child Care System**

*Interviewees across systems and across geographic areas, reported conflicts between parents' need to work and the policies which governed the provision of special services to children with disabilities. Many of these same policies also undermined inclusion of children with special needs with their non-disabled peers even though IDEA requires that to the maximum extent possible children receive services in their "natural environment" under Part C (for children ages 0 to 2) or the "least restrictive environment" under Section 619 of Part B (for children ages 3 to 5).*

- Interviewees reported that parents sometimes were caught between conflicting programmatic missions of the agencies administering early intervention/preschool special education services under IDEA and the child care assistance and welfare to work programs in Maine.
- In the view of the service providers we spoke to, CDS is focused on involving the family in addressing the special needs of the child without, in their view, having sufficient regard for the need of the parents to work. IFSPs and IEPs don't address families' child care and work issues. CDS case managers too often assume, and at times even encourage, the availability of parents during the work day to support the delivery of services, attend meetings, facilitate communication, and deal with paperwork.
- Therapeutic programs serving children with disabilities are usually part-day, part-week and don't operate during school breaks and summer. Depending on the severity of the child's special needs, the family may not be able to access a program for the additional hours necessary to enable the parent to work. Because of this mismatch of hours, specialists reported that some parents with inflexible jobs choose all-day child care instead of a specialized program where the child may get more help. Other parents struggle to arrange a way for the child to be transported from the part-day program to a regular child care program so they can remain employed.
- Even when a child can be mainstreamed in a regular child care program, a number of service providers said that because IDEA is focused solely on the child's individual educational needs and not on the parents' need to work, supports the child may need to attend (e.g. one-on-one aide, deaf interpreter) are only approved for a few hours per day even if the child is enrolled for the full day because of the parents' employment. According to one Head Start Director, CDS considers the hours of 12 PM to 6 PM as child care and won't fund any supports after 12 noon even where the child is attending all day. In some cases, Child Care Plus ME is able to access funding from DHHS to cover the additional hours. But in other cases, children are going without. This undermines the ability of the provider to include the child in program activities and sometimes jeopardizes the stability of the child care arrangement.
- While child care providers reported that parents were generally receptive when told they should have their child evaluated for a potential problem, some said they had encountered resistance. One provider said that parents on TANF felt particularly uneasy possibly for fear that the state would remove their child if a problem was found. This was also a problem if the mother was involved in a custody battle with the father.
- Another provider said that parents in rural areas felt particularly hesitant to have their child evaluated because they felt more of a stigma about having a child with special needs and they

didn't want anyone in their small community to find out. One child care provider reported that she has had to remove children from her program because the parents refused to have their children evaluated. The provider felt that she couldn't care for the children without the services CDS would have provided if the child had been evaluated and found eligible.

- Another frustration expressed by child care providers was the lack of reimbursement to enable professionals evaluating children to observe the child in the child care setting. A child is referred for evaluation and seen only in the clinician's office or at home. The parents are delighted to be told their child has no issues and the difficulties the child care providers see in the more stimulating child care setting are never addressed.
- One Child Care Plus ME staff member expressed concern that specialists aren't getting enough training in how to deliver services in the classroom. As a result, many children are getting pulled out for the sessions. This separates them from their non-disabled peers and means that they have to experience many more transitions. She felt that children with special needs are not being given the same opportunities as other children in the child care setting.
- While for the most part, parents were reported to be happier and to have less work-related stress when child care programs had services on site, some child care providers cautioned that they thought it was important for parents to have a choice of specialists to suit their needs and those of their child. Even though their center had services delivered on site by itinerant specialists, they said that some parents opted not to use those services. According to one staff member at Head Start this is partly due to the fact that some specialists pull children out of the classroom to provide services. Parents don't like the fact that their child is missing out on some of the group activities so they opt to use a specialist elsewhere and take their child to the appointments themselves. Other parents, whose children had already "bonded" with a specialist they had seen while a toddler, wanted to continue that relationship into the preschool years. According to providers, parents in outlying areas were the most likely to choose to receive services on site, most likely because of transportation issues and a lack of alternative specialists in rural areas.

***Across systems and geographic areas, service providers expressed frustration about inconsistent interpretations of policy among the sixteen CDS offices.<sup>25</sup>***

- Service providers across the state reported problems with a lack of uniform interpretations of policies regarding eligibility, service provision and reimbursement of specialists among the sixteen CDS offices in Maine. Varying local interpretations of eligibility for IDEA services, for example, meant that in some areas social/emotional difficulties were ignored as long as the child was reaching "academic" milestones (e.g. knowing their shapes and colors) on time. Indeed, one Head Start staff person said that the CDS screening tool she has seen used in her area doesn't cover mental health issues. Child care providers reported a need for support to care for a growing number of children with undiagnosed behavioral issues yet felt that without CDS eligibility, they couldn't get services for these children. One Head Start staff person reported using Head Start funds to pay for mental health services when they were unable to obtain these through CDS. Child Care Plus ME staff also said that sensory integration issues alone do not qualify a child for CDS services even though sensory problems can significantly interfere with learning and cause behavioral difficulties.

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<sup>25</sup> As of the writing of this report, CDS in Maine is in the middle of a reorganization to reduce the number of regional offices, provide more oversight from the state agency and make their policies and procedures more uniform across the state.

- One provider operating a program specifically for children with special needs reported that when she held support groups for parents coming from different catchment areas of CDS, part of the meeting always entailed parents saying they didn't understand why one parent had been told one thing by her CDS office while another was told the opposite by her CDS office.
- Specialists complained that the differences between CDS offices made the process of working with CDS much more time consuming than it needed to be.
- Opinions of CDS case managers also seemed to vary by the region specialists dealt with – the staff at some offices were viewed very positively while staff in other offices were viewed less favorably. Among the concerns expressed: Some service providers felt that many case managers who by their description were “young and middle class,” didn't seem to understand low income parents' need to work nor the unforgiving nature of many low wage jobs. Other service providers reported that there was a high turnover of case managers at their CDS office which made communication more time consuming than they would like.
- Some ASPIRE caseworkers reported having no contact with CDS case managers. Others had limited contact. Multi-barrier agency staff seemed to have had the most communication with CDS. They said that the CDS case managers were sometimes helpful in arranging services to be delivered on one or two days so parents could work on the other days. They were not found to be as helpful in preventing expulsions of children from child care arrangements. In those situations, case workers relied on Child Care Plus ME to intervene.
- Some of the multi-barrier agency staff and Head Start staff expressed concern about the lack of interpreters at CDS for immigrant parents for whom English is a second language. Reports of evaluations of children weren't being translated and no translators were being provided at meetings. They also said cultural differences can make it difficult to obtain consent from parents for evaluations of their children. And, speech delays are particularly hard to diagnose in children living in these households without having professionals who can speak the child's primary language.
- ASPIRE staff said they felt that there were too many players working with families of children with special needs. Sometimes they worked at cross purposes and families still felt there was no one person to go to for answers. Others said families need one-stop shopping where all of their needs and the needs of their child were addressed in one place in a seamless way.

***Transportation was cited as a major problem by interviewees across systems, particularly in rural areas and particularly in accessing special services such as OT, speech, medical care, etc. Some of these difficulties were attributed to policies related to restrictions on reimbursement for travel time to specialists which also created barriers to delivering services in the child's “natural environment” as required under Part C of IDEA or “least restricted environment” as required under Part B of IDEA.***

- Specialists reported that the ideal mode of delivery of services was a combination of delivery at home and in the child care setting. This serves the need of parents to work but also means that there is at least some contact between the specialists, the child care staff and parents in order to share information to make sure “everyone is on the same page.”
- However, in some regions, specialists are paid a very low hourly rate for travel time and in

- other regions, specialists aren't paid at all for that time. As a result, particularly in rural areas, specialists are less likely to provide services in the child care setting or at home. This often means that the parent must transport the child to the specialist's office during the work day.
- In some areas, Regional Transportation Programs (RTPs), using volunteer drivers, provide that service, relieving parents of the need to leave work. Low income parents with inflexible jobs and/or lacking cars, are particularly dependent on this service. However, several concerns were expressed by parents and service providers alike regarding this service, including:
    - Use of volunteer drivers meant the service was often unreliable although one specialist attributed this not to the drivers but to dispatch errors. Drivers don't show up, parents are frustrated and children miss their appointments. Specialists also said that because of the high turnover of drivers, parents have been reluctant to turn their child over to a strange man who comes to their door to pick their child up. Some parents reportedly changed work hours or stopped working altogether so they could transport their child themselves.
    - Policies to protect the safety of children were sometimes not followed by volunteers. One provider told of having a preschooler dropped off in her parking lot without an adult to walk the child into the building.
    - No adults, besides the driver, accompany the children because according to child care providers, CDS does not consider the van an "educational setting" under IDEA and so will not fund an aide to ride with the child. The children, some as young as eighteen months, travel alone with other adult riders who have disabilities that to a very young child may seem frightening. One child care provider said a little girl who rode alone on the van would refer to the adult riders as the "scary people."
    - Delays in picking up the children meant that children leaving a part-day therapeutic program to attend a regular child care program for the rest of the day, would arrive hungry at the center after lunch had been served and would have to be fed while the other children had nap time.
    - Even when things went smoothly, providers expressed concern about children having to weather so many transitions – these were children who had a harder time with transitions to begin with and yet the lack of coordination between systems meant that they were experiencing more of these transitions than the "typical" child. In rural areas in particular, providers also worried about the impact on very young children of riding such long distances to access services. Some service providers in rural areas said that because there were so few medical specialists, children had to travel two and three hours each way to be evaluated and treated.
    - Transportation challenges caused one child to be expelled, according to a Director of a specialized program. The child was from a low income family and was missing as many as two days a week. As a result, he was regressing and becoming dangerous to himself and the other children. His mother would call and tell staff she couldn't make the trip because she couldn't afford the gas. The program reimbursed her for mileage but the money went to other household necessities and she would run out of funds.
    - The concern over transportation was not universal, however. One Head Start staff person said she thought the transportation services provided to the kids attending whose parents chose to use different specialists than those on-site worked well. She described these services as usually reliable. The only problems happen when therapists cancel appointments and no one notifies the driver.

*Shortages of specialists were also reported, particularly in rural areas which compounded access and transportation issues. In Aroostook County a one year waiting list was reported for speech therapy. Some specialists attributed this shortage at least in part to low rates of reimbursement for services from Medicaid. When a child's IFSP or IEP calls for a certain therapy at a certain frequency this shortage can mean a delay in receiving those services or less frequent sessions. As a result, many specialists can't afford to spend the time traveling to children's homes or to child care programs – they need to be able to see more children per day than that would allow.*

- Related to the problem of shortages, some service providers also cited a high turnover rate among specialists. Children bond with a therapist only to see he or she leave. One child had three different therapists in one month. When a specialist does leave, often the shortage means that a child has to be put on a waiting list for services. One child had to wait five months before her services were resumed. The turnover problem was reported to be across the board with all types of specialists.





## CHAPTER FOUR

# Child Care Provider Survey

## Methodology

After speaking with parents of children with special needs about their experiences with the child care system, we wanted to gain the perspective of child care providers on the issues of access and inclusion that parents raised. In addition to conducting individual in-depth interviews with providers in our field study (see Chapter Three), we also conducted a statewide survey of child care providers selected at random from the list of licensed providers in Maine given to us by the state licensing agency.

We obtained this list from the Division of Licensing, Child Care Licensing Unit at the Maine Department of Health and Human Services and drew a random sample of 430 providers for our mail-in survey. Surveys were returned anonymously. Despite the incentive of a raffle prize, there was a low response rate initially and a second survey was mailed. In the end, a total of 179 surveys were completed and collected during the period from May to July, 2003 resulting in a 41.6% return rate.

The survey data were coded, cleaned, and entered into SPSS for analysis. Because of the relatively small number of surveys, data were analyzed using cross-tabs and for qualitative information.

## Profile of Child Care Provider Survey Respondents

### Location of Respondents

<b>County</b>	<b>Number</b>	<b>Percent</b>
<b>Cumberland</b>	<b>31</b>	<b>17.3</b>
<b>Androscoggin</b>	<b>28</b>	<b>15.6</b>
<b>York</b>	<b>25</b>	<b>14.0</b>
<b>Penobscot</b>	<b>17</b>	<b>9.5</b>

<b>Kennebec</b>	<b>13</b>	<b>7.3</b>
<b>Aroostook</b>	<b>10</b>	<b>5.6</b>
<b>Knox</b>	<b>8</b>	<b>4.5</b>
<b>Sagadahoc</b>	<b>8</b>	<b>4.5</b>
<b>Somerset</b>	<b>8</b>	<b>4.5</b>
<b>Franklin</b>	<b>6</b>	<b>3.4</b>
<b>Hancock</b>	<b>6</b>	<b>3.4</b>
<b>Waldo</b>	<b>5</b>	<b>2.8</b>
<b>Washington</b>	<b>5</b>	<b>2.8</b>
<b>Oxford</b>	<b>4</b>	<b>2.2</b>
<b>Lincoln</b>	<b>1</b>	<b>.6</b>
<b>Piscataquis</b>	<b>1</b>	<b>.6</b>
<b>Unknown*</b>	<b>3</b>	<b>1.7</b>
<b>Total Survey Respondents</b>	<b>179</b>	<b>100</b>

\*Three survey respondents did not indicate their locations

## **Type of Facility and Provider Experience**

We asked how providers categorize their facility. The majority of providers surveyed (70.4%) were family child care homes. Almost nine out of ten of the centers and family child care homes were open all year.

- Family child care home (126) 70.4%
- For-profit child care center (16) 8.9%
- Private non-profit child care center (16) 8.9%
- Head Start Agency (7) 3.9%
- Other (6) 3.4%
- Contracted child care agency (4) 2.2%
- Combination (2) 1.1%
- Program solely for children with special needs (1) 0.6%
- Therapeutic program for children with and without special needs (1) 0.6%

(N=179)

- Nearly half of the centers and family child care centers surveyed had been open for 10 years or more (88). One-third (57) of the directors who responded have worked in the child care field for 11-20 years.
- Forty-seven percent of survey respondents indicated that they had a waiting list for children hoping to get a spot in their facilities.
- Less than one-quarter (43) of the facilities are fully handicapped accessible, and only 7% (12) of facilities have handicapped accessible transportation for children.

## Findings

### Caring for Children with Special Needs

We asked respondents a series of questions concerning their experiences in caring for children with special needs.

- Seventy percent (125) of respondents have served children with diagnosed special needs.
- Sixty-five percent (115) of respondents believed they had served children with special needs who had not yet been diagnosed.
- Nearly 36% (63) of the providers had a child admitted to their program and learned later that the child had a diagnosed special need.
- Eighty-one percent (135) of directors stated that they could administer medication.
- Of the 131 respondents who answered a question asking whether they find it more difficult accepting and caring for children with behavioral or physical/medical special needs, nearly 75% (98) indicated that *behavioral* issues presented more challenges.
- The top three challenges providers noted in accommodating children with special needs are: not have having enough staff for necessary supervision, disruptions to other children, and a lack of staff training.

Survey respondents were given a chart to complete to indicate, on average, at what level of severity their programs could best meet the needs of children requiring specific types of attention or assistance.

- Over one third said they could not accommodate even mild seizure disorders (35.6%); almost one quarter cannot accommodate even mild mobility issues (24.4%), toileting issues (22.5%) or mild mental retardation (24.8%). One in five (19%) cannot accommodate even mild neurological/social/behavioral issues.

Issue	Range of Severity	Level of Severity			
<b>Mobility</b> ( <i>needs help walking or stair climbing, more than other children same age; wheel chairs, crutches, braces, etc.</i> ) N=160		Mild (54) 33.8%	Moderate (56) 35.0%	Severe (11) 6.9%	Cannot Accommodate (39) 24.4%
<b>Eating</b> ( <i>needs help eating, more than other children same age; intubation</i> ) N=160		Mild (49) 30.6%	Moderate (67) 41.9%	Severe (16) 10%	Cannot Accommodate (28) 17.5%
<b>Neurological/social/behavioral</b> ( <i>attentional; socially withdrawn; bullying, aggressive behavior; child rocks or does repetitive actions that can cut her/him off from others; child does not relate/respond to others</i> ) N=163		Mild (43) 26.4%	Moderate (72) 44.2%	Severe (17) 10.4%	Cannot Accommodate (31) 19%
<b>Toileting</b> ( <i>needs more help than other children same age; catheterization, incontinence, wears diapers beyond age of other children</i> ) N=160		Mild (47) 29.4%	Moderate (57) 35.6%	Severe (20) 12.5%	Cannot Accommodate (36) 22.5%
<b>Medications</b> ( <i>needs meds on regular basis; needs injection/shot on regular basis</i> ) N=163		Mild (50) 30.7%	Moderate (57) 35%	Severe (12) 7.4%	Cannot Accommodate (44) 27%
<b>Seizures</b> ( <i>seizures that are mostly controlled by medication; intermittent seizures; frequent seizures that currently cannot be controlled by meds</i> ) N=160		Mild (60) 37.5%	Moderate (34) 21.3%	Severe (9) 5.6%	Cannot Accommodate (57) 35.6%
<b>Mental retardation</b> ( <i>mildly, moderately, or severely retarded</i> ) N=161		Mild (66) 41%	Moderate (41) 25.5%	Severe (14) 8.7%	Cannot Accommodate (40) 24.8%
<b>Speech and language</b> ( <i>articulation problems, difficulty expressing/understanding language, completely non-verbal at age when most children are verbal</i> ) N=167		Mild (53) 31.7%	Moderate (65) 38.9%	Severe (37) 22.2%	Cannot Accommodate (12) 7.2%
<b>Asthma</b> ( <i>needs nebulizer, sometimes requires treatment at ER</i> ) N=164		Mild (55) 33.5%	Moderate (65) 39.6%	Severe (34) 20.7%	Cannot Accommodate (10) 6.1%
<b>Allergies</b> ( <i>food allergies, pets; life-threatening allergies – severe food allergy, bee stings</i> ) N=163		Mild (48) 29.4%	Moderate (60) 36.8%	Severe (38) 23.3%	Cannot Accommodate (17) 10.4%
<b>Eyes/ears</b> ( <i>partial blindness or deafness, blind or deaf</i> ) N=161		Mild (56) 4.8%	Moderate (46) 28.6%	Severe (24) 14.9%	Cannot Accommodate (35) 21.7%

## Benefits of Inclusion

Child care providers were asked about the benefits of including children with special needs in their programs. (Respondents could check all that applied.)

