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Child Care and Children with Special Needs - Challenges for Low Income Families: Parents' Voices

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Child Care and Children with Special Needs:

Challenges for Low Income Families



Parents' Voices

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Challenges for Low Income Families

Parents' Voices

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Note to Reader:

"Findings" from focus groups and semi-structured interviews are a collection of perceptions that can be used to shed light on a topic from a particular point of view. This report simply captures for the reader what participants said and then organizes this information into themes. The opinions expressed are those of the participants and do not necessarily represent the opinions of the research staff or the members of the Advisory Committee.

Acknowledgements

Child Care and Children with Special Needs: Challenges for Low Income Families is a project of the Child Care Policy Research Consortium, supported by the Child Care Bureau, Administration on Children, Youth and Families, U.S. Department of Health and Human Services. We wish to thank them for their support.

We are very grateful to the members of our Advisory Committee who assisted us in thinking through the methodology for this project, selecting the communities where we conducted our research, developing our recruitment strategies, and gathering information on programs and policies within their respective states. These individuals are listed in the beginning of this report.

We are also grateful to the staff of the following organizations who agreed to co-sponsor our project in their communities and who helped us recruit families for our focus groups and in-depth interviews:

Aroostook County Action Program, Presque Isle, ME

City of Norwich Children First Initiative, Norwich, CT

Family Development Center, Manchester, CT

Family Focus, Bath, ME

Family Service of Greater Waterbury, Inc., Waterbury, CT

Healthy Families Androscoggin, Lewiston, ME

Most of all, we wish to express our appreciation to the parents and guardians who participated in our focus groups and interviews and who went to considerable lengths to attend the sessions and share with us their personal experiences with raising a child with special needs, and balancing work and family. Confidentiality prevents us from thanking them by name but without their candor and insights this report would not have been possible.

The photographs on the cover of this report are for illustrative purposes only and bear no relationship either to the individuals who participated in our focus groups and interviews or to any member of their families.

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Introduction

Background

Child Care and Children with Special Needs: Challenges for Low Income Families, is a project of the Child Care Policy Research Consortium, supported by the Child Care Bureau, Administration on Children, Youth and Families, U.S. Department of Health and Human Services. While the primary focus of this research is access to child care by low income families of children with special needs, we are also looking at the related issues of welfare reform, the impact on work force participation of having a child with special needs, and the issue of coordination of early intervention services with the child care system. This is a three-year study which began on October 1, 2001.

Because this inquiry cuts across so many policy arenas—child care, welfare reform, early intervention and preschool special education, as well as other ancillary but relevant issues affecting these families—we decided to spend the first year of our study conducting qualitative, exploratory research with families of children with special needs. This phase of our research was useful in several respects. First, by gaining an understanding of these issues from the families' perspective, we were able to obtain a more holistic understanding of how services are designed and delivered at the local level.

Second, what we learned from this initial stage has permitted us to design appropriate methodologies for the remaining years of our three-year project. In light of the complexities of the policies which affect these families, we have developed a mixed method approach which will produce richer information and enable us to make more effective policy recommendations when our research is completed. We believe this combination of qualitative and quantitative methods is necessary to gain a more complete picture of the experiences of these families and the policy implications of the issues they raised in our discussions.

This is a preliminary report and is meant to provide only an impression of the emerging themes of our research. It is based on conversations with parents who represented a total of 39 families. Despite intensive recruitment efforts (described in greater detail in our section on methodology) we experienced significant difficulty reaching this population. The reasons for this became apparent when we conducted the focus groups and in-depth interviews. The high levels of stress and the complications of these families' lives made it very difficult for them to come to a session. Those who did come, however, seemed grateful for the opportunity to speak with us and provided us with rich and consistent information.

Because of our small sample, we are also not able to discuss policy implications or make any policy recommendations at this stage. As described in our methodology section, the qualitative and quantitative data we are collecting in our second and third years will supplement this information and provide us with a sound basis for making policy recommendations in our final report.

Contents of this report

Methodology: This section explains in detail how we carried out this phase of our study and also describes how this research is nested in the larger, mixed method study we are conducting in Maine. Recruitment methods, eligibility criteria, and limitations of the data are discussed.