- |   |       |       |
|---|-------|-------|
| • Offering all the children a chance to learn about differences | (130) | 73.4% |
| • Seeing a child overcome challenges                            | (127) | 71.8% |
| • Feeling a part of a team helping a child                      | (108) | 61.0% |
| • Encouraging/helping parents under stress                      | (104) | 58.8% |
| • Learning about disabilities                                   | (101) | 57.1% |
| • Other   | (7)   | 4.0%  |
- (N=177)

## Obtaining Information and Assistance

- Forty-one percent of survey respondents (71) indicated that they rely on the parent's knowledge *most* for information on how to best care for and accommodate a child's special need.
- Other top responses from child care providers included 15% (26) who said they used multiple sources equally and 13% (23) who rely on information from medical or special service providers.
- Over one-quarter of respondents indicated that they have sought outside help in accommodating a child with special needs.

## Challenges/Expulsions

Providers were asked if they ever had to ask a child to leave their program.

- Thirty-five percent (62) of respondents said they have had to ask a child to leave their program because of the child's special needs. The following options were most frequently selected as the reasons why they had to take this action:

○ Felt we couldn't appropriately meet the special needs of the child	(41)	23%
○ Little/no support from parent of child	(29)	16.3%
○ Parents of other children complained of behavior/time devoted/disruptions to schedule, etc.	(27)	15.2%

Child care providers were asked to indicate the most challenging issues in appropriately accommodating children with special needs. (Respondents could check all that applied.)

- Not enough staff for necessary supervision (103) 58.5%
  - Disruptions to other children (91) 51.7%
  - Lack of training (78) 44.3%
  - Difficulties including children with special needs in all activities (42) 23.9%
  - Child provided with assistance (e.g., interpreter, one-on-one aide) but not for full day child is in attendance (32) 18.2%
  - Administering medications (21) 11.9%
- (N=176)

## Financial Issues

Respondents were asked about their experience with the child care subsidy program.

- Sixty percent of respondents reported caring for children who are receiving child care subsidies.
- Providers were asked if they were satisfied with the level of these payments. Of those who answered the question, 21% (35) of respondents stated that they were “very satisfied” with the level of payment for children *without* special needs, while only 6% (10) of respondents indicated that they were “very satisfied” with the payment level for children *with* special needs.

Respondents were asked how they would use funds if they were provided with a grant to build capacity to enable them to serve children with special needs. The frequencies and percentages of the options ranked first and second by providers are indicated below.

	<b><u>Rank 1</u></b>		<b><u>Rank 2</u></b>	
• Specialized training	(52)	38.2%	(36)	28.1%
• Hire additional staff	(32)	23.5%	(33)	25.8%
• Building accessibility	(26)	19.1%	(17)	13.3%
• Hire therapeutic staff	(13)	9.6%	(13)	10.2%
• Equipment	(5)	3.7%	(26)	20.3%
• Other	(8)	5.9%	(3)	2.3%
	(N=136)		(N=128)	

## Special Services for Children with Special Needs

We asked survey respondents about children in their care receiving special services such as speech therapy, occupational therapy, physical therapy, etc. and how those services were *most often* delivered.

- We have never served children receiving special services (56) 33.1%
- Specialists from an outside agency provide services at our location (38) 22.5%
- Multiple methods (31) 18.3%
- Parents transport children to special services (22) 13%
- Other (9) 5.3%
- Children receive these services at home (6) 3.6%
- Children are transported by us to specialist's office or other location (5) 3.0%
- Our staff provides services on the premises (2) 1.2%

(N=169)

A little over half of respondents (50.5%) (54) agreed or strongly agreed with the statement that specialists providing services to a child such as speech therapy or OT regularly communicates with child care staff concerning the child's needs and progress.

## Training Received and Desired

We asked respondents about training they and their staff may have received or would like to receive in order to care for children with special needs.

- 61% (82) of respondents stated that they and/or their staff had received specialized training in behavioral issues, yet nearly 66% (103) of respondents indicated that they would like training, or additional training, in that area.
- In order to receive training, the top three supports respondents indicated that they would need are: tuition reimbursement, substitute staff, and/or an expert/trainer to come to the child care site.

Areas in which they have already received specialized training:

- Specific disabilities (39) 29.1%
- Behavioral issues (82) 61.2%



- Special needs in general (67) 50.0%
- Inclusion (51) 38.1%
- Communication with parents surrounding special needs (49) 36.6%
- Administering medications (41) 30.6%
- Special health procedures (e.g. intubation, catheterization, nebulizer) (28) 20.9%
- Other areas (14) 10.4%

(N=134)

Desired areas of specialized training:

- Behavioral issues (103) 65.6%
- Special needs in general (73) 46.5%
- Specific disabilities (65) 41.4%
- Communication with parents surrounding special needs (63) 40.1%
- Inclusion (40) 25.5%
- Administering medications (35) 22.3%
- Special health procedures (e.g. intubation, catheterization, nebulizer) (28) 17.8%
- Other (15) 9.6%

(N=157)

Providers were then asked what resources or supports they would need in order to receive training.

- Tuition reimbursement (113) 72%
- Substitute staff (104) 66.2%
- Expert (such as Child Care Plus ME) comes to my site (70) 44.6%
- Work release time (42) 26.8%
- None (12) 7.6%
- Other (9) 5.7%

(N=157)

## Parents of Children with Special Needs

We asked survey respondents about their general experiences with *parents* of children with special needs.

- Only 4% (7) of providers disagreed with the statement that compared to other parents, parents of children with special needs have higher levels of stress in balancing work and family.
- 55% (95) of respondents agreed or strongly agreed with the notion that compared to other parents, parents of children with special needs experience more child-related work disruptions (e.g. calls from child care provider, transporting child to appointments/services, medical or other emergencies).
- Nearly half (48.8%) responded that parents of children with disabilities *that affect their behavior* experience greater stress and work disruptions than parents of children with other kinds of disabilities.



## CHAPTER FIVE

# Parent Survey

## Methodology

In late 2004 and early 2005, we conducted a statewide phone survey of 441 parents of children with special needs residing in Maine. Because of the difficulties we faced recruiting parents of children with special needs in the qualitative phase of our study, we determined that doing a survey by mail would be difficult and would not produce the response rate we needed. After consulting with other researchers in Maine who had conducted surveys of this population, we determined that a phone survey would produce a larger sample size.

## Our Sample

We chose to draw our sample of parents from the case loads of two programs providing services to children with special needs:

- **Maine's Child Development Services (CDS)** which administers the Part C early intervention program under the Individuals with Disabilities Education Act (IDEA) for children birth to three and Section 619 of Part B of IDEA which provides special education services to preschoolers.<sup>26</sup>
- **Maine's Medicaid Program, Maine Care**, which provides coverage to low income and disabled children. In order to identify those families on Maine Care who had children with disabilities we selected three eligibility groups on Maine Care: children on SSI because of their disability, children receiving services under Title V because of special health care needs and children with disabilities who are covered under the Katie Beckett waiver.

We identified and removed any duplications on the two lists since some children receiving CDS services are also enrolled in Maine Care. By drawing our sample from these groups we hoped to be able to make comparisons by income (This is because eligibility for CDS is not based on income and the Katie Beckett waiver permits children with more serious disabilities to obtain Medicaid coverage even if their family income would otherwise be too high to qualify.) These groups would also provide us with a mix of types of disabilities. We acknowledge, however, that these lists may not have included those children with milder or undiagnosed conditions which wouldn't qualify for CDS or Maine Care but which might still raise child care/work issues for the parents. Our community-based approach to recruitment of parents in the qualitative phase of our study was designed to enable us to recruit families of such children. In the end, however, those we were able to recruit for the

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<sup>26</sup> Maine is one of only two states in which the same agency that administers Part C for children 0 to 3 also administers Section 619 of Part B of IDEA for children 3 to 5. In all other states, the school districts administer special education services for preschoolers.

qualitative research did not differ significantly from those who participated in our survey in terms of the type of disability of the child. It may be that those families with children with diagnosed or more serious disabilities are more motivated to participate in a study like ours.

Initially we hoped to be able to contact a random sample of parents on these lists directly by telephone to solicit their participation in the survey. Other researchers at the Muskie School, working under contracts with the state agency, had been permitted to do this with some of the same populations and had achieved remarkable response rates as a result. However, because ours was an independent research study, we were not permitted to call these families for confidentiality reasons and were asked instead to use a mailing to which the state agency would apply address labels to protect the identities of the families. At first many requirements were made regarding the content and language we were allowed to use for the mailing which raised concerns that the mailing would be hard to understand and would not produce the desired response. Nevertheless, we drew a random sample from the caseload lists and sent out the required mailing. Not surprisingly, out of the 500 families who received the mailing, only 65 responded.

In light of such a low response, we decided to make the following changes:

- Persuade the agency to allow us to develop more user friendly, simplified materials for the mailing.
- Send these mailings to the entire caseloads in each of the groups listed above (a total of 6,200 families) rather than to a random sample in order to increase our chances of obtaining a large enough response.

We got permission from the agencies to use the more user friendly materials, including a letter of explanation about the studies signed by agency officials. This mailing was sent to all 6,200 parents of children with special needs on the CDS and Maine Care caseloads (approximately 4,000 on the CDS list and approximately 2,200 on the Maine Care list.) Parents were asked to call a 1-800 number if they wished to participate and we contracted with the Survey Research Center at Muskie to conduct the phone surveys. A lottery offering five \$100 gift certificates, was used as an incentive.

While we had to give up randomness in order to gain a large enough sample to allow for the analysis we wanted, we are pleased that the 441 families in our survey reflect a very good balance in terms of demographics, type of disability of their child(ren), and distribution across the state. We are also reassured by the fact that with only a few exceptions, our findings from the survey do not differ significantly from our findings from our qualitative research with families, nor from our analysis of the data on a sample of parents of children with special needs drawn from the National Survey of America's Families (NSAF).

The phone surveys took place in December, 2004 and January, 2005. Each interview took approximately 15 minutes and was conducted by trained interviewers at the Survey Research Center at Muskie.

## **Subgroup Analyses**

### *Urban/Rural*

We divided the sample of 441 respondents into two groups; one being Cumberland County residents - the largest and most populous county in the state - and the other being the fifteen other counties. Cumberland county contains the only true "metropolitan statistical area" in Maine ("Portland-South

Portland” which includes surrounding communities) designated by the Census Bureau – with a combined population of 487,568.

Cumberland County	127	28.8%
Other Counties	314	71.2%

### ***Age of Child***

We divided the sample into four age categories corresponding with major transitions. Five children were excluded because they were over the age of 18.

0-2	66	15.1%
3-5	201	46.1%
6-10	81	18.6%
11-18	88	20.2%

### ***Income Level***

We looked at income level in two ways. First, we did a straight split at 225% of poverty - about \$2,800/a month at the time of our study. So the comparison was families above and below 225% of poverty.

Low income (\$0-2799/mo)	221	50.7%
High income (\$2800+/mo)	215	49.3%

We also compared those at the lowest end of our income range (150% of poverty) and those at the highest income (at least \$48,000 annual salary) to get a better sense of the contrast.

Very low income (\$0-1900/mo)	146	33.1%
Very high income (\$4000+/mo)	129	29.3%

### ***Education Level***

For education level of the primary respondent, we compared those who had at least a four year degree to those who did not.

No four year degree	233	54.1%
Four year degree	198	45.9%

### ***Type of Diagnosis***

With the help of two pediatricians, one who provides care to a cross section of children and one who provides specialized care to children with a wide range of developmental problems, we categorized the diagnoses according to how they would impact a child care provider and the child care environment. In other words, what would be the obvious symptoms that would affect a child care provider's care of the child and daily schedule as well as the care of the other children in the program? With that in mind, we categorized the diagnoses of children according to diagnoses reported by parents *and* according to two additional questions, "Does the child have any social or behavioral problems that go along with this diagnosis?" and "Does the child require medicine or medical procedures on a regular basis during the work day?"

Examining the data produced four diagnosis categories as follows:

- **Speech/Language Only:** children who are *only* receiving speech and language therapies with no behavioral or medical issues reported.

- **Behavioral:** children with one or more primarily behavioral diagnoses (e.g., Autism, Aspergers Syndrome, ADHD). These diagnoses are neurological in nature and they present primarily with behavioral challenges in the child care setting.
- **Non-Behavioral:** children with one or more diagnoses that are not behavioral in how they present in a child care setting (e.g, asthma, diabetes, mental retardation). We relied heavily upon the parent's report of whether the child had any "social or behavioral problems" in addition to the diagnosis, to confirm that the diagnosis *did not* present with behavioral manifestations in the child care setting.
- **Multiple Diagnoses with Behavioral Component:** children with multiple diagnoses, *one of which had a behavioral component* (e.g, autism and seizure disorder, Cerebral Palsy with behavioral problems reported).

The pediatricians also reviewed and approved our decisions about which child represented in our survey fit into which category based on the information their parents gave us.

Note: For those families reporting more than one child with special needs we asked the respondent to answer our questions for the child with the most severe special needs.

## Characteristics of the Households

### Significant Data

#### *Relation of respondent to child*

- Almost all (93%) of respondents are the mother of the child.
- Only 4% of respondents are the father of the child.

#### *Number of children in household*

- There is an average of 2.2 children in the household.
- 31% of families have three or more children in the household.
- Almost one-third of families (29%) have more than one child with a disability or special need in their family.

#### *Age of child*

- Children range in age from six months to 26 years. However, five were eliminated from the sample because the subject was over eighteen.
- Almost half of the children (46%) are between the ages of 3 and 5.

#### *People living in the household*

- Almost 4 out of 5 respondents (79%) are currently married.

- 87% of families are either married or living as partners in the same home.
- 12% of families have only one adult living in the home.

***Type of Diagnosis of Child***

- More than one-third (37%) of the children have a primarily behavioral diagnosis.
- A quarter of the children (25%) in the sample have a diagnosis in the Autism spectrum.
- More than half of the children (53%) in the sample have social or behavioral problems that go along with their diagnosis.
- More than a third of the children (38%) in the sample require medicine or medical procedures on a regular basis.

***Income***

- Over half of households have incomes below \$45,000 per year.
- 14% have an income under \$20,000 per year.

***Level of Education***

- 21.3% have a high school degree or less

***Survey Data***

1. What is your relationship (of respondent) to child?

Mother or father	430	97.5%
Grandparent	3	0.7%
Aunt or uncle	1	0.2%
Older brother or sister	0	0.0%
Other relative	1	0.2%
Legal guardian	0	0.0%
Foster parent	6	1.4%

2. During the previous year, 2003, what is your best estimate of your family's total annual income, including income from work?

Less than 20,000	63	14.4%
20,000-44,999	167	38.3%
45,000-64,999	92	21.1%
65,000-79,999	55	12.6%
80,000-100,000	32	7.3%
more than 100,000	27	6.1%



3. In the past year, did you or anyone in your household participate in any of the following programs?

Food Stamps	74	16.8%
WIC	95	21.5%
TANF	38	8.6%
ASPIRE	24	5.4%
MaineCare/Medicaid	306	69.4%
Child Care assistance	50	11.3%
None of these programs	119	27.0%

4. Does your family own a car or other vehicle?

Yes	425	96.4%
No	16	3.6%

5. In what year were you born?

Average = 37 years; Range from 20 to 50 years of age

6. What is the highest grade or level of education you have completed, so far?

Less than High School	10	2.3%
High School (tech, GED)	84	19.0%
Some College (AA)	149	33.8%
Four year degree	109	24.7%
Some graduate courses	28	6.3%
Graduate degree	61	13.8%

7. What is the highest grade or level of education your spouse or partner has completed, so far?

Less than High School	15	3.9%
High School (tech, GED)	114	29.7%
Some College (AA)	104	27.1%
Four year degree	94	24.5%
Some graduate courses	12	3.1%
Graduate degree	45	11.7%

8. Gender?

Male	18	4.1%
Female	423	95.9%

9. How many children currently live in your household?

1	87	19.7%
2	219	49.7%
3	101	22.9%
4	28	6.3%
5	4	0.9%
6	1	0.2%
7 or more	1	0.2%

10. Do you have more than one child with special needs? *Note: If the respondent said yes, we asked that responses be for the child with the most severe special needs.*

Yes	103	29.0%
No	252	71.0%

11. What is child's primary diagnosis?<sup>27</sup>

Speech/language	64	14.5%
Primarily Behavioral	163	37.0%
Non-Behavioral	127	28.8%
Multiple Diagnoses	87	19.7%

12. Does child have any social or behavioral problems that go along with this diagnosis? For example, hyperactivity, trouble getting along with others, withdrawn, fearful of others, bullying or hitting others, and so on?

Yes	232	53.0%
No	206	47.0%

13. Does child require medicine or medical procedures on a regular basis during the work day? For example: oral/pills, inhalation/nebulizer, injections/shots, or procedures such as intubation, catheterization, etc.

Yes	168	38.1%
No	273	61.9%

### ***Level of Education***

<b>Type of Diagnosis</b>	<b>No four year degree</b>	<b>Four year degree</b>
1. Speech/Language	55.7%	44.3%
2. Behavioral	55.6%	44.4%
3. Non-Behavioral	51.2%	48.8%
4. Multiple Diagnoses	54.1%	45.9%

### ***Income***

<b>Type of Diagnosis</b>	<b>Low income (0-\$1900)</b>	<b>High income (\$4000+)</b>
1. Speech/Language	59.5%	40.5%
2. Behavioral	59.0%	41.0%
3. Non-Behavioral	49.4%	50.6%
4. Multiple Diagnoses	44.3%	55.7%

<sup>27</sup> One out of four children in our sample were in the Autism Spectrum (Autism, Aspergers and PDD/NOS). Autism Spectrum: (110) 24.9%; Not Autism Spectrum: (331) 75.1%.

*Location*

Type of Diagnosis	Cumberland County	Other Counties
1. Speech/Language	18.8%	81.2%
2. Behavioral	28.8%	71.2%
3. Non-Behavioral	31.5%	68.5%
4. Multiple Diagnoses	32.2%	67.8%

14. How old is the child?

0-2	66	15.0%
3-5	201	45.6%
6-10	81	18.4%
11-14	55	12.5%
15-18	33	7.5%

Type of Diagnosis	Average Age	Comments
1. Speech/Language	3.6	
2. Behavioral	6.6*1	2 > 1
3. Non-Behavioral	7.3*1	3 > 1
4. Multiple Diagnoses	7.6*1	4 > 1

\* = Significant at least at the  $p < .05$  level indicating that the number is statistically different from the item indicated (\*1 = is significantly different from Item 1).

15. Are you currently married or living with a partner?

Married	348	79.1%
Partner	36	8.2%
Not married/no partner	56	12.7%

Type of Diagnosis	% Married or with Partner	Comments
1. Speech/Language	90.6%	no difference
2. Behavioral	87.1%	no difference
3. Non-Behavioral	82.7%	no difference
4. Multiple Diagnoses	91.9%	no difference

Type of Diagnosis	% married or with partner	Comments
1. Autism Spectrum	94.5%*2	1 > 2
2. Not on the Autism Spectrum	84.8%	

\* = Significant at least at the  $p < .05$  level indicating that the number is statistically different from the item indicated (\*2 = is significantly different from Item 2).

16. Are there any other adults living in your household?

Yes	29	6.6%
No	412	93.4%

## Child Care

### Child Care Arrangements (0-5 Sample)

In this section, we report on the child care arrangements used for children aged 0 to 5. Categorizing the kinds of care arrangements for children in this age group was particularly challenging. We discovered in our parent interviews that when children were in part-day therapeutic programs or preschools they were considered by their parents to be in “school,” not “child care.” The focus of our study, however, was on the child care and work experiences of these families. Even if a child was in a part-day therapeutic program or a preschool program, it still might cover some of the hours the parent was working. In our survey instrument, therefore, we gave parents a definition by listing the types of settings they could consider “child care”, including preschools and therapeutic programs. The list read to them was as follows:

- Preschools or therapeutic programs at the local public school or elsewhere. These could be:
  - Typical preschool programs without accommodations for special needs
  - Special preschools or therapeutic programs only for children with special needs
  - Preschools that serve disabled and non-disabled children together
  - Head Start, Early Head Start
- Friend, relative or neighbor taking care of the child either in the child’s home or in theirs
- Day care centers
- Family child care homes

### Significant Findings

- 66% of children 0 to 5 are in some form of child care.

- Half of children (50%) are in care for 10 or fewer hours. Almost a third of children (31%) are in care for between 21 and 40 hours.
- Almost a quarter of those families using child care (23%) are using more than one arrangement.
- Families of children with special needs are much more likely to rely on family, friends or neighbors to care for their child in either the child's home or caregiver's home than are families in the population at large in Maine (51% compared to 23%) (Child Care Advisory Council, 2002).
- Only 12% of children use family child care homes.
- Children with speech and language problems are much more likely to be in center-based care (30.0%) than are children with non-behavioral (17.3%), behavioral (9.4%) or multiple diagnoses with a behavioral component (7.1%).

## Survey Data

1. Is child currently receiving any child care or other care arrangement from someone other than you?

Yes	175	65.5%
No	92	34.5%

2. For those using child care, for how many hours a week is child in care in a typical week?

1-10 hours	87	50.3%
11-20 hours	25	14.5%
21-40 hours	53	30.6%
41 hour plus	8	4.6%

3. Do you regularly, at least weekly, use more than one child care provider or other care arrangement? (*not asked of 160 who are not currently using any child care*)

Yes	41	23.4%
No	134	76.6%

4. What type of child care do you use most often? (*primary child care arrangement*)

Family member, neighbor or friend in their home (FFN)	43	24.9%
Family member, neighbor or friend in your home (FFN)	45	26.0%
Family Child Care (FCC)	20	11.6%
Child Care Center (CENTER)	36	20.8%

Care giving program only for children with special needs	2	1.2%
After school program	4	2.3%
Respite/personal attendant in your home (RESPITE)	12	6.9%
Therapeutic or respite care in agency or other facility	2	1.2%
Nanny/babysitter	9	5.2%

Type of Diagnosis	FFN	FCC	Center	Respite
Speech/Language	50%	7.5%	30.0%	5.0%
Behavioral	67.9%	7.5%	9.4%	7.6%
Non-behavioral	32.7%	17.3%	17.3%	9.6%
Multiple diagnoses	53.7%	7.1%	7.1%	3.6%

## Satisfaction with Current Child Care Arrangement (0-5 Sample)

In light of the special needs of the children represented in our sample, we felt it was important to separate parents' perceptions of the degree to which the current child care arrangement is meeting their *child's* needs (e.g. structure, activities, safety, provider knowledge) from their perceptions of the degree to which it is meeting their *own* needs (e.g. cost, hours matching work hours, location, flexibility). While that separation of perceptions is important for assessing satisfaction of parents of all children, it seemed particularly important for this population of children whose needs require additional attention.

### Significant Findings

- 65 % of families rated their current primary child care arrangement as "excellent" at meeting their *child's* needs. Only 7% of families rated their child care arrangement "fair" or "poor."
- 54% of families rated their current child care arrangement as "excellent" at meeting their *own* needs. 18% of the families rated the child care arrangement as "fair" or "poor" at meeting their *own* needs.
- However, there were significant differences among parents of children with different special needs. Parents with children with multiple diagnoses (54%), behavioral diagnoses (57%), and non-behavioral diagnoses (62%) were significantly less likely to think their child care arrangement was "excellent" at meeting the needs of their child than were parents of children with speech/language problems (88%).
- Parents of children with behavioral diagnoses were significantly less likely to say that their

child care arrangement was meeting their *own* needs than were parents of children with other diagnoses.

- There were no significant differences by level of education, income or location in the degree to which parents felt that their child care arrangement was meeting their *child's* needs.
- Parents with less education felt the child care arrangement was significantly less able to meet their *own* needs than parents with more education.

## Survey Data

1. How well is your current primary child care arrangement meeting your CHILD'S needs? For example, in terms of the provider's understanding of their special needs, structure, appropriate activities, safety, and so on.

Excellent	114	65.1%
Good	49	28.0%
Fair	11	6.3%
Poor	1	0.6%

Type of Diagnosis	% Excellent at meeting child's needs	Comments
1. Speech/Language	87.8%	
2. Behavioral	56.6%* <sup>1</sup>	2 < 1
3. Non-Behavioral	62.3%* <sup>1</sup>	3 < 1
4. Multiple Diagnoses	53.6%* <sup>1</sup>	4 < 1

\* = Significant at least at the  $p < .05$  level indicating that the number is statistically different from the item indicated (\*1 = is significantly different from Item 1).

Level of Education	Less than four year degree	Four year degree or more	Comments
Excellent at meeting child's needs	65.0%	61.5%	no difference

Level of Income	\$1900/mo or less	\$4000+ a month	Comments
Excellent at meeting child's needs	69.2	61.5	no difference

Location	Cumberland (suburban)	Other counties (rural)	Comments
Excellent at meeting child's needs	67.3%	64.3%	no difference

2. How well is your current primary child care arrangement meeting YOUR needs, in terms of hours, cost, location, etc.?

Excellent	95	54.3%
Good	49	28.0%
Fair	23	13.1%
Poor	8	4.6%

Type of Diagnosis	% Excellent at meeting your needs	Comments
1. Speech/Language	63.4%	
2. Behavioral	45.3%* <sup>1</sup>	2 < 1
3. Non-Behavioral	54.7%	no difference
4. Multiple Diagnoses	57.1%	no difference

\* = Significant at least at the  $p < .10$  level indicating that the number is statistically different from the item indicated (\*1 = is significantly different from Item 1).

Level of Education	Less than four year degree	Four year degree or more	Comments
Excellent at meeting your needs	45.4%	64.9%*	statistically significant

\* = Significant at least at the  $p < .05$  level

Level of Income	\$1900/mo or less	\$4000+ a month	Comments
Excellent at meeting your needs	49.2	53.9	no difference

Location	Cumberland (suburban)	Other counties (rural)	Comments
Excellent at meeting your needs	59.2%	52.4%	no difference

### Problems with Child Care Now or in the Past (Full Sample)

Even though the focus of our study is child care for children with disabilities age 0 to 5, we included data from the full sample here because we asked parents if they had experienced these problems with child care now or *in the past*.



## ***Significant Findings***

### ***Type of Disability***

- Children with multiple diagnoses and those with primarily behavioral diagnoses have experienced significant levels of exclusion in educational or play activities (34% and 27% respectively compared to 2% of speech/language children).
- One-quarter of children with behavioral and multiple diagnoses have been asked to leave a child care arrangement.
- One-third of children with multiple diagnoses have experienced a significant lack of safety in the child care setting.
- Children with non-behavioral and multiple diagnoses (those who are more likely to have a physical disability) have experienced a significant lack of accessibility in the child care setting.
- About 40% of parents of children with behavioral and multiple diagnoses have experienced a lack of support concerning the child's special needs from child care providers.
- Almost one-quarter (24%) of children with multiple diagnoses with a behavioral component have had problems with providers not administering medications.
- About 15% of parents of children with primarily behavioral and with multiple diagnoses with a behavioral component thought the child care provider called them more often than necessary.
- 18% of children with primarily behavioral and multiple diagnoses with a behavioral component became too old for care but were not able to be left alone and had no other options for child care.
- Regardless of type of diagnosis, about a third of parents have found that the child care hours did not match their work hours.
- Regardless of type of diagnosis, about a fifth of parents (20%) have found that child care was too expensive causing them to remove their child.

### ***Location***

- Parents in Cumberland County had more problems with the providers including their child in educational or play activities than parents living in other counties.<sup>28</sup>

### ***Income***

- Parents with lower incomes had moderately more problems with providers administering medication than those with higher incomes.

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<sup>28</sup> These differences by location may be hard to interpret. Cumberland County, which is made up of the Portland/South Portland metropolitan area, is a service center for children with special needs and their families. It could be that a greater exposure to these issues has made parents in that area more conscious of issues of exclusion than are parents in other localities. In addition, typically children living in rural areas are more likely to be in neighbor care or family child care homes than are children in more urban Cumberland County and it may be that in those smaller groups, there is less chance for children to be excluded.

## Education

- Parents with more education reported significantly more problems with providers including their child in educational or play activities than parents with less education.

## Survey Data

1. Have you had any of the following problems with a child care provider or other care arrangement for your child, now or in the past?

Child Care Problems Now or in the Past	Number	Percentage of Parents
Provider wouldn't administer medication	47	13.7%
Provider didn't include child in educational or play activities	76	22.5%
Experienced lack of safety	75	22.1%
Experienced lack of accessibility	57	16.7%
Experienced lack of support	103	30.2%
Child care hours didn't match work hours	123	36.1%
Child care too expensive/had to remove child due to cost	65	19.1%
Provider called more often than you felt necessary	39	11.4%
Child became too old for care and you didn't have other options	53	15.5%
Lost child care because provider asked parent to take child out of program	62	18.1%

Type of Disability	1. Speech/ Language	2. Primarily Behavioral	3. Non- Behavioral	4. Multiple Diagnoses	Comments
Provider wouldn't administer medication	4.3%	10.9%	14.7%	23.9%* <sup>1,2</sup>	4 > 1,2
Provider didn't include child in educational or play activities	2.2%	26.8%* <sup>1</sup>	18.1%	33.8%* <sup>1</sup>	2 > 1 4 > 1
Experienced lack of safety	6.4%	23.4%	20.2%	32.4%* <sup>1</sup>	4 > 1
Experienced lack of accessibility	2.2%	11.6%	27.4%* <sup>1,2</sup>	21.1%* <sup>1</sup>	3 > 1, 2 4 > 1
Experienced lack of support	4.3%	44.2%* <sup>1,3</sup>	17.0%	39.4%* <sup>1,3</sup>	2 > 1, 3 4 > 1, 3
Child care hours didn't match work hours	23.4%	39.5%	40.0%	32.9%	no difference
Child care too expensive/had to remove child due to cost	6.4%	19.4%	22.3%	22.5%	no difference
Provider called more than you felt necessary	0.0%	14.1%* <sup>1</sup>	7.4%	19.7%* <sup>1,3</sup>	2 > 1 4 > 1, 3
Child became too old for care and you didn't have other options	2.1%	18.0%* <sup>1</sup>	16.8%	18.3%* <sup>1</sup>	2 > 1 4 > 1
Lost child care because provider asked parent to take child out of program	4.3%	25.6%* <sup>1,3</sup>	9.5%	25.4%* <sup>1,3</sup>	2 > 1, 3 4 > 1, 3

\* = Significant at least at the  $p < .05$  level indicating that the number is statistically different from the item indicated (\*1 = is significantly different from Item 1).

<b>Location</b>	<b>1. Other Counties</b>	<b>2. Cumberland County</b>	<b>Comments</b>
Provider wouldn't administer medication	13.4%	14.6%	no difference
Provider didn't include child in educational or play activities	19.6%	29.1% * 1	2 > 1
Experienced lack of safety	21.4%	23.5%	no difference
Experienced lack of accessibility	16.4%	17.5%	no difference
Experienced lack of support	29.3%	32.4%	no difference
Child care hours didn't match work hours	34.9%	38.8%	no difference
Child care too expensive/had to remove child due to cost	18.8%	19.6%	no difference
Provider called more than you felt necessary	13.0%	7.8%	no difference
Child became too old for care and you didn't have other options	14.6%	17.6%	no difference
Lost child care because provider asked parent to take child out of program	18.0%	18.4%	no difference

\* = Significant at least at the  $p < .05$  level

<b>Income</b>	<b>1. low income</b>	<b>2. high income</b>	<b>Comments</b>
Provider wouldn't administer medication	16.4%*	9.2%	1 > 2
Provider didn't include child in educational or play activities	21.6%	25.2%	no difference
Experienced lack of safety	23.3%	17.8%	no difference
Experienced lack of accessibility	15.5%	13.8%	no difference
Experienced lack of support	28.4%	33.9%	no difference
Child care hours didn't match work hours	34.5%	26.9%	no difference
Child care too expensive/had to remove child due to cost	20.7%	16.5%	no difference
Provider called more than you felt necessary	11.2%	9.3%	no difference
Child became too old for care and you didn't have other options	15.5%	16.7%	no difference
Lost child care because provider asked parent to take child out of program	14.7%	17.4%	no difference

\* = Significant at least at the  $p < .10$  level

<b>Education</b>	<b>1. no 4 year degree</b>	<b>2. 4 year degree</b>	<b>Comments</b>
Provider wouldn't administer medication	13.1%	14.9%	no difference
Provider didn't include child in educational or play activities	16.7%	29.6%* 1	2 > 1
Experienced lack of safety	23.9%	20.8%	no difference
Experienced lack of accessibility	19.3%	14.4%	no difference
Experienced lack of support	27.3%	34.4%	no difference
Child care hours didn't match work hours	39.8%	32.5%	no difference
Child care too expensive/had to remove child due to cost	19.4%	19.3%	no difference
Provider called more than you felt necessary	13.6%	9.4%	no difference
Child became too old for care and you didn't have other options	13.6%	18.1%	no difference
Lost child care because provider asked parent to take child out of program	17.0%	19.9%	no difference

\* = Significant at least at the  $p < .05$  level

## Number of Child Care Problems (Full Sample)

We also added up the number of child care problems that families reported they had experienced now or in the past to examine whether the number of child care problems differed by diagnosis or other factors. Number of child care problems ranged from 0 to 8 problems.

### Significant Finding

- Children with multiple diagnoses with a behavioral component had the highest number of child care problems. Children with primarily behavioral, non-behavioral and multiple diagnoses all had a significantly higher number of child care problems than children with speech and language diagnoses.
- There is no difference in number of child care problems by level of education, level of income or location in the state of Maine.