Profile of the Population Studied: This section contains a profile of the families represented in our focus groups and in-depth interviews on a variety of factors including their socioeconomic status, race and ethnicity, employment, type of disability, etc.

Parents' Voices: In this section we analyze the transcripts of our conversations with the parents and organize their quotes by the major themes which emerged. Each quote is identified by the relationship of the speaker to the child and the exact diagnosis of the child's disability as given to us by the parent. A number of these families had multiple children with special needs but since our questions were directed toward that child under age seven with the most severe special needs, as identified by the parents, we only included information about that child. To help ensure confidentiality, we also did not identify the community or the state where that family lives, and in some cases, we changed the gender of the child.

Vignettes of Selected Families: In many ways, a written report of these findings cannot adequately convey the impressions we received firsthand from talking to these parents. So much of the emotion involved in these issues does not come across on paper. Nor can the reader glean from a collection of quotes organized by theme, the "gestalt" of each family's life. That is why, in addition to discussing major themes and grouping quotes under those themes, we include vignettes which we hope will enable the reader to have a better sense of the daily lives of some of these families. In these vignettes, we changed the names and, in some cases, the gender of the children and have not identified the state of residence in order to protect confidentiality.

Glossary: Many of the children referenced in this report have diagnoses or complex medical needs that may be unfamiliar to a layperson. Accordingly, we supply a glossary of the terms that have been used in the quotes and in the identification of the disabilities of the children in our sample. We have also included here brief descriptions of the programs parents referred to in their discussions with us.

Emerging themes

What impressions did we come away with after speaking to these parents? First and foremost, we were struck by the degree to which the laws and missions of the various agencies delivering services to these families seemed to conflict and how these differences were pulling parents in so many directions at once. For example, while staff in one agency were encouraging parents to become employed, staff in another were encouraging parents to stay home either because it was easier to deliver special services to their children that way or because, as several parents were told, no child care provider would ever be able to take care of their children. While one agency was providing child care so parents could work, another couldn't provide the support the child required to be in that setting for the requisite number of hours the parent needed in order to be employed. While comprehensive programs in some ways seemed better designed to reflect the need for parents to work by providing special services on site, many offered only part-day or part-week coverage and access to these programs was extremely limited, especially in rural areas.

Despite these challenges, most of the parents we spoke to were remarkably resilient and spoke movingly of the rewards and life lessons gained from caring for their child with special needs. We were impressed by this resiliency since our impression from the stories these parents told us is that the system, as currently structured, has not made it easy for these mothers and fathers to meet their obligations as parents.

We hope that these and the other findings that emerge from our research will help bring the voices of these parents into the debates about child care, welfare reform and special education that are taking place at the state and federal level. Our aim in conducting the research in the manner we did, was to emphasize for policy makers the importance of looking across policies and programs to understand how the system as a whole affects this population of children and families. By focusing on the families' experiences first, and then looking at all the sectors of the system which serve them, we hope by the end of this project to provide a sense of where inconsistencies in policies, gaps in services and fragmentation of programs may be making the work/family balance for these families more difficult. We also will identify models of integration of services here in Maine and elsewhere in the nation which have shown promise in supporting parents' responsibilities to meet both the economic and emotional needs of their children.

Methodology

This report represents the first, exploratory phase of a larger study to learn about the experiences of low income families of children with special needs in finding and keeping child care and balancing work and family. Our interest in this area focused on a number of policy arenas including the child care system, workplace policies, welfare reform and the system of early intervention and special education for children zero to five. We recognized that all of these programs and policies affected employment decisions and strategies and the ability of parents to balance work with the needs of their families. Given the complexity of our study, we chose to begin by conducting qualitative research with families in order to explore what issues were involved and what methodologies in the larger study would best address those issues. Therefore, 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 20th and November 13th, 2002.

Limitations of our data

It is important to note that the information in this report is based on interviews and focus groups involving only 39 families. And, our sample was not randomly selected but made up of families who responded to broad-based recruitment efforts at the grassroots level which are described below. While the issues identified and the opinions expressed were remarkably similar across the focus groups and interviews, caution still should be exercised in weighing the significance of the themes we have uncovered. These are the opinions and experiences of these 39 families and cannot be applied to any larger population. These preliminary data also cannot be used to make any comparisons between states. Given this reality, and the desire to preserve confidentiality, we have chosen not to indicate the state of residence for parents when they are quoted in this report although in a few instances we recognize that references to specific locations or programs in the quotes themselves will reveal the state in which parents live.