0 problems	101	36.7%
1 problem	73	26.5%
2-3 problems	58	21.1%
4-5 problems	25	9.1%
6-8 problems	18	6.5%

### Survey Data

Type of Disability	1. Speech/ Language	2. Primarily Behavioral	3. Non- Behavioral	4. Multiple Diagnoses	Comments
Number of child care problems	.55	1.93* <sup>1</sup>	1.47* <sup>1</sup>	2.22* <sup>1</sup>	2 > 1; 3 > 1; 4 > 1

\* = Significant at least at the  $p < .05$  level indicating that the number is statistically different from the item indicated (1\* = is significantly different from Item 1)

Level of Education	Less than four year degree	Four year degree or more	Comments
Number of child care problems	1.75	1.54	no difference

Level of Income	\$1900/mo or less	\$4000+ a month	Comments
Number of child care problems	1.65	1.49	no difference

Location	Cumberland (suburban)	Other counties (rural)	Comments
Number of child care problems	1.54	1.66	no difference

## Regression Analysis - Number of Child Care Problems

We conducted a linear regression analysis on the entire sample with “number of child care problems” as the dependent variable.

- Controlling for age of child, location of residence and monthly income, having a child with multiple diagnoses with a behavioral component was significantly related to having more child care problems ( $t = 2.31, p < .05$ ) while having a child with speech and language issues was related to having fewer child care problems ( $t = 3.56, p < .001$ ).

We reported results for the entire sample because we asked parents about child care problems now or *in the past*. To test whether the results were different for parents whose experiences were more recent, we did a separate analysis for parents of children ages 0 to 10 and found the exact same pattern.

- Parents with a child with multiple diagnoses with a behavioral component experienced more child care problems ( $t = 2.22, p < .05$ ) and parents with a child with speech and language issues experienced significantly fewer child care problems ( $t = 3.46, p < .001$ ).

## Receipt of Special Services (0-2 and 3-5 Sample)

Under IDEA, services are to be delivered to the maximum extent possible in the child’s “natural environment” for infants and toddlers or in the “least restrictive setting” for preschool children ages 3 to 5, meaning in the community where the child normally is and alongside his or her non-disabled peers. Providing services that way permits children to apply what they learn to their everyday life and also reduces the amount of time they are excluded from normal daily routines and activities. Our qualitative research revealed that lack of coordination of the delivery of special services with child care was also an important factor in the work challenges of families of young children with special needs. Once children reach school age, the school system provides most special services in the school setting. Therefore, we report below only data on where special services are provided to children younger than school age.

## Significant Findings

- Over 90% of children ages 0 to 5 (93%) receive “special services” to address their special needs (e.g., OT, speech therapy, counseling, etc.)
- More than half (53%) of 3 to 5 year old children receive some or all of their services at school.

- More than 40% of children ages 0-5 receive some or all of their services at a specialist's office.
- More than 60% of children ages 0 to 2 receive some or all of their services at home.

## Survey Data

1. Does child receive special services, such as occupational therapy (OT), physical therapy (PT), speech therapy, counseling, or "talk" therapy, etc.?

	ages 0-2		ages 3-5	
Yes	59	89.4%	190	94.5%
No	7	10.6%	11	5.5%

2. Are child's special services delivered at . . .<sup>29</sup>

	ages 0-2		ages 3-5	
Early care setting	9	15.3%	19	10.0%
Home	37	62.7%	39	20.8%
Specialist's office	25	42.4%	89	46.8%
School	10	16.9%	101	53.2%

## Work

For our findings on work, we report data for two age groups (full sample and 0-5 sample) because our study focuses on the 0 to 5 population and maternal decisions regarding employment often change when children reach school age.

## Employment Status (Full Sample and 0-5 Sample)

### Significant Findings

- The proportion of parents employed did not differ by type of diagnosis.
- The number of hours parents were employed was higher for parents of children with non-behavioral diagnoses than for parents of children with multiple diagnoses with a behavioral component.
- Parents with children with speech and language issues and parents with behavioral diagnoses

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<sup>29</sup> Parents could choose more than one setting because some children received services in more than one location. Therefore the percentages do not add up to 100%.

were more likely to work off-hours than parents with children with non-behavioral diagnoses.

- Parents with children with non-behavioral diagnoses were the least likely to work off-hours.

## Survey Data

1. Are you currently employed?

(full sample)  
 Yes 277 62.8%  
 No 164 37.2%

(0-5)  
 Yes 157 58.8%  
 No 110 41.2%

### Full sample

Type of Diagnosis	% Employed	Comments
1. Speech/Language	59.4%	no difference
2. Behavioral	60.7%	no difference
3. Non-Behavioral	64.6%	no difference
4. Multiple Diagnoses	66.7%	no difference

### 0-5 sample

Type of Diagnosis	% Employed	Comments
1. Speech/Language	61.3%	no difference
2. Behavioral	56.7%	no difference
3. Non-Behavioral	63.0%	no difference
4. Multiple Diagnoses	52.4%	no difference

2. Have you ever worked outside the home? (of those who are not currently employed)

(full sample)  
 Yes 157 95.7%  
 No 7 4.3%

(0-5 sample)  
 Yes 105 95.5%  
 No 5 4.5%

3. Do you have a second job? (asked of those who are currently employed)

	(full sample)	
Yes	29	10.4%
No	249	89.6%

	(0-5 sample)	
Yes	19	12.0%
No	139	88.0%

4. In a typical work week, how many hours do you work?

	<i>(full sample)</i> Range = 1 hour to 70 hours; Average = 32.3 hours	
1-10	31	11.2%
11-20	34	12.3%
21-30	47	17.0%
31-35	28	10.1%
36-40	83	30.0%
41+	54	19.5%

	<i>(0-5 sample)</i> Range = 1 hour to 70 hours; Average = 30.8 hours	
1-10	21	13.3%
11-20	24	15.3%
21-30	27	17.2%
31-35	17	10.8%
36-40	40	25.5%
41+	28	17.8%

**Full sample**

Type of Diagnosis	# of Hours per week	Comments
1. Speech/Language	30.2	no difference
2. Behavioral	33.4	no difference
3. Non-Behavioral	33.5	no difference
4. Multiple Diagnoses	30.4	no difference

**0-5 sample**

Type of Diagnosis	# of Hours per week	Comments
1. Speech/Language	30.2	no difference
2. Behavioral	31.1	no difference
3. Non-Behavioral	33.1* 4	3 > 4
4. Multiple Diagnoses	25.9	

\* = Significant at least at the  $p < .05$  level indicating that the number is statistically different from the item indicated (\*4 = is significantly different from Item 4)



5. For all your jobs combined, does your entire workday or shift usually fall between 6am and 6pm?

(Full sample)  
 Yes 205 73.7%  
 No 73 26.3%

(0-5 sample)  
 Yes 108 68.4%  
 No 50 31.6%

**Full Sample**

Type of Diagnosis	Off-hour work	Comments
1. Speech/Language	41.0% *3	1 > 3
2. Behavioral	27.3%	no difference
3. Non-Behavioral	19.5%	
4. Multiple Diagnoses	24.0%	no difference

\* = Significant at least at the  $p < .05$  level indicating that the number is statistically different from the item indicated (\*3 = is significantly different from Item 3).

**0-5 sample**

Type of Diagnosis	Off-hour work	Comments
1. Speech/Language	41.0% *3	1 > 3
2. Behavioral	31.5% *3	2 > 3
3. Non-Behavioral	17.4%	
4. Multiple Diagnoses	31.8%	no difference

\* = Significant at least at the  $p < .05$  level indicating that the number is statistically different from the item indicated (\*3 = is significantly different from Item 3)

**Employment of Partner/Spouse (Full Sample)**

**Survey Data**

1. Is your partner/spouse currently employed?

Yes 341 88.8%  
 No 43 11.2%

2. Does he/she have a second job? (asked of those who are currently employed)

Yes 42 12.3%  
 No 299 87.7%

3. In a typical work week, how many hours does he/she work?  
 Range = 4 hours to 100 hours; Average = 46.5 hours

1-10	3	0.9%
11-20	7	2.1%
21-30	10	2.7%
31-35	10	2.7%
36-40	103	30.6%
41+	204	60.5%

4. For all his/her jobs combined, does his/her entire workday or shift usually fall between 6am and 6pm?

Yes	226	66.7%
No	113	33.3%

Type of Diagnosis	Off-hour work	Comments
1. Speech/Language	30.4%	no difference
2. Behavioral	36.6%	no difference
3. Non-Behavioral	28.4%	no difference
4. Multiple Diagnoses	36.9%	no difference

## Flexibility of Care Arrangements to Cover Work Schedule Changes (Full Sample)

### Significant Findings

- Only 20% of parents with children with special needs always have a way to cover a sudden work schedule change.
- Parents with children with behavioral diagnoses are less likely to always have a way to cover a sudden work schedule change than are parents of children with other types of diagnoses.

### Survey Data

1. If you were to have an unexpected or sudden change in your work schedule, how often would you be able to get someone to help you cover child care for (child's name)? Would you say . . .

Always	56	21.2%
Usually	68	25.7%
Sometimes	96	36.2%
Never	45	17.0%

Type of Diagnosis	Always have flexible care	Comments
1. Speech/Language	35.1%	
2. Behavioral	14.4%* 1	2 < 1
3. Non-Behavioral	23.0%	no difference
4. Multiple Diagnoses	21.0%	no difference

\* = Significant at least at the  $p < .05$  level indicating that the number is statistically different from the item indicated (\*1 = is significantly different from Item 1).

## Work Problems Now or in the Past (Full Sample)

Although our study focused on the work experiences of parents of children 0 to 5, we report here data for the full sample because we asked parents to tell us about their work problems now or *in the past*.

### Significant Findings

#### *Type of disability*

- More than half of parents of children with behavioral, non-behavioral and multiple diagnoses with a behavioral component had to reduce their work hours to care for their child - significantly more than parents with children with speech and language issues.
- Parents with children with multiple diagnoses were more likely than parents with children with a behavioral diagnosis to have had to reduce their work hours to care for their child (76% versus 56%).
- 30% or more of parents with children with non-behavioral and multiple diagnoses with a behavioral component had to quit working - significantly more than parents with children with speech and language issues.
- Parents with children with multiple diagnoses were more likely than parents with children with a behavioral diagnosis to have had to quit their jobs (45% versus 28%).
- 38% of parents with children with multiple diagnoses had to change their job because of their child with special needs - significantly more than parents of children with speech and language issues (only 11%).
- 6-7% of parents with children with behavioral, non-behavioral or multiple diagnoses lost or were fired from their job because of the demands of their child's needs.
- More than 40% of parents with children with behavioral, non-behavioral and multiple diagnoses had to change their work hours to a different time of day because of their child. Parents with children with multiple diagnoses were significantly more likely than parents with children with speech/language issues to change their work hours (51% versus 29%).

- At least one-quarter of parents with children with behavioral, non-behavioral and multiple diagnoses turned down a job or promotion - significantly more than parents with children with speech and language issues (32%, 25%, 45% versus 10%).
- Parents of children with multiple diagnoses turned down a job or promotion significantly more often than parents with children with non-behavioral diagnoses and with speech and language issues (45% versus 25%, 10%).
- Parents with children with behavioral, non-behavioral or multiple diagnoses were significantly more likely to worry about losing their job than parents with children with speech and language issues (26%, 27%, 38% versus 3%).

***Location***

- There were no differences in work problems by location.

***Income***

- Low income parents were more likely to have lost their job or been fired than higher income parents.

***Education***

- Parents with more education were less likely to have lost or been fired from their job than parents with less education.
- Parents with more education were moderately more likely to have turned down a better job or promotion than parents with less education.

***Survey Data***

1. Did you have the following problems with work now or in the past?

<b>Employment Problems</b>	<b>Number</b>	<b>% of Parents</b>
Had to reduce work hours to care for child	247	57.2%
Quit working, other than for normal maternity or family leave	131	30.3%
Changed jobs	116	26.9%
Lost job or been fired	23	5.3%
Change work hours to a different time of day	191	44.2%
Turned down better job or promotion	127	29.4%
Worried that at risk of losing job	110	25.5%

Type of Disability	1. Speech/ Language	2. Primarily Behavioral	3. Non- Behavioral	4. Multiple Diagnoses	Comments
Had to reduce work hours to care for child	14.5%	55.6%*1	67.5%*1	76.2%*1,2	2 > 1 3 > 1 4 > 1, 2
Quit working, other than for normal maternity or family leave	11.3%	28.1%*1m	32.5%*1	45.2%*1,2	2 > 1 (m) 3 > 1 4 > 1, 2
Changed jobs	11.3%	26.9%*1m	27.0%*1m	38.1%*1	2 > 1 (m) 3 > 1 (m) 4 > 1
Lost job or been fired	0.0%	5.6%	7.1%	6.0%	no difference
Change work hours to a different time of day	29.0%	46.9%*1m	43.7%	51.2%*1	2 > 1 (m) 4 > 1
Turned down better job or promotion	9.7%	31.9%*1	25.4%*1m	45.2%*1,3	2 > 1 3 > 1 (m) 4 > 1,3
Worried that at risk of losing job	3.2%	26.3%*1	27.0%*1	38.1%*1	2 > 1 3 > 1 4 > 1

\* = Significant at least at the  $p < .05$  level indicating that the number is statistically different from the item indicated (\*1 = is significantly different from Item 1)  
(m) = Moderate difference or significant at least at the  $p < .10$  level

Location	1. Other Counties	2. Cumberland County	Comments
Had to reduce work hours to care for child	55.6%	61.1%	no difference
Quit working, other than for normal maternity or family leave	29.1%	33.3%	no difference
Changed jobs	27.5%	25.4%	no difference
Lost job or been fired	4.6%	7.1%	no difference
Change work hours to a different time of day	43.5%	46.0%	no difference
Turned down better job or promotion	29.1%	30.2%	no difference
Worried that at risk of losing job	25.2%	26.2%	no difference

<b>Income</b>	<b>1. Low income</b>	<b>2. High income</b>	<b>Comments</b>
Had to reduce work hours to care for child	53.6%	59.4%	no difference
Quit working, other than for normal maternity or family leave	33.6%	28.1%	no difference
Changed jobs	27.1%	30.5%	no difference
Lost job or been fired	10.7%	3.1%*	1 > 2
Change work hours to a different time of day	44.3%	46.9%	no difference
Turned down better job or promotion	30.0%	31.3%	no difference
Worried that at risk of losing job	27.1%	23.4%	no difference

\* = Significant at least at the  $p < .05$  level

<b>Level of Education</b>	<b>1. No 4 year degree</b>	<b>2. Four year degree</b>	<b>Comments</b>
Had to reduce work hours to care for child	54.9%	60.9%	no difference
Quit working, other than for normal maternity or family leave	28.8%	32.5%	no difference
Changed jobs	27.0%	27.9%	no difference
Lost job or been fired	7.5%	3.0%*	1 > 2
Change work hours to a different time of day	42.0%	47.7%	no difference
Turned down better job or promotion	26.1%	34.5%*	1 < 2 (m)
Worried that at risk of losing job	23.9%	27.9%	no difference

\* = Significant at least at the  $p < .05$  level

(m) = Moderate difference or significant at least at the  $p < .10$  level

## **Number of Employment Problems (Full Sample)**

As we did with child care problems, we added up the number of work problems that families experienced to examine whether number of work problems differed by diagnosis or other factors. Number of work problems ranged from 0 to 7 problems. Again, we report data only for the full sample because we asked parents whether they had experienced these problems now or *in the past*.

### **Significant Findings**

- Children with multiple diagnoses had the highest number of employment problems. Children with primarily behavioral, non-behavioral and multiple diagnoses all had statistically significantly higher numbers of employment problems than children with speech and language diagnoses.

- There is no difference in number of employment problems by level of education, level of income or location in the state of Maine.

0 problems	122	28.2%
1 problem	71	16.4%
2-3 problems	118	27.3%
4-5 problems	90	20.8%
6-8 problems	31	7.2%

### Survey Data

Type of Disability	1. Speech/ Language	2. Primarily Behavioral	3. Non- Behavioral	4. Multiple Diagnoses	Comments
Number of employment problems	.79	2.21*1	2.30*1	3.00*1,2,3	2 > 1; 3 > 1; 4 > 1,2,3

\* = Significant at least at the  $p < .05$  level indicating that the number is statistically different from the item indicated (\*1 = is significantly different from Item 1)

Location	Cumberland (suburban)	Other counties (rural)	Comments
Number of employment problems	2.29	2.14	no difference

Level of Income	\$1900/mo or less	\$4000+ a month	Comments
Number of employment problems	2.26	2.22	no difference

Level of Education	Less than four year degree	Four year degree or more	Comments
Number of employment problems	2.10	2.35	no difference

### Disruptions at Work (Full Sample)

#### Significant Findings

- Parents with children with behavioral, non-behavioral or multiple diagnoses were significantly more likely to be disrupted “often” at work for reasons related to their child

with special needs (e.g. phone calls, attending meetings related to their child, taking their child to services) than parents with children with speech and language issues.

- Parents with less education were moderately more likely to be disrupted “often” than parents with more education.
- Those reporting being disrupted “often” at work report an average of 3.5 disruptions per week.

### Survey Data

1. How often are you disrupted at work by having to meet your child's special needs? For example, for appointments, making and answering phone calls, etc. Would you say . . .