The qualitative research reported here is nested in a larger, ongoing study of this population

The focus groups and interviews we conducted in our first year and are reporting on in this preliminary report are part of a larger, ongoing mixed method study of this population. Initially, we chose to conduct this study in two New England states, Connecticut and Maine, because they represented important contrasts in policy and in demographics. We chose six communities, three in each state, from which to

recruit families for this phase of our study and then conducted our focus groups and interviews in those communities. At the end of the first year, however, we made the decision to limit the rest of our research to Maine. We did this for two reasons. First, a literature review to update our knowledge of research completed or underway elsewhere in the country, led us to believe that we could make a significant contribution to the existing research on this population of families by focusing on how *rural* issues might affect child care and balancing work and family for low income families with children with special needs. Secondly, our experience with recruiting families in both states led us to the conclusion that within the resources we had available, we would not be able to draw a large enough sample to make any valid comparisons of programs and policies between the two states.

In our larger study, we are combining qualitative and quantitative research, guided by what we learned from parents in the first year, to present a more definitive picture of how issues of access to child care and delivery of early intervention/special education services affect employment and the balancing of work and family for low income families of children with special needs. Research for the second phase of our study includes statewide surveys of a random sample of parents and child care providers in Maine and a field study of three Maine communities involving interviews with child care providers, case managers for the state's program of early intervention and special education services for children younger than school age, caseworkers for the state's welfare to work program, ASPIRE, case managers at the agencies that contract with ASPIRE to serve families with multiple barriers to work, staff at the child care resource and referral agencies, and staff of an initiative to help child care providers serve children with special needs. Our second phase will also include analyses of large national data bases to see if what we learn here in Maine is bolstered by national research on these same issues. We will incorporate the stories told us by parents in this report into our analyses and report of all of our findings at the end of this project.

Advisory Committee

Throughout our research we have benefited from the wise counsel of our Advisory Committee. These individuals were selected both for their multi-disciplinary expertise and their knowledge of the communities we were studying in Connecticut and in Maine. In addition to advising us through all phases of this project, individual members also made presentations to the Committee at the beginning of the grant period on the policies and programs operating within their states so that we would have a fuller understanding of the issues which might surface when we spoke to parents. The members of the Advisory Committee are listed in the beginning of this report.

Research questions

Research questions, developed and refined by our project staff, were created to guide the entire process of conducting the focus groups and interviews. These questions were critical to all aspects of the methodology of the project because they informed the identification of the population to be included in the focus groups, the communities in which focus groups would be held, the content of the recruiting and screening materials, and the development of the focus group and interview questions used by the facilitator and the interviewers during the sessions. Our research questions are as follows:

Broad Research Questions:

- What are the experiences of low income families with children with special needs in finding child care and balancing work and family?
- What constellation of supports make it possible for these families to work and successfully balance work and family? What are the triggers that cause things to fall apart?
- What is the economic and emotional impact on the family?

Questions Specific to Policy Areas:

- Is the system of child care referral, subsidy and provider training and support adequate to respond to the need for child care by low income families with children with special needs?
- Do workplace policies accommodate the circumstances of low income families with children with special needs?
- Do the policies under welfare reform accommodate the circumstances of low income families with children with special needs?
- Does the manner in which early intervention and preschool special education services are delivered reflect the needs of parents to maintain employment?

Selecting the communities

We selected geographic areas and communities which allowed us to make rural and urban comparisons and which had a sufficient number of low income families with children with special needs. Our selection of the communities was based on demographic information from aggregated data sources such as KIDS Count, census data, and the Current Population Survey, as well as administrative data on the programs which serve this population. Additional information about the communities under consideration was gathered from our Advisory Committee members whose advice we considered when making our final selections.

Communities Selected:

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

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.

| Focus Group Sponsors | Community | Sponsor |
|-----------------------------|------------------|--------------------------------------------|
| | 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 who did not have children with special needs. However, we failed to realize just how time consuming this recruitment effort would be. Participants (parents/guardians) needed to have at least one child under the age of seven 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 hoped 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 also would 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 barrier to access to child care and/or have an impact on parents' employment.

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 working and nonworking parents whose children were or were not in some form of child care arrangement. The list below reflects the variety of recruitment sources we used for posting and handing out flyers, placing ads and making presentations in our six communities:

- Churches
- Laundromats
- Community Centers
- Libraries
- Supermarkets
- Town Halls/Town Offices
- Bus Stations/Bus Stops
- Pharmacies
- Hairdressers
- Video Stores
- Court Houses
- Convenience Stores
- Fast Food Restaurants
- YMCAs
- Boy's and Girl's Clubs
- Thrift Stores
- Community Health Centers
- Hospital Outpatient Clinics
- Child Care Centers
- Pediatric Health Centers
- Human Services Centers
- Child Development Centers
- Catholic Family Services
- Program for Displaced Homemakers
- Community Colleges
- Town Social Services
- Department of Children & Families
- Adult Education Centers
- Youth and Family Services
- Catholic Charities
- Cultural Centers
- Easter Seals
- Housing Authorities
- Career Centers
- WIC/Nutritional Programs
- Home Health Agencies
- Navel Base
- United Ways
- Community Action Programs
- Soup Kitchens/Food Pantries

In addition, flyers were also sent home in elementary school children's backpacks, mailed to all child care providers 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.

To aid in these recruitment efforts we hired two field workers in Connecticut to post flyers and meet with our co-sponsors when necessary. These graduate students were trained by our staff and participated via conference call in our weekly staff meetings. Our research staff did all of the field work to recruit parents in Maine.

Screening and registration

A screening instrument was constructed and two of our researchers split the task of screening potential participants. Screening those who responded to the recruitment materials was important to ensure the families fit the criteria we established. The instrument asked respondents questions which gave us some background information on the family and whether they met our eligibility criteria in terms of income and age of the child with special needs. The screening instrument also ensured uniformity in how the project was described to parents and how they were informed of confidentiality.

All participants were required to fill out a registration form before the start of the focus group sessions. This allowed us to collect more detailed information than was possible during the screening process. The registration data gave us a profile of our focus group population and assisted us in matching statements made in the focus groups to the individual circumstances of the participant when the transcripts were analyzed.

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 nonparticipants 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. This allowed the research team to evaluate our instruments—particularly the protocol of questions used by the facilitator. The pilot also enabled our research team to assess the logistical aspects of our approach.

All focus groups were facilitated by Linda Rich, an experienced facilitator the research team had worked with on a previous project involving low-income families. A protocol was used to ensure that questions were asked in a similar way and in a similar sequence.

| Focus Groups | Community | Number of Groups Held |
|---------------------|------------------------------|------------------------------|
| | Manchester | 2 |
| | Norwich | 1 |
| | Waterbury | 1 |
| | Lewiston/Auburn | 2 |
| | Presque Isle | 1 |
| | Total Number of Focus Groups | 7 |

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 go on with the next phase of our plan—in-depth interviews.

These semi-structured interviews had many of the advantages of focus groups but allowed us to gather more detailed information. The in-depth stories gained through this methodology were invaluable to gaining a more thorough understanding of the lives of the parents. 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 the end, we held seven focus groups and conducted 20 interviews for a total of 39 families represented.

| In-depth Interviews | Community | Number of Interviews Held |
|----------------------------|-----------------------------------|----------------------------------|
| | Manchester | 5 |
| | Norwich | 1 |
| | Waterbury | 1 |
| | Lewiston/Auburn | 6 |
| | Presque Isle | 4 |
| | Bath/Brunswick | 3 |
| | Total Number of Interviews | 20 |

Data analysis

Focus groups and interviews were audiotaped and transcribed. As previously mentioned, a note-taker also attended each focus group session 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. Using this software allowed for efficient management of non-numerical unstructured data with processes for indexing, searching, and theorizing. It allowed our research team to code and search the qualitative data and to monitor and manage emerging themes.

Confidentiality

In order to work with human subjects, we had to receive approval from the Institutional Review Board (IRB) of the Office of Research Compliance at the University. The IRB is a standing committee comprised of professors, physicians, and community members who ensure that research involving human subjects is well planned and ethical.

Confidentiality was stressed throughout the process; it was discussed during the screening process and at the beginning of each interview or focus group. Consent forms were signed by all participants. These forms stated that the identities of the participants would be kept confidential. All project staff members signed statements promising to honor the confidentiality agreement. Information entered into databases and names in transcripts were coded so they could not be attached to the statements made by participants.