Often	82	29.8%
Occasionally	91	33.1%
Rarely	62	22.5%
Never	40	14.5%

Type of Diagnosis	Disrupted Often	Comments
1. Speech/Language	2.7%	
2. Behavioral	36.4%*1	2 > 1
3. Non-Behavioral	30.9%*1	3 > 1
4. Multiple Diagnoses	34.5%*1	4 > 1

\* = Significant at least at the  $p < .05$  level indicating that the number is statistically different from the item indicated (\*1 = is significantly different from Item 1).

Level of Education	Less than four year degree	Four year degree or more	Comments
Disrupted often	2.33	2.10	Moderate difference

\* = Significant at least at the  $p < .10$  level

Level of Income	\$1900/mo or less	\$4000+ a month	Comments
Disrupted often	2.23	2.05	No difference

Location	Cumberland (suburban)	Other counties (rural)	Comments
Disrupted often	2.08	2.28	No difference



2. In general, how many times does this happen during a typical work week? (This question was asked only of those who reported that they were “often” disrupted at work.)

Average = 3.5 times

## **Regression Analysis – Number of Employment Problems**

We conducted a linear regression model with “number of work problems” as the dependent variable for the full sample.

- Controlling for age of child, location of residence and monthly income, having a child with multiple diagnoses was significantly related to having more work problems ( $t = 4.45, p < .001$ ) while having a child with speech and language issues was related to having fewer work problems ( $t = 4.04, p < .001$ ).

We reported results for the entire sample because we asked parents about work problems *now or in the past* related to meeting the special needs of their child. To test whether the results were different for parents whose experiences were more recent, we did a separate analysis for parents of children ages 0 to 10 and found the exact same pattern.

- Controlling for age of child, location of residence and monthly income, having a child with multiple diagnoses was significantly related to having more work problems ( $t = 4.05, p < .001$ ) while having a child with speech and language issues was related to having fewer work problems ( $t = 4.29, p < .001$ ).

## **References**

Maine Child Care Advisory Council, *State of Child Care in Maine 2002* [Web Page] URL [http://www.maine.gov/dhhs/occhs/state\\_of\\_child\\_care.pdf](http://www.maine.gov/dhhs/occhs/state_of_child_care.pdf)

# NSAF: National Data on Families with Children with Special Needs

## Introduction

Data from a sample of over 80,000 families from the National Survey of America's Families (NSAF) provided insight into the workforce participation, employment stability and financial security of families with and without children with special needs on a national level. In general, findings from the NSAF corroborated our findings from our research in Maine.

Using the NSAF, we examined the following questions:

- Are parents of children with special needs working less than parents of “typical”<sup>30</sup> children?
- Are working parents of children with special needs having greater difficulty retaining jobs than parents of “typical” children?
- Do some types of special needs have a greater impact on maternal employment than others?
- Are families of children with special needs more likely to be poor and experiencing financial insecurity than families of “typical” children?
- Do low-income parents of children with special needs have more difficulty balancing work and caregiving compared to more financially secure parents with children with special needs?
- Do single parents of children with special needs have more difficulty balancing caregiving and work compared to married or partnered parents with children with special needs?

While a detailed description of the methodology, analysis, and results follow, our major findings indicate that:

- Low income families are more likely to have a child with special needs and to have more than one child with special needs than are higher income families.
- Mothers of children with special needs are less likely to be employed outside the home,

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<sup>30</sup> When we use the term “typical” it means children without special needs.

compared with mothers of children without special needs.

- Mothers of children with special needs have significantly shorter job durations and work fewer weeks during the previous year.
- Once employed, mothers of children with health problems are more likely to be working full time compared to mothers of “typical” children.
- There are statistically significant and large differences in the prevalence of poverty (family income under 150% of official poverty line) and food- or rent-related hardship between families with children with special needs and families with “typical” children.
- Mothers with children with special needs are significantly less likely to have health insurance coverage compared with other mothers.

## **Methodology**

### **Description of Data**

The National Survey of America’s Families is a collaborative project of the Urban Institute and Child Trends.<sup>31</sup> Data are collected on social, economic, and health dimensions of well-being from a sample of households representative of the non-institutionalized, civilian population of persons under age 65 in the U.S. and in 13 states: Alabama, California, Colorado, Florida, Massachusetts, Michigan, Minnesota, Mississippi, New Jersey, New York, Texas, Washington and Wisconsin.

The survey was administered in 1997, 1999 and 2002 to three samples of approximately 40,000 households each. The NSAF can be used to produce cross-sectional estimates for a variety of child, parent and family outcomes. Specifically, the NSAF collected data on employment, earnings and income, use of public assistance programs, family structure and the health status and psychological well-being of both parents and children. In each of the three waves, over 28,000 interviews were conducted with primary caregivers of children. In households with children under the age of 18, up to two children were sampled for in-depth data collection: one under the age of 6 and one between the ages of 6 and 17. Interviews were conducted with “the most knowledgeable adult” (MKA): the adult in the household who was most knowledgeable about the well-being of the sampled children. The survey enables the identification of special needs children through specific questions about disabilities, chronic health conditions, current health status and social, emotional, and behavioral problems.

### **Sample Description**

In order to generate sample sizes large enough to reliably investigate relationships between child special needs, parental employment outcomes, and child care, data were extracted from all three waves (1997, 1999 and 2002) of the NSAF and merged to create a pooled sample of primary caregivers and their children.

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<sup>31</sup> For more information about the NSAF go to:  
<http://urban.org/Content/Research/NewFederalism/AboutANF/AboutANF.htm>

The pooled sample consists of: 81,841 Most Knowledgeable Adults (MKAs) (biological, step, or adoptive parent to the focal child(ren))

- 81% (N=66,154) of MKAs are mothers.
- 104,556 children under the age of 18.
- 7% of the children age 6 to 17 (N=4,713) are reported by their parent to have behavioral or emotional problems. (Only mothers of children 6-17 were asked questions about behavior/emotional problems.)
- 11% (N=8,914) of families have a child with a mental, physical or health disability.
- 5.2 % (N=4,240) of families have a child in poor health.

The NSAF over-samples lower income households to enable analysis of the relationships between socioeconomic variables, employment, and child and family well-being. Among the 81,841 families:

- 25.6% (N=20,931) are poor (within 150% of the poverty line).
- 31.3% (N=25,620) are near-poor (between 150 and 300% of the poverty line).
- 42.6% are not poor (above 300% of the poverty line).
- 81% of the MKAs have a high school diploma.
- 26.6% have a four-year college degree or more.
- 68% are married.
- 18.7% are divorced or separated.
- 12.1% have never been married.

The sample used in this study was restricted to *female* primary caregivers, representing 66,154 families. This was done for several reasons. First, research shows (see for example, Blau, Ferber, and Winkler, 2002; Folbre and Nelson, 2000; Williams, 2000) that despite substantial increases in the overall labor force participation of women with children and some smaller increases in overall caregiving participation among fathers, women continue to be the primary person in charge of child and family caregiving. This means that labor force participation decisions and dynamics among women with children is going to be more heavily impacted by the presence and severity of a child's special needs. Second, the employment-related decision-making and labor force experience for men and women is different enough that labor economists recommend analyzing employment outcomes for men and women separately<sup>32</sup>; however, the sample of male caregivers of children with special needs in the NSAF is not always large enough to produce reliable analyses. When sample sizes permitted, we did examine the effects of children's special needs and disabilities on father's labor force participation; however, in the interest of space, we report here only the results from the mother sample.<sup>33</sup>

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<sup>32</sup> In other words, it is not reliable to analyze employment on a sample of men and women combined with a dummy variable indicating gender.

<sup>33</sup> In general, while we found that both parents' employment outcomes were similarly affected by the presence of a child with a special need, we found that the impact on father's employment to be much less than the impact on the mother's employment. If the reader is interested in the results related to the employment of fathers of children with special needs, please contact Lisa Morris at [lmorris@usm.naine.edu](mailto:lmorris@usm.naine.edu).

## **Variables Used in the Analysis**

### *Special Needs*

Parents are asked by NSAF interviewers whether their child has a physical, learning, or mental health condition that limits his/her participation in the usual kinds of activities done by most children his/her age.<sup>34</sup> This information was used to create a variable (DISABLED) that identifies children with a disability or chronic health condition. A variable (POORHLTH) identifying children who are currently in fair or poor health was computed based on the parent's answer to the following question: In general, would you say child's health is excellent, very good, good, fair, or poor. The variable was given a value of 1 if the parent stated that her child's health rated as fair or poor and zero otherwise."

For children ages 6 to 17, parents are asked to assess their child's behavior and emotional state over the course of the past month. For children aged 6 to 11, a behavior problem scale (BEHAVIOR) was created by totaling the responses to the following: whether the child has felt worthless or inferior, has been nervous, high-strung or tense, whether the child acts too young for his/her age, has had trouble sleeping, regularly lies or cheats, and whether or not the child is doing poorly in school. The response categories include often true (assigned a value of 1), sometimes true (assigned a value of 2), and never true (assigned a value of 3). Responses are totaled, creating a scale score ranging from 6 to 18. A higher score indicates fewer behavior problems. For older children, aged 12 to 17, a behavior problem scale is created by totaling the responses to the following: whether the child has had trouble sleeping, regularly lies or cheats, is doing poorly in school, has been unhappy, sad or depressed, can't concentrate or pay attention for long, and doesn't get along with others. Again, responses are totaled, creating a scale score ranging from 6 to 18, with a higher score indicating fewer behavior problems.

In addition to continuous variables (BEHAVIOR) based on the above described scale scores, two dichotomous variables were created identifying children with high levels of behavioral and emotional problems (PROBLEM) and children who exhibit no problematic behavior (NOPROBLEM). Children who scored 18 points on the behavior scale received a value of 1 for NOPROBLEM, indicating no evidence of behavioral problems. Children whose score was less than 18 points received a value of 0 for NOPROBLEM. Children whose behavior scale score was 12 points or less received a value of 1 on PROBLEM, indicating a high level of behavioral problems. Children whose score was greater than 12 points received a value of 0 on PROBLEM.

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<sup>34</sup> For children under age 6, the interviewer clarifies the question by stating the following: A permanent impairment or condition that limits the child's ability to move, to make sounds or to speak, to see or to participate in other activities of infants and young children such as playing, running, or jumping. Do not include an injury that occurred 3 months ago or less as a condition (unless it resulted in obvious permanent limitation). Also, do not include the effects of an operation that took place 3 months ago or less (unless effects are obviously permanent). For children six years and older, the interviewer explains the question stating the following: An ongoing or chronic impairment or condition that limits the child's ability to participate in routine physical education and learning activities at public, private, vocational, or parochial schools. Do not include an injury that occurred three months ago or less as a condition (unless injury resulted in obvious permanent limitation). Also, do not include pregnancy, childbirth, or effects of an operation that took place three months ago or less (unless effects are obviously permanent).

## *Parent Employment and Earnings*

A number of employment variables were constructed, both for the interviewed parent and her/his spouse or partner. The variable EMPLOYED indicates whether or not the parent is currently employed. The variable HRSWEEK measures the number of hours typically worked per week and FULLTIME indicates the parent works 35 or more hours.

In order to examine whether a parent's ability to juggle work and family caregiving impacts job retention and employment stability, we created two additional variables. The variable JOBDUR measures the length of time (in months) a person has been with her/his current employer. Another variable measuring the level of work is WEEKSLY. This is a continuous variable indicating the number of weeks worked during the previous year.

## *Economic Well-Being*

In order to compare child care and employment outcomes for families with children with special needs by socioeconomic status, a number of variables were created that measure income security and wealth. While the NSAF does not provide exact information on household earnings in its public use files, it does produce a categorical variable that indicates the family's income level. The variable FAMINC is set to 1 if the household's income is less than 50% of poverty line (adjusted for family size), 2 if household income is between 50% and 100% of the poverty line, 3 if between 100% and 150% of the poverty line, 4 if between 150% to 200%, 5 if between 200 and 300% of poverty line, and 6 if the family's income is 300% of the poverty line or more. We also created three dummy variables used to flag families whose total income is within 150% of poverty line (POOR), between 150% and 300% of poverty line (NEARPOOR) and greater than 300% of the poverty line (NOTPOOR).

However, because earnings and income are endogenously linked to employment and hours worked, we also use education level instead of income to measure household economic status. Level of education is a strong indicator of economic status but unlike income is not likely to be affected by employment or welfare policy changes, at least in the short term (Moffitt and Cherlin, 2002). In the empirical analysis, the variable for parent education will be LOWEDUC, set equal to 1 if the individual has less than a high school diploma and zero otherwise, and COLLEGE, set equal to 1 if the individual has a four year college degree or more and 0 otherwise.

A number of other variables were created to measure income security. For example, the variable WELFARE is set equal to 1 if the family received any public assistance in the past year including AFDC/TANF, Food Stamps, Emergency Assistance, General Assistance or SSI during the previous year. Separate dummy variables flagging AFDC/TANF, Food Stamps, and SSI, were also used. We also examined participation in the various public assistance programs separately. Other measures of poverty included a variable indicating whether or not the family has in the past year experienced food-related hardship including running out of food or adults having to cut meals (FOODPOV), and a variable flagging those families who were unable to pay rent, mortgage or utility bills over the course of the past 12 months (RENTPOV).

We also created variables that indicate whether the family has insurance and if so, what type. The variable NOINSUR equals 1 if they have no health insurance (and 0 if they have some type of health insurance coverage). The variable EMPINSUR flags those who have employer-provided coverage.

The variable PRIVINSUR indicates they have private insurance and PUBINSUR indicates they have public-provided insurance (SCHIPS, Medicaid, etc.).

### ***Demographics and Family Characteristics***

The typical demographic information will be used as control variables. The variable MARRIED is set to 1 if the MKA is married or living with a partner and 0 if she/he is separated, divorced, widowed or never married. Two education variables include DIPLOMA which equal 1 if the MKA has a high school diploma and zero if she/he does not, and COLLEGE which is set to 1 if she/he has a bachelor's degree and zero if she/he does not. Other variables include the MKA's age (AGE) and her race/ethnicity (WHITE, BLACK, OTHER).

We also created variables that measure family size (NUMKIDS) and the presence of a preschool aged child (PRESCHLER). These variables have been shown in previous research to impact the parents' ability to work and retain jobs.

Table 1 describes the study sample and shows the variables used in the analyses.

**Table 1: Description of the Sample (N=66,154 families)**

<b>Characteristics of Mothers</b>		<b>Average/%/Number</b>
Average Age (Range)		36 (range 15 to 82)
Married		65.4
Single		34.6
Never Married		13.8
Black		14.0
White		82.7
Other		3.4
High School Diploma		87.6
Bachelor's Degree		24.4

<b>Family Characteristics</b>		<b>Average/%/Number</b>
Average Number of Children (Range)		2.0 (Range 1 to 11)
Preschool Aged Child (0 to 5 years)		44.6
Teenager (12 to 18 years)		31.6
Older Teenager (15 to 18 years)		13.2

<b>Economic Well-Being</b>		<b>Average/%/Number</b>
Poor		27.8
Near Poor		31.7
Not Poor		39.9
Public Assistance		15.5
No Health Insurance		17.1
Experienced Food-Related Poverty		17.3
Unable to Pay Rent		19.1

<b>Child Characteristics</b>		<b>Average/%/Number</b>
Families with child aged 0-5 with disability		2.2 (N=1,435)
Families with child aged 6-17 with disability		9.8 (N=6,466)
Families with child aged 0-5 with health condition		2.0 (N=1,298)
Families with child aged 6-17 with health condition		4.0 (N=2,636)
Families with child aged 6-17 with behavior problems		6.1 (N=4,038)
Families with multiple special needs children or children with multiple special needs		5.1 (N=3,352)

<b>Parental Employment</b>		<b>Average/%/Number</b>
<b>Mothers</b>		
Employed		67.4
Average Hours/Week		36.6
Employed Full-Time		68.9
<b>Fathers/Partners</b>		
Employed		91.5
Average Hours/Week		47.4
Employed Full-Time		96.1



## **Limitations**

The information on child special needs status is reported by the parent and not measured by a clinician. Parents may not be trained or able to objectively and reliably assess their own child. Moreover, while widely used and tested scales were used to assess behavioral and emotional status, assessment of a child's health and (dis)ability status was not done as thoroughly as it might be in a clinical setting. Because the survey had to be conducted in a reasonable amount of time, the child's health and (dis)ability status are assessed using only one or two questions. This may lead to an under-reporting of children with special needs or an under-estimate of the severity of the child's special needs status.

If parents worry that their employment is causing or worsening the child's problems, this may influence how they respond to the questions regarding child well-being. For example, if a parent feels guilty about working, they may assess the child's special needs status as less severe. On the other hand, if a parent is having a difficult time balancing work and family, they may perceive their child's special needs status to be more severe than it is, relative to other children. However, the survey was designed so that parents were asked questions regarding employment and child well-being separately to reduce these effects.

Ideally, longitudinal data are required to examine the impact of a child's special needs on a parent's employment or on the family's economic well-being. However, the data are cross-sectional (three separate samples surveyed each wave). This means that some of the effects we find may involve some reverse causality so that the observed effect may be larger than the actual effect. Rather than observing the impact of a child's special needs on the ability of parents to juggle work and family, we may also be observing some impact of the parent's employment on the child's special needs status. Or, rather than observing the child's special needs impacting the parents' ability to work and the family's economic well-being, we may be observing a greater prevalence of special needs among lower-income families (due to lower quality health care, less access to prenatal and health care services, early detection, environmental causes, etc.). While it is unlikely that the entire observed effect is from reverse causality, part of the effect found using cross-sectional data may, in fact, be due to these reverse relationships. We test for the possibility of reverse causality analytically.

## **Analysis and Results**

### **What are the Effects on Parental Employment of Having a Child with Special Needs?**

We begin by examining the impact of the presence of a child with special needs on the labor force participation of mothers, including whether or not they are employed outside the home, the number of hours typically worked per week, and employment stability and job retention.

## Methods

Standard univariate and bivariate statistics were used to compare the employment outcomes of mothers of children with various special needs and mothers of “typical” children. Multivariate regression techniques<sup>35</sup> were then used to examine the impact of a child with special needs on a mother’s employment while controlling for other factors related to labor force participation, including the mother’s education, race, age, and marital status as well as the number and age of her children.

To investigate whether maternal employment varies according to type of special need, we compare the employment of mothers with children with each type of special need to mothers of children with no special needs. To further isolate the effect of a child with special needs by type, we exclude from the sample mothers of children with multiple special needs and mothers with more than one child with special needs (Table 3 examines the impact of children with multiple special needs and multiple children with special needs). So, for example, in order to examine the impact of a child’s disability on the mother’s employment, we compare the employment of mothers of disabled children (who have no other special need, including a health condition, or, for children 6 to 17, behavior problems) to that of mothers whose children have no special needs. Similarly, the employment of mothers of children in poor health is compared to that of mothers of children who are in good health and have no other special needs (including a disability or, for children 6 to 17, behavior problem). For children 6 to 17, the same is done to isolate the effect of children with behavior problems on maternal employment. As stated earlier, questions in the NSAF regarding behavioral or emotional problems were asked only of mothers of children age 6 to 17. Therefore, in all of our analyses based on type of special need, we examine the two age groups (0 to 5 and 6 to 17) separately. Comparisons based on behavioral problems are made only for children age 6 to 17.

Finally, we also analyze the employment of mothers of children aged 0 to 5 and the employment of mothers of children aged 6-17 separately. This is done because mothers of younger children generally work less than mothers of older children and we want to isolate the effect of the special needs on maternal employment from the effect of the presence of a preschool aged child(ren).

## Findings

Table 2 below displays statistics comparing employment rates and levels of mothers of children with various special needs to a sample of mothers of children without special needs. We examine overall employment rates as well as the percent working full-time (more than 35 hours per week). We also

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<sup>35</sup> Regression techniques are used to simultaneously examine multiple factors assumed to influence outcomes like labor force participation, employment levels and job retention and to isolate the effects of specific factors such as the presence of a child with special needs from other factors that impact parental employment. For example, using regression models we can examine the impact of the presence of a child with special needs on employment rates or job duration controlling for the parent’s age, education, and marital status as well as the number and age of other children. This means we can estimate separate impacts for each of these variables. Regression methods enable us to determine whether the independent variables of interest (e.g., presence and type of child disability or special need) have statistically significant and separate impacts on the dependent variables (in this case, employment, hours worked per week, weeks worked per year and job duration) and if so, in what direction (positive or negative) as well as the relative size of each independent variable’s impact on the dependent variable.

examine employment stability among mothers with children with special needs and other mothers.

- Overall, we find that mothers of children with special needs are less likely to be employed outside the home, compared with mothers of children without special needs.
- However, while we find significantly lower levels of labor force participation among mothers of children with special needs, we find little difference in the likelihood of full-time work versus part-time work among mothers of children with special needs and mothers of “typical” children.
- More significantly, mothers of children with special needs are having a harder time holding onto jobs and maintaining continuous employment, compared with mothers of “typical” children.

**Table 2: Maternal Employment and Child’s Special Needs<sup>36</sup>**

<b>Type of Child</b>	<b>% Employed</b>	<b>% Full-time</b>	<b>Weeks Last Year</b>	<b>Job Duration (months)</b>
<b>Families with children aged 0-5</b>				
No Special Needs	58.83	63.46	41.13	50.92
Disabled Child	53.85**	61.26	39.58*	45.89*
Health Condition	53.11**	71.54**	37.79***	33.79***
<b>Families with at least one child aged 6 to 17 and no child aged 0 to 5</b>				
No Special Needs	76.8	71.87	45.59	79.25
Disabled Child	69.60***	71.86	44.75*	71.84***
Health Condition	64.64***	73.70*	42.39**	58.65***
Behavior Problem	71.27***	76.29**	44.57*	69.58***

<sup>36</sup> The asterisks indicate that the differences between the employment outcome among mothers with special needs children and mothers of “typical” children are statistically significant. \*\*\* ( $p < 0.001$ ), \*\* ( $p < 0.01$ ), and \* ( $p < 0.1$ ). The comparison is to families with no children with special needs. For example, families with a disabled child aged 0 to 5 are compared to families without any special needs children of any age; and families with a child aged 6 to 17 with a health condition are compared to families without any other children with special needs. This is done to isolate the effect of the different special needs at different ages. Tests of statistical significance provide evidence that employment differences found between parents with and without children with special needs are a reflection of the reality of these families’ lives and not the result of biased sampling or random events. For example, using the 99 % level of significance ( $p < 0.01$ ) means that observed differences in employment between mothers with and without children with special needs occurred by chance in only 1 out of 100 cases (or, in other words, we are 99 % sure that the differences observed are meaningful and not the result of chance.)

## ***Labor Force Participation***

- Overall, mothers of children with special needs are somewhat less likely to be employed than are mothers of children without special needs. This holds true for mothers of children with disabilities, health conditions and behavioral problems and for mothers of younger children and mothers of children ages 6 to 17. However, the differences are more pronounced among mothers of older children than among mothers of younger children.
  - Mothers of children 0 to 5:
    - There is about a 5% difference in the employment rate among mothers of young children (aged 0 to 5) with a health or disability-related special need and mothers of children with no special needs.
    - Among mothers of children aged 0 to 5, 53.8% of mothers with disabled children and 53.1% of mothers of children with health conditions are employed compared with 58.3% of mothers of “typical” children.
  - Mothers of children 6 to 17:
    - Among mothers of older children, we find larger and more strongly statistically significant differences in the employment rates between mothers of children with health or disability-related special needs and mothers of other children. This likely reflects the fact that more mothers of “typical” children return to the labor force when their children become school aged than do mothers of children with special needs, making the contrast between the two groups greater.
    - Compared to mothers of “typical” children, we find that mothers of older children with disabilities are 7.2% less likely to be working and mothers of older children in poor health are 12.2% less likely to be working.
    - These differences in labor force participation rates are found to be quite robust with statistical significance to at least the 99% significance level.
    - The data indicate that the presence of a child with behavior problems (measured only for children aged 6 to 17) also impacts a mother’s labor force participation decisions. Mothers of children with behavior problems are 5.3% less likely to be employed, compared with mothers of typical children.

## ***Level of Employment***

- Overall, while the effect of a child with a disability or health-related special need or behavior problems on maternal labor force participation appears to be quite robust, the impact on her *level* of work (likelihood of full-time employment) is found to be less consistent.
- We find no statistically significant differences in full-time employment versus part-time employment between mothers of disabled children and mothers of typical children. This holds true for both older children and younger children. However, we do find mothers of children with health conditions are actually *more* likely to be working full-time than are mothers of “typical” children.

- Mothers of children 0 to 5:
  - We find an 8% increase in the likelihood of full-time work for working mothers of young children with health conditions. For example, among employed mothers, 63.5% of mothers of children without special needs are working full-time compared with 71.5% of those with a child in poor health. This may reflect a need for employer-provided health insurance that comes with full-time employment.
- Mothers of children 6 to 17:
  - We also find a statistically significant increase in the likelihood of full-time work among working mothers of older children with health conditions compared with working mothers without children with special needs; however, while statistically significant, the difference is slight compared with mothers of younger children.

### ***Employment Stability and Job Retention***

The statistics contained in Table 2 also compare employment *stability* among mothers with and without a child with special needs. Employment stability is measured in two ways: as the number of weeks employed (nonzero hours) in the previous year (among those who worked at least one week) and the number of consecutive months with current employer.

- Overall, our findings show that mothers of children with special needs, including disabilities, health conditions and behavior problems, have shorter job durations and worked fewer weeks during the previous year. Moreover, the impact of children’s special needs on mother’s employment stability appear to be even stronger and more consistent than the effects on employment rate and level.
- Mothers of children 0 to 5:
  - Among those who worked at least one week during the previous year, mothers of disabled children aged 0 to 5 worked an average of 1.5 fewer weeks, compared with mothers of typical children.
  - Mothers of young children in poor health worked 3.3 fewer weeks compared with mothers of typical children.
  - Mothers of young children with disabilities have been in their current jobs an average of 5 months less than mothers of typical children.
  - Mothers of children aged 0 to 5 in poor health have been in their jobs an average of 17 months less than mothers of “typical” children aged 0 to 5.
- Mothers of children 6 to 17:
  - We find evidence suggesting that the impact of an older child with a special need on maternal job stability is greater than the impact of younger children with special needs. Again, this may reflect difficulty in obtaining child care for older children with health and disability-related special needs.

- Among mothers of older children we find small but statistically significant differences in the number of weeks worked in the previous year among mothers of disabled children (1 week less) and children with health conditions (3.2 weeks less), compared to other mothers.
- Among mothers of children aged 6 to 17 we find small but statistically significant differences in the number of weeks worked among mothers of children with behavior problems and those without.
- However, the differences in job *duration* among mothers of older children with special needs compared to mothers of typical children are larger and more strongly significant. Mothers of children aged 6 to 17 who have a disability have remained in their current jobs for an average of 7.5 months less than mothers whose children are not disabled.
- The average job duration among mothers whose children are in poor health is 20.6 months shorter than mothers of “typical” children .
- Mothers of children aged 6 to 17 with behavior problems have been in their current jobs an average of 10 fewer months, compared to other mothers.<sup>37</sup>

## **The Impact of Multiple Needs Children and Multiple Children with Special Needs**

Many families have more than one child with special needs or they have a child with more than one type of special need. Presumably, these families have even greater caregiving responsibilities and will thus have a harder time balancing work and family. Table 3 presents maternal employment outcomes for families with children with multiple special needs and families with more than one child with special needs.

- Overall, we find that the more special needs a child has the lower the mother’s rate of employment.
- Similarly, we also find lower maternal employment rates among families who have more than one child with special needs.
- We also find that mothers of children with multiple special needs and mothers with more than one child with special needs have significantly shorter job durations and less continuous employment than other mothers.

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<sup>37</sup> When we compared job duration and weeks worked among mothers of children with only positive behaviors, mixed behavior and severe behavior problems, we find no evidence to suggest a reverse relationship (i.e., that the mother’s employment stability or job duration aggravates the child’s behavior problems).

**Table 3: Maternal Employment and Multiple Needs Child(ren)<sup>38</sup>**

Type of Families (N=number of families)	% Employed	% full- time	Mean Number of Weeks Worked Last Year	Mean Number of Months with Current Employer
<b>Children with more than one special need<sup>39</sup></b>				
<b>Children aged 0 to 5 (N=14,923)<sup>40</sup></b>				
No special needs (N=13,929)	59.8	64.6	40.4	45.9
One health or disability-related special need (N=854)	<b>52.7***</b>	65.8	<b>37.5</b>	<b>38.2</b>
Two health or disability-related special needs (N=140)	<b>37.9***</b>	<b>58.5**</b>	<b>33.6***</b>	<b>24.9***</b>
<b>Children aged 6 to 17 (N=36,625)<sup>41</sup></b>				
No special needs (N=28,993)	76.9	71.9	45.6	79.4
One health or disability-related special need (N=4,723)	<b>65.4***</b>	71.7	<b>37.5***</b>	<b>65.9***</b>
Two special needs: health condition and a disability (N=457)	<b>56.0***</b>	69.1	<b>41.3**</b>	<b>54.9***</b>
Two special needs: a health condition or a disability, plus behavior problems (N=1,844)	<b>63.3***</b>	72.5	<b>37.0***</b>	<b>61.8***</b>
Three special needs: health condition, disability and behavior problems (N=335)	<b>51.0***</b>	72.5	<b>42.6**</b>	<b>66.3***</b>
<b>Families with more than one child with special needs<sup>42</sup> (N=14,578)</b>				
Families with child aged 0 to 5 and a child aged 6 to 17 neither who have special needs	57.6	62.0	42.1	57.7
Child aged 0-5 and child aged 6-18, both with health or disability-related special need (N=464)	<b>48.3***</b>	<b>69.6***</b>	39.5	<b>46.6***</b>
Child aged 0-5 with health or disability-related special need and child 6-17 with a behavior problem (N=194)	<b>47.4***</b>	<b>76.1***</b>	39.1	<b>40.3***</b>

<sup>38</sup> \*\*\* ( $p < 0.0001$ ), \*\* ( $p < 0.001$ ), and \* ( $p < 0.01$ ). Note: The level of significance is always relative to families with no children with special needs.

<sup>39</sup> Recall that the NSAF collects information on only one child aged 0 to 5 and one child aged 6 to 17 from each family. If a family has more than one child in either of the two age categories, one child is selected randomly and information is collected on only that child. Therefore, our analysis of the impact of multiple children with special needs is limited by the data. If a family has two children with special needs within either of the two categories, we are unable to capture this. However, if the family has two children with special needs, one aged 0 to 5 and one aged 6 to 17, we are able to capture this situation.

<sup>40</sup> Sample includes those families whose children are all younger than 6 years of age (N=14,923).

<sup>41</sup> Sample includes those families whose children are all older than 5 years of age (N=36,625).

<sup>42</sup> Sample includes those families with children in both age categories. One child from each age category was randomly selected for data collection purposes.

- Mothers of children 0 to 5:
  - Among mothers with younger children with no special needs, the employment rate is 59.8%. This compares with 52.7% among mothers with a child who has one health or disability-related special need and 37.9% among mothers with a child with both a health condition and a disability.
  - While the impact of a child with one special need on the likelihood that the mother works full-time is not significantly different from mothers of “typical” children, there is a statistically significant drop of 6.1% (64.6% compared to 58.5%) in the likelihood of full-time employment among mothers whose young children have multiple special needs.
  - The impact of a child with multiple needs on the mother’s job stability is quite large and statistically significant. For example, employed mothers of young children with no special needs worked an average of 40.4 weeks over the course of the previous year, compared to 37.5 weeks for mothers of children with one special need and 33.6 weeks for mothers of children with two special needs.
  - We also find statistically significant and fairly large differences in job retention outcomes. For example, mothers of young children with one special need have been in their current jobs an average of 8 months less than mothers of children with no special needs and mothers of young children with multiple special needs have been in their current jobs an average of 21 months less than mothers of typical children.
  
- Mothers of children 6 to 17:
  - We obtain similar results on a sample of families whose children are older (aged 6 to 17) and have health or disability-related special needs. We find that employment rates drop about 10% for each additional special need.
  - Among mothers with older children with both a health condition and a disability, the rate of employment is 56%. This compares with 65.4% for mothers with a child with one health or disability-related special need, and 76.9% for mothers of “typical” children aged 6 to 17. The rate of employment is 51% among families with children aged 6 to 17 who have three special needs (a health condition, a disability and behavior problems).
  - However, as is the case with mothers of younger children, we find no statistically significant difference in the likelihood of full-time employment.
  - Similar to the case of families with younger children, among mothers of older children we find that the more complex the child’s special needs, the lower the mother’s job retention. For example, we find that mothers of children aged 6 to 17 with no special needs have been in their current jobs an average of 13.5 months longer than mothers with children with one special need, and 24.5 months longer than mothers of children with both health and disability-related special needs. Moreover, all these differences are statistically significant to the 99% significance level.
  - Interestingly, the addition of a behavior problem to health or disability-related special needs does not automatically reduce maternal labor force participation even further. Among mothers with children aged 6 to 17 who have a disability or a health-related need plus behavior problems, the employment rate is 63.3% which is not statistically different from mothers whose children have only one disability or health-related special need (65.4% employed) and is actually higher than mothers whose children have both a health condition and a disability (56%).



- The same sort of pattern is found when we examine number of weeks worked over the course of the previous year and job retention. The smaller effects of behavior problems in addition to health and disability-related problems could reflect the fact that mothers of children with complex special needs that include behavioral issues use work outside the home as a respite thereby tempering the negative impact of the additional behavior problem on her employment. It may also reflect the fact that parents of children with health and disability-related special needs are in even greater need of maintaining their employer-provided health insurance (thereby tempering the effect of the addition of a behavior special need.)

## **The Impact on Maternal Employment of the Presence of More than One Child with Special Needs**

- Overall, mothers of multiple children with complex needs that include behavior problems appear to be working at higher than expected levels but are still experiencing significant challenges to job stability.
  - Mothers with a child aged 0 to 5 and a child aged 6 to 17, neither with special needs, are employed at a rate of 57.6%, compared to 48.3% for mothers with two children both with a health condition or a disability and 47.4% for mothers with a younger child with a health or disability-related special need and an older child with a behavior problem.
  - Mothers with two children both with multiple special needs, including behavior problems, are also more likely to be employed full-time (76.1%) compared with mothers of two children both with health or disability-related conditions (69.6%).
  - Mothers with a child aged 0 to 5 and a child aged 6 to 17 neither with special needs have been in their current jobs for an average of 17.4 months longer than mothers with two children both with a health condition or a disability and 11 months longer than mothers with a younger child with a health or disability-related special need and an older child with a behavior problem.

## **Regression Analysis: Family and Mother's Characteristics, Marital Status, and Socioeconomic Status**

The bivariate analyses above suggest significant negative relationships between mother's employment and the presence of a child with special needs. However, the question remains: do the above findings regarding the impact of children with special needs on maternal employment outcomes persist when we simultaneously control for other factors that impact employment outcomes, such as the woman's age, education, and the number and age of her children?

Regression techniques are used to isolate the effects of specific factors such as the presence of a child with special needs from other factors that impact parental employment. Specifically, regression methods enable us to determine whether the independent variables of interest (e.g., presence and type of child disability or special need) have statistically significant and separate impacts on the

dependent variables (in this case, employment, hours worked per week, weeks worked per year and job duration) and if so, in what direction (positive or negative) as well as the relative size of each independent variable's impact on the dependent variable. Ordinary least squares regression techniques were used to examine the effects of the different types of child special needs on mother's employment, typical number of hours per week, number of weeks worked last year, and job duration.<sup>43</sup>

In general, the regression results corroborate the results from the bivariate analyses above and indicate that children with special needs do indeed have a separate effect on maternal employment outcomes. When we control for family and mother's characteristics and marital status and socioeconomic status, the special needs variables remain significantly related to maternal employment outcomes. We also find that older children (aged 6 to 17) with special needs have larger impacts on maternal employment outcomes than do younger children (aged 0 to 5) with special needs. Finally, using regression analysis we find that children with special needs have larger effects on employment stability and job retention and smaller effects on employment rates and average weekly hours worked. Results are discussed more specifically below.

In Table 4, results from regression models are displayed, which examine the impact of children with various special needs on the likelihood that the mother is employed outside the home, controlling for demographic and family factors that also impact maternal labor force participation decision. Table 5 shows the results from regression analyses examining the impact of these variables on the number of hours worked per week. Table 6 includes the results for regression analyses examining the impact of the variables on the number of weeks worked during the previous year, and Table 7 does the same for number of months in current job.

All regression models contain the following control variables: mother's age and marital status, race, mother's education level, number of children, and whether there is a preschool aged child in the home (standard demographic and family factors that have been shown by labor economics research to also impact maternal labor force participation decision). In the interest of space, only the variables of key interest – those indicating the presence of a child with special needs and type of special need – are included in the tables.

In general, the effects of the *control* variables are as follows:

- Women without a high school diploma are less likely to be employed, work fewer hours per week and fewer weeks in the previous year, and have shorter job durations compared to women with a high school diploma.
- Women with a four year college degree are more likely to be employed, work more hours per week and more weeks in the previous year, and have been in their current job for longer than women without a bachelor's degree.
- African-American women are more likely to be employed outside the home, work more

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<sup>43</sup> While logistic regression is a mathematically more accurate model to use when the dependent variable is dichotomous (EMPLOYED yes or no) with large samples, results from linear probability models and logistic regression are often quite similar. Results from linear probability models are reported here instead of logistic regression results because the coefficients from LPMs are easier to interpret and understand and thus accessible to a wider audience. All LPM results were verified using the more mathematically reliable logistic models. Differences between LPM and logistic regression models are minor and do not affect the quantitative conclusions. If you would like the logistic regression results, please contact Lisa Morris at [lmorris@usm.maine.edu](mailto:lmorris@usm.maine.edu) or (207) 780-5876.

- hours per week and more weeks in the previous year, and have been in their current jobs more months compared to other women.
- Married women are less likely to be employed outside the home, work on average fewer hours and fewer weeks in the previous year and have been in their current jobs for fewer months compared to unmarried women.

## **Regression Analysis: Impact on Maternal Employment of Having a Child with Special Needs<sup>44</sup>**

### *Labor Force Participation*

- The results displayed in Table 4 show that the presence of a child with special needs, including a disability, health condition or behavior problem, has a significant and negative impact on the mother's labor force participation, even after controlling for demographic and family factors that also impact her labor force participation decisions.
  - Overall, the results show that the absence of a child with special needs increases the likelihood that the mother is employed outside of the home by 5.1 %.
  - The presence of a child with a disability has a negative and significant impact on the mother's labor force participation. The effects are about the same size for older and younger children. The presence of a child aged 0 to 5 with a disability reduces the likelihood that the mother is employed by 6.9%, and the presence of a child aged 6 to 17 with a disability reduces the likelihood that the mother is employed by 5.7%.
  - Older children with health conditions have a somewhat larger effect on maternal employment than does a younger child with health problems. For example, the presence of a child aged 0 to 5 with a health condition reduces the likelihood that the mother is employed by 2.9% and the presence of a child aged 6 to 17 with a health condition reduces the likelihood that the mother is employed by 8.2%.
  - Mothers with children who have behavior problems are 4.1% less likely to be working, compared with other mothers.
  - The presence of a child with multiple needs or more than one child with special needs reduces the likelihood that the mother will be employed by about 8%.

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<sup>44</sup> All the regression results in this section were tested for robustness by simultaneously testing the impact of the presence of children with health conditions and children in excellent health and children with behavior problems and children who exhibit only positive behaviors. In all cases, the results showing a negative effect of the child with a special need on mother's employment outcomes remain even when the variables flagging children in excellent health or without negative behaviors are included. The results indicated that while there may be some endogenous effects (mother's employment has negative effects on child's well-being, perhaps aggravating existing conditions), the predominant effects are in the hypothesized direction: mother's labor force outcomes are negatively impacted by the presence of a child with special needs. This suggests that negative effects of a child with special needs on mother's labor force participation are not confounded by endogeneity.

**Table 4: Regression Models Predicting Employment Status  
(Dependent Variable EMPLOYED)<sup>45</sup>**

<b>variables</b>	<b>Model 1</b>	<b>Model 2</b>	<b>Model 3</b>	<b>Model 4</b>	<b>Model 5</b>
NO SPEC NEEDS	<b>0.051</b> (0.005) [p=0.000]				
DISABLED 0-5		<b>-0.069</b> (0.012) [p=0.000]			
DISABLED 6-17		<b>-0.057</b> (0.006) [p=0.000]			
POORHEALTH 0-5			<b>-0.029</b> (0.013) [p=0.025]		
POORHEALTH 6-17			<b>-0.082</b> (0.009) [p=0.000]		
BEHAVIOR 6-17				<b>-0.041</b> (0.007) [p=0.000]	
MULTIPLE NEEDS					<b>-0.081</b> (0.0080) [p=0.000]

### *Employment Levels*

- The results in Table 5 indicate that mothers with children with special needs work slightly more hours per week on average than do mothers of typical children, even after controlling for other mother and family characteristics. However, although statistically significant, the actual increase in hours appears to be quite small. This may reflect the tension between a need or desire for more hours of work – perhaps reflecting the need to qualify for employer-provided health insurance, more income or respite from caregiving – and the ability to find affordable child care for special needs children.

<sup>45</sup> All models control for the mother’s age, race, marital status and education level as well as the number of children and the presence of a child less than 5 years of age. Bolded coefficients are statistically significant to at least the 5% level ( $p < 0.05$ ). The first number in each square is the parameter estimate, the number in the parentheses is the standard error, and the p value in the brackets reflects the level of statistical significance.

**Table 5: Regression Models Predicting Hours/Week<sup>46</sup>**

variables	Model 1	Model 2	Model 3	Model 4	Model 5
NO SPEC NEEDS	<b>-0.838</b> (0.163) [p=0.000]				
DISABLED 0-5		-0.020 (0.485) [p=0.967]			
DISABLED 6-17		<b>0.736</b> (0.207) [p=0.000]			
POORHEALTH 0-5			<b>1.941</b> (0.512) [p=0.000]		
POORHEALTH 6-17			<b>0.757</b> (0.331) [p=0.022]		
BEHAVIOR 6-17				<b>1.156</b> (0.254) [p=0.000]	
MULTIPLE NEEDS					<b>1.016</b> (0.291) [p=0.000]

- Among mothers who work at all, those with only “typical” children work almost one hour less, on average, per week than do mothers of children with some form of special need.
- Mothers of older children (aged 6 to 17) with disabilities work an average of three quarters of an hour more per week than do other mothers. There is no significant difference in number of hours worked among mothers of younger children with disabilities and other mothers.
- Mothers of younger children with health conditions work approximately 2 hours more per week, on average, compared to other mothers and mothers of older children with health conditions work 0.76 hours more, on average.
- Mothers of children (aged 6 to 17) with behavior problems work an average of just over one hour more a week than do mothers of other children.
- Mothers with more than one child with special needs or a child with more than one special need work an average of one hour more per week than do other mothers.

<sup>46</sup> Sample includes only those women who worked nonzero hours (N=44,505). All models contain the mother’s age, race, marital status and education level as well as the number of children and the presence of a child less than 5 years of age. Bolded coefficients are statistically significant to at least the 5% level ( $p < 0.05$ ). The first number in each square is the parameter estimate, the number in the parentheses is the standard error, and the p value in the brackets reflects the level of statistical significance.

*Employment Stability - Number of Weeks Worked in Previous Year*

- Table 6 displays the results from regression analyses examining the impact of special needs variables on a mother’s employment stability, measured as the number of weeks worked during the previous year. We find that women with children with special needs worked significantly fewer weeks during the previous year compared to other mothers, even after controlling for other mother and family characteristics. Again, while the findings are statistically significant, the impacts are relatively small.

**Table 6:Regression Models Predicting Weeks Worked Previous Year<sup>47</sup>**

<b>variables</b>	<b>Model 1</b>	<b>Model 2</b>	<b>Model 3</b>	<b>Model 4</b>	<b>Model 5</b>
NO SPEC NEEDS	<b>1.208</b> (0.155) [p=0.000]				
DISABLED 0-5		<b>-1.452</b> (0.436) [p=0.001]			
DISABLED 6-17		<b>-0.895</b> (0.196) [p=0.000]			
POORHEALTH 0-5			<b>-2.361</b> (0.465) [p=0.000]		
POORHEALTH 6-17			<b>-2.168</b> (0.309) [p=0.000]		
BEHAVIOR 6-17				<b>-0.579</b> (0.240) [p=0.016]	
MULTIPLE NEEDS					<b>-1.571</b> (0.270) [p=0.000]

<sup>47</sup> Sample includes only those mothers who worked at least one week during the previous year (N=50,651). All models contain for the mother’s age, race, marital status and education level as well as the number of children and the presence of a child less than 5 years of age. Bolded coefficients are statistically significant to at least the 5% level (p<0.05). The first number in each square is the parameter estimate, the number in the parentheses is the standard error, and the p value in the brackets reflects the level of statistical significance.

- Mothers of “typical” children worked 1.2 more weeks on average than did other mothers.
- Mothers with disabled children aged 0 to 5 worked on average 1.5 weeks less than did mothers of typical children.
- Mothers of disabled older children worked an average of 0.9 weeks less.
- Somewhat larger negative effects are found among mothers of children with health conditions. For example, mothers of younger children with health conditions worked 2.4 fewer weeks, on average, compared to mothers of “typical” children, and mothers of older children with poor health worked an average of 2.2 fewer weeks.
- Mothers of children with behavior problems worked 0.6 weeks less than other mothers, on average.
- Mothers with children with multiple special needs or mothers of multiple children with special needs worked an average of 1.6 fewer weeks.

### ***Employment Stability – Number of Months in Current Job***

- Table 7 displays the results from regression analysis examining the impact of a child with special needs on a mother’s job retention, as measured by the number of consecutive months in current job. The regression results show that all three types of special needs – disabilities (at least among older children), health conditions, and behavior problems – have a statistically significant and negative impact on mother’s job retention, even after controlling for other mother and family characteristics.

**Table 7: Regression Models Predicting Months in Current Job<sup>48</sup>**

variables	Model 1	Model 2	Model 3	Model 4	Model 5
NO SPEC NEEDS	<b>6.327</b> (0.911) [p=0.000]				
DISABLED 0-5		-1.017 (2.706) [p=0.707]			
DISABLED 6-17		<b>-6.203</b> (1.154) [p=0.000]			
POORHEALTH 0-5			<b>-6.246</b> (2.815) [p=0.027]		
POORHEALTH 6-17			<b>-10.025</b> (1.841) [p=0.000]		
BEHAVIOR 6-17				<b>-5.364</b> (1.414) [p=0.000]	
MULTIPLE NEEDS					<b>-9.108</b> (1.618) [p=0.000]

- Mothers of children without special needs remain in their jobs an average of 6.3 months longer than mothers of children with special needs.
- Mothers with a disabled child aged 6 to 17 have job durations of 6.2 months shorter, on average, than do mothers of typical children. There is no statistically significant effect of a disabled child aged 0 to 5 on a mother’s job retention.
- Mothers whose children aged 0 to 5 are in poor-to-fair health have been in their jobs an average of 6.2 months less than other mothers, while mothers of older children (aged 6 to 17) in poor-to-fair health have been in their jobs an average of 10 months less.
- Mothers of children with behavior problems remain in their jobs 5.4 fewer months, on average, compared to other mothers.
- Mothers with multiple needs children or more than one child with special needs have job durations 9 months shorter, on average than do mothers of typical children.

<sup>48</sup> All models control for the mother’s age, race, marital status and education level as well as the number of children and the presence of a preschool aged child. Bolded coefficients are statistically significant to at least the 5% level ( $p < 0.05$ ). The first number in each square is the parameter estimate, the number in the parentheses is the standard error, and the p value in the brackets reflects the level of statistical significance.



## What are the Rates of Poverty and Economic Insecurity among Families with Children with Special Needs?

After finding evidence that parents of children with special needs are having a harder time retaining employment, the next logical concern is whether families with children with special needs are also more likely to be experiencing income insecurity and poverty. While the cross-sectional nature of the NSAF does not enable us to determine which came first, poverty and financial insecurity or the child’s special needs, the prevalence of hardship among already struggling families is still a relevant public policy concern. Moreover, given the relationships between employment outcomes and the presence of a child with special needs demonstrated above, we can assume that at least some of the observed effects on economic status are caused by the presence of the child with special needs.

Table 8 shows the prevalence of poverty among families with and without children with special needs.

**Table 8: Economic Insecurity (% ages)<sup>49</sup>**

Type of Family	N	Near Poor	Poor	Food Poverty	Rent Poverty	Parent Has No Health Insurance
No Special Needs	54,481	31.57	25.00	14.2	16.57	15.87
Disabled	4,642	32.40	33.93***	23.3***	24.73***	17.94***
Health Condition	1,962	30.53	53.31***	34.4***	31.14***	35.58***
Behavior Problem	1,717	33.72*	35.53***	34.65***	33.72***	20.03***
Multiple	3,352	31.71	45.32***	45.32***	40.96***	24.16***

- While we find no statistical difference in the prevalence of near poor (family income between 150 and 300% of the official poverty line) we find significant and large differences in the prevalence of poverty (family income within 150% of official poverty line) among families with and without children with special needs.
- We also find large and statistically significant differences in the percentage of families who have experienced food or rent related hardship.
- The prevalence of hardship is even greater among families with children with health conditions and behavior problems.
  - For example, while 25% of families with “typical” children have incomes that place them within 150% of the poverty line, 34% of families with a child with a disability and over half of families with a child with a health condition are poor.
  - Nearly twice as many families with children with health conditions or behavior problems experienced food insecurity (having to cut meals or running out of food) or an inability

<sup>49</sup> The asterisks indicate that the differences between poverty among mothers with special needs children and mothers of “typical” children are statistically significant. \*\*\* (p < 0.001), \*\* (p < 0.01), and \* (p < 0.1).

to pay rent, mortgage or utility bills (RENTPOVERTY) compared to families with typical children.

- Also, 35.6% of all families with a child with a disability are without health insurance compared to 15.9% of other families.
- Not surprisingly, we also find participation in public assistance programs to be significantly higher among families with children with special needs (Table 9).

**Table 9: Welfare Participation<sup>50</sup>**

Type of Family	N	AFDC/TANF	Food Stamps	SSI
No Special Needs	53,864	5.72	12.69	3.18
Disabled	4,613	10.30***	20.72***	12.42***
Health Condition	1,933	12.11***	27.83***	6.73***
Behavior Problems	1,715	12.24***	22.97***	7.23***
Multiple Special Needs	3,336	15.80***	30.79***	19.03***

## Regression Analysis: Economic Insecurity

To determine whether families with children with special needs were still more likely to be experiencing economic insecurity if we controlled for other mother and family characteristics, we conducted another round of regression analyses. Table 10 contains these regression results.<sup>51</sup>

### *Food or Rent-related Hardship*

- We found that even when we control for demographics and socioeconomic status, families with children with special needs are still more likely to be experiencing food or rent-related hardship or have no health insurance. In other words, among poor families, those with a child with special needs are even more likely to experience economic hardship.
- Even after controlling for demographics and socioeconomic status, the presence of a child with special needs has a separate and significant effect on family economic insecurity as measured by going without food, the inability to pay rent, mortgage or utility bills, and having no health insurance coverage.

<sup>50</sup> The asterisks indicate that the differences between the welfare recipient status among mothers with special needs children and mothers of “typical” children are statistically significant. \*\*\* (p < 0.001), \*\* (p < 0.01), and \* (p < 0.1).

<sup>51</sup> See Footnote 18.

**Table 10: Regression Results Examining Economic Hardship<sup>52</sup>**

<b>variables</b>	<b>Dependent Variable: Food Poverty</b>	<b>Dependent Variable: Rent Poverty</b>	<b>Dependent Variable: No Insurance</b>
NO SPEC NEEDS	<b>-0.132</b> (0.004) [p=0.000]	<b>-0.102</b> (0.004) [p=0.000]	<b>-0.036</b> (0.004) [p=0.000]
DISABLED 0-5	<b>0.075</b> (0.010) [p=0.000]	<b>0.071</b> (0.010) [p=0.000]	-0.003 (0.010) [p=0.774]
DISABLED 6-17	<b>0.108</b> (0.005) [p=0.000]	<b>0.085</b> (0.005) [p=0.000]	<b>0.011</b> (0.005) [p=0.027]
POORHEALTH 0-5	<b>0.104</b> (0.010) [p=0.000]	<b>0.083</b> (0.011) [p=0.000]	<b>0.064</b> (0.010) [p=0.000]
POORHEALTH 6-17	<b>0.184</b> (0.007) [p=0.000]	<b>0.101</b> (0.008) [p=0.000]	<b>0.106</b> (0.006) [p=0.000]
BEHAVIOR 6-17	<b>0.178</b> (0.006) [p=0.0006]	<b>0.148</b> (0.006) [p=0.000]	<b>0.016</b> (0.006) [p=0.008]
MULTIPLE NEEDS	<b>0.191</b> (0.006) [p=0.0006]	<b>0.140</b> (0.007) [p=0.000]	<b>0.031</b> (0.006) [p=0.000]

- For example, the presence of a disabled child aged 6-17 increases the likelihood that the family will have experienced food-related hardship by nearly 10.4%, and the likelihood of not being able to pay rent or utilities by 8.5%. The presence of a disabled child aged 0 to 5 has similar though somewhat smaller effects.
- Families with a child aged 6 to 17 who has a health condition are 18.4% more likely to experience food-related hardship and 10.1% more likely to have been unable to pay rent, mortgage or utility bills. Again, the presence of a younger child with chronic health problems has similar though somewhat smaller effects.
- Families with a child who has a behavior problem are nearly 18% more likely to experience food-related hardship and 14.8% more likely to have been unable to pay housing or utility bills.

<sup>52</sup> Bolded coefficients are statistically significant to at least the 10% level ( $p < 0.10$ ). All Models contain the following control variables: mother's age, race, and education, her marital status and the number of dependent children. AGE is negatively related to poverty outcomes and BLACK is positively related. The variable COLLEGE is negatively related to poverty outcomes and having no high school diploma is positively related. Married couple families are significantly less likely than single mother families to be poor and the greater the number of kids the more likely the family is to be poor.

- Families with more than one child with special needs or a child with multiple special needs are 19.1% more likely to experience food-related hardship and 14% more likely to be unable to pay the rent or utilities, compared with families without children with special needs.

### ***Health Insurance***

- Again, we find separate and significant effects after controlling for demographics and socioeconomic status. Mothers with children with special needs are significantly less likely to have health insurance coverage compared with other mothers, even after controlling for her age, marital status, race, education and family size. The lack of insurance undoubtedly reflects lower rates of employment and job instability demonstrated above.

## **What are the Experiences of Low Income Families with Children with Special Needs?**

We then investigated whether there are differences in employment outcomes between poor parents with children with special needs and non-poor parents with children with special needs. The question of whether poor and near-poor families are having an even harder time balancing caregiving of children with special needs and employment is particularly important because lower income families, especially those not quite poor enough to qualify for public assistance and Medicaid, need steady employment for both the income and the access to health insurance. In addition, they may be having an even harder time affording child care for children with special needs. If poor and near-poor families are experiencing more employment problems, they may be even more at risk of severe financial insecurity.

## **Prevalence of Special Needs**

We begin by examining the prevalence of special needs according to family income and mother's education level.

### ***Family Income***

- Poor families are more than twice as likely to have a child with special needs and are almost three times as likely to have a child with multiple special needs or more than one child with special needs than are non-poor families.

**Table 11: The Presence of Special Needs by Family Income<sup>53</sup>**

<b>Type of Child(ren)</b>	<b>Poor (N=18,369)</b>	<b>Near Poor (N=20,945)</b>	<b>Not Poor (N=26,415)</b>
No Special Needs	67.7	78.4	84.4
Disabled	16.0	11.8	8.6
Health Problem	11.0	5.4	2.2
Behavior Problem	11.4	8.2	5.5
Multiple Special Needs	12.4	7.0	4.8

***Mother's Education Level***

- Mothers with low education levels (no high school diploma) are more than twice as likely to have children with special needs and almost three times more likely to have a child with multiple special needs or more than one child with special needs than are mothers with higher education levels (Bachelor degree).

**Table 12: The Presence of Special Needs by Mother's Education Level**

<b>Type of Child(ren)</b>	<b>No High School Diploma (N=8,205)</b>	<b>High School Diploma (N=57,949)</b>	<b>Bachelor's Degree (N=16,144)</b>
No Special Needs	62.1	76.5	84.8
Disabled	16.8	12.0	8.0
Health Problem	14.6	5.3	2.4
Behavior Problem	12.7	8.2	5.0
Multiple Special Needs	11.8	6.8	4.2

<sup>53</sup> Poor families whose total income is within 150 % of poverty line (POOR), between 150 % and 300 % of poverty line (NEARPOOR) and greater than 300 % of the poverty line (NOTPOOR).

## **Regression Analysis: Socioeconomic Status, Employment, and Children with Special Needs**

When examining relationships between employment outcomes and socioeconomic status, we can't use family income to designate socioeconomic status because of the strong correlation between employment and income. Instead we used mother's education level as a proxy for income level because it is not as directly related to employment. Table 12 shows that the prevalence of children with special needs follows the same patterns when examined according to mother's education level (no high school diploma, high school diploma, and bachelor's degree) as does the prevalence of children with special needs by family income reported in Table 11. The patterns displayed in Table 12 are also borne out by correlation statistics. A comparison of Tables 11 and 12 shows very similar patterns of prevalence of children with various special needs using family income and mother's education. This makes sense for several reasons. First, women with higher levels of education will have higher earnings and, second, women with higher levels of education tend to have partners and spouses with similar education levels and earning power. Therefore, we will use mother's education as a proxy for socioeconomic status since it is not as directly related to employment and income.

Because women with college degrees are more likely to be married to partners with higher earning potential and are more likely to receive financial assistance from family and fathers they may be more able to reduce work effort. Because lower income families tend to have jobs that are less flexible and have a harder time affording child care and reliable transportation, they may have a harder time balancing work and caregiving for children with special needs. In addition, they are generally more likely to be eligible for public assistance programs such as Food Stamps, Medicaid, and TANF, which can reduce somewhat the consequences of less work. On the other hand, because poorer households have a greater need for the mother's earned income, these mothers may maintain their labor force participation even in the face of more difficult work/family conflict.

To test whether lower-income parents with children with special needs are having an even harder time balancing work and family compared with higher income parents with children with special needs, we conducted regression analyses on sub-samples of families separated according to socioeconomic status, using education levels as a proxy for income.

Table 13 contains these regression results.

- Overall, we find evidence to suggest that mothers with lower educational levels (no high school degree) who have children with special needs are having a more difficult time balancing work and caregiving compared with mothers with children with special needs who have higher levels of education (those with a four-year college degree), even after controlling for other mother and family characteristics.

**Table 13: Regression Results on Socioeconomic Sub-Samples<sup>54</sup>**

<b>Regression Models ↓</b>	<b>Estimated Coefficients on DISABLED</b>	<b>Estimated Coefficients on HEALTH CONDITION</b>	<b>Estimated Coefficients on BEHAVIOR PROBLEM</b>
<b>Employed (yes/no)</b>			
No Diploma	<b>-0.052****</b> (0.011) p=0.000	<b>-0.046***</b> (0.015) p=0.003	<b>-0.056***</b> (0.019) p=0.003
College Degree	<b>-0.033***</b> (0.012) p=0.007	<b>-0.039*</b> (0.022) p=0.078	-0.019 (0.018) p=0.295
<b>Hours/Week</b>			
No Diploma	0.509 (0.585) p=0.384	0.379 (0.606) p=0.532	0.193 (0.706) p=0.784
College Degree	<b>1.091*</b> (0.444) p=0.014	<b>2.952****</b> (0.804) p=0.000	<b>2.077***</b> (0.629) p=0.001
<b>Weeks/Year</b>			
No Diploma	<b>-3.718****</b> (0.662) p=0.000	<b>-2.946****</b> (0.701) p=0.000	<b>-1.652**</b> (0.0843) p=0.050
College Degree	<b>-0.971**</b> (0.576) p=0.092	<b>-2.449*</b> (1.028) p=0.017	0.511 (0.831) p=0.589
<b>Months in Job</b>			
No Diploma	<b>-9.497****</b> (2.618) p=0.000	<b>-5.247**</b> (2.728) p=0.054	-3.222 (3.151) p=0.307
College Degree	-2.232 (2.752) p=0.413	<b>-8.743**</b> (4.923) p=0.076	-2.354 (3.860) p=0.542

<sup>54</sup> All the regression equations used to estimate the coefficients in Table 13 contain the following control variables: MARRIED, AGE, BLACK, KIDS, and PRESCHOOLER. In the interest of space, only the estimated parameters for the variables of interest - those indicating the presence of a child with a special need – are included in the table.

### ***Labor Force Participation***

- The presence of a child with a disability reduces the likelihood that the mother is employed by 5.2% for women with no high school diploma compared with 3.3% for women with a college degree.(Table 13)
- The impact of a child with behavior problems is found to have no statistically significant impact on mothers with college degrees while for mothers with no diploma their employment rate is reduced by a statistically significant 5.6%.

### ***Employment Levels***

The second panel of Table 13 displays results from regression equations estimating the effects of children with special needs on the number of hours worked per week.

- There is a statistically significant increase in hours per week among mothers with college degrees and an insignificant relationship between the presence of a child with special needs and hours worked by mothers with no high school diploma. This may reflect the fact that highly educated women are more likely to have jobs that offer health care benefits. It may also reflect greater access to reliable transportation and the ability to afford child care for children with special needs.

### ***Employment Stability – Number of weeks worked in previous year***

Table 13 also examines the relationship between child special needs and the number of weeks worked the previous year.

- We find larger and more strongly significant effects for the sample of women with no high school diploma.
  - Women with no high school diploma who have a child with a disability worked 3.7 fewer weeks the previous year compared with mothers with no high school diploma without children with disabilities, while among women with college degrees the difference between mothers with and without a disabled child is only 0.97 weeks.
  - Among mothers with no high school diploma, those with a child with a behavior problem worked a significant 1.6 fewer weeks than those with typical children. Among mothers with college degrees, the impact of a child with a behavior problem on weeks worked was statistically insignificant. The impact of a child with a health condition is about the same for both groups.



### *Employment Stability – Number of Months in Current Job*

- The impact of a child with special needs on job retention between mothers with high and low educational attainments is more mixed. On the one hand, mothers in higher socioeconomic groups may have jobs that provide more flexibility and time off to deal with heavier caregiving responsibilities presented by children with special needs. On the other hand, higher income families can also better afford to have the mother take time out from the labor force.
  - We find no statistically significant impact of a disabled child on job retention for more educated mothers but we find that mothers of children with special needs with no high school diploma had worked 9.5 months less in their current jobs than mothers of typical children who have no high school diplomas.
  - On the other hand, we find a greater negative impact of a child with a health condition on more educated mothers compared to mothers with less education (8.7 fewer months in current job compared to 5.2 fewer months).
  - The impact of a child with a behavior problem is not found to be statistically significant for either sub-sample.

### **What are the Experiences of Single Parent Families with Children with Special Needs?**

Single-parent families are another vulnerable group that may find it more difficult to balance work and caregiving for children with special needs. The question of whether single parents are having an even harder time than married/partnered parents juggling caregiving and work is a particularly important public policy issue because single-parent families are already more likely to be poor and financially insecure.

- Overall, Table 14 shows that single parent families are more likely to have a child with special needs compared with dual parent families, and are almost twice as likely as dual parent families to have a child with multiple special needs or more than one child with special needs. Again, given the cross-sectional nature of the data we cannot know which came first, the child with special needs or the single-parent status.

**Table 14: The Presence of Special Needs by Marital Status**

<b>Type of Child(ren)</b>	<b>Married (N=43,243)</b>	<b>Not Married (N=22,911)</b>
No Special Needs	80.6%	65.7%
Disabled	9.9%	15.0%
Health Problem	4.1%	8.6%
Behavior Problem	5.9%	12.1%
Multiple Special Needs	6.1%	13.5%

## Regression Analysis: Single-Parent versus Dual-Parent Families

To test whether single parents of children with special needs are having an even harder time balancing work and family compared with married parents, we conducted regression analyses on separate samples of single and married mothers. Table 15 displays the results.

**Table 15: Regression Results on Single and Dual-Parent Sub-Samples<sup>55</sup>**

<b>Regression Models ↓</b>	<b>Estimated Coefficients on DISABLED</b>	<b>Estimated Coefficients on HEALTH CONDITION</b>	<b>Estimated Coefficients on BEHAVIOR PROBLEM</b>
<b>Employed (yes/no)</b>			
Single	<b>-0.104****</b> (0.008) p=0.000	<b>-0.083****</b> (0.010) p=0.000	<b>-0.073****</b> (0.010) p=0.000
Married	<b>-0.032****</b> (0.007) p=0.000	<b>-0.059****</b> (0.011) p=0.000	<b>-0.009****</b> (0.011) p=0.000
<b>Hours/Week</b>			
Single	<b>-0.567**</b> (0.269) p=0.035	-0.094 (0.354) p=0.790	-0.020 (0.328) p=0.950
Married	<b>1.330****</b> (0.267) p=0.000	<b>2.304****</b> (0.435) p=0.000	<b>2.098****</b> (0.374) p=0.000
<b>Weeks/Year</b>			
Single	<b>-4.119****</b> (0.369) p=0.000	<b>-4.731****</b> (0.471) p=0.000	<b>-2.789****</b> (0.460) p=0.000
Married	<b>-1.233****</b> (0.345) p=0.000	<b>-3.288****</b> (0.522) p=0.000	0.722 (0.493) p=0.143
<b>Months in Job</b>			
Single	<b>-5.241****</b> (1.443) p=0.000	<b>-8.914</b> (1.899) p=0.000	<b>-4.193**</b> (1.760) p=0.017
Married	<b>-6.043****</b> (1.536) p=0.000	<b>-9.847</b> (2.492) p=0.000	<b>-6.297***</b> (2.153) p=0.003

<sup>55</sup> All the regression equations used to estimate the coefficients in Table 15 contain the following control variables: MARRIED, AGE, BLACK, KIDS, and PRESCHOOLER. In the interest of space only the estimated parameters for the variables of interest - the variables indicating the presence of a child with a special need - are included in the table.

### ***Labor Force Participation***

- Table 15 shows that while the presence of a child with special needs has a significant and negative impact on the labor force participation of single and married mothers, the impact on single mothers is greater, even after controlling for other mother and family characteristics. This holds true for all three types of child special need.
  - The drop in employment is three times as large for single mothers with disabled children compared with married women with disabled children, Single mothers are 10.4% less likely to be employed if they have a child with special needs compared with 3.2% for married mothers of children with special needs.
  - Single mothers with a child with a health condition are 8.3% less likely to be employed compared with mothers of healthy children, while married mothers of children with health conditions are 5.9% less likely to be employed.
  - Single mothers with children with behavior problems are 7.3% less likely to be employed compared to other mothers while the impact of a child with a behavior problem on a married mother's employment is a much smaller 0.9% decrease.

### ***Employment Levels***

- As we found with lower versus higher educated mothers, married mothers with children with special needs tend to work a few extra hours relative to married mothers with typical children, even after controlling for other mother and family characteristics. However, there is little or no statistical difference in the hours worked per week among single mothers with and without children with special needs.
  - Single mothers of children with a disability work on average 0.57 hours less per week compared with single mothers of typical children. We find no statistically significant difference in the hours worked among single mothers with children with health conditions and healthy children and children with and without behavior problems.
  - On the other hand, married mothers of disabled children work on average 1.33 hours more per week than married mothers of typical children. Married mothers of children with health conditions work an average of 2.3 hours more per week than do married mothers of healthy children. Married mothers with children who have behavioral problems work an average of 2.1 hours per week more than married mothers of children without behavior problems.

### ***Employment Stability – Number of Weeks Worked in Previous Year***

- We also find larger differences in the number of weeks worked during the previous year between single mothers of children with special needs and mothers of typical children than we do with their married counterparts.

- For example, single mothers of disabled children worked an average of four weeks less than did single mothers of “typical” children, while married mothers of disabled children worked an average of one week less than married mothers of typical children.
- We also find larger reductions in weeks worked among single mothers with children with health conditions or behavior problems than we do among married mothers.

### ***Employment Stability – Number of Months in Current Job***

- While we find significant reductions in job durations among all mothers with special needs, married mothers with children with special needs have slightly larger reductions in job duration than do single mothers of children with special needs. This may reflect the fact that married mothers with access to dual incomes have a greater ability to opt out of a job.
  - For example, we find that married mothers of disabled children have been in their current jobs an average of six months less than married mothers of “typical” children while single mothers of disabled children have been in their current jobs an average of 5.2 months less than single mothers of “typical” children. The findings are similar for married and single mothers of children with health conditions and children with behavior problems.

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