Profile of Focus Group Participants

n=39 (CT=21, ME=18)

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
- 50% (19) have a spouse or partner
- Average of 3.6 people per household
- 79% (30) Caucasian; 13% (5) African-American; 8% (3) Hispanic/Latina
- Average number of children is 2.1
- Average age of child with special needs is four years old
- 58% (22) have some college or a college degree; 34% (13) are high school graduates; 8% (3) have completed less than high school
- Average annual income is \$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 seven with the most severe special needs*. These children were almost evenly split between those with primarily behavioral issues (53%, 20 children) and those with primarily physical issues (47%, 18 children). Many children had multiple special needs.

The most frequently reported disabilities included: AD/HD, 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. (See the Glossary for descriptions of these disabilities.)

- 58% (22) 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

- 66% (25) have their child with special needs in nonparental care
- Types of care primarily used for these children:
 - 20% (5) in their home
 - 20% (5) in school (3 children in nursery school and 1 child each in elementary and after school care)
 - 16% (4) therapeutic child care
 - 12% (3) Head Start
 - 8% (2) child care centers
 - 8% (3) in provider's home
 - 8% (3) didn't indicate type of care
- Average time in child care was approx. 28 hours a week
- Average payment for child care was \$83 per week

Early Intervention and Preschool Special Education Services

- 82% (31) receive services (speech therapy, physical therapy, etc.). Of those:
 - 44% (14) receive services in child care setting or at school
 - 22% (7) receive services both at child care and at home
 - 19% (6) receive services at home
 - 6% (2) receive services at the specialist's office or another location
 - 6% (2) didn't indicate location of services

Work

- 53% (20) of participants work outside the home. Of those:
 - 65% (13) are employed full time
 - 35% (7) work 2nd shift or nights
 - 55% (11) have no sick days
- 92% (11) of the 12 spouses or partners who are employed work full time outside the home. Of those:
 - 50% (6) work 2nd shift or nights
 - 33% (4) have no sick days

Income/Public Benefit Programs

- 40% (15) are on TANF or receiving some type of assistance (Food stamps, etc.)
- 57% (21) receive SSI
- 31% (11) receive child care assistance

PARENTS' VOICES
Child Care¹

Parents were asked what their experiences had been with finding child care for their children with special needs and the degree to which their child care was meeting their needs and those of their children. From these discussions several major themes emerged. Many parents faced significant difficulties finding child care providers who were willing to take their children. Parents of children with more severe disabilities expressed concern over whether any child care provider could adequately meet the needs of their children. Our population included a number of parents whose children were cared for in programs that were either for children with special needs exclusively or which had a mix of children but had significant experience caring for children with disabilities. These parents seemed more satisfied with the care their children were receiving than the parents whose children attended regular child care programs. However, while their satisfaction with the care was greater, they complained that the limited hours of many of these programs made it difficult to get adequate coverage for their work hours. Lastly, many parents of children in regular child care programs expressed concerns over a lack of inclusion — they described situations where their children were excluded from the activities of the other children and/or ignored by the child care staff.

¹ See the Glossary for definitions of disabilities and medical terms and for descriptions of programs mentioned in this section of the report.

PARENTS' VOICES

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.

They wouldn't tell you that, "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 and maybe when some of them are transitioning out and they put you on waiting lists and then you never hear back from them. I called Infoline and they gave me listings in East Hartford and Manchester. Let me say 20 I called 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, "Yeah, 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

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

One parent said she didn't tell potential child care providers about her child's special needs until her 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 can't find child care.... or an after school program. Nobody will take her, because she is flipping 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

PARENTS' VOICES

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.

My sister watches my son. There weren't any day cares that were willing to take him. It is good that I trust her with my kids but she gives me a hard time sometimes. She is young still and she wants to live her life. So she is not always the greatest baby-sitter. But at least I know she knows how to do the medications. She knows how to do the catheterization, so I trust her. I can't just have anybody to do these things. She gets paid from the child assistance program to watch them. If I need someone else, it is always a family member or I have a couple of close friends. But then they don't know how to do the medical things. So I may have to do it before I go and then right when I get back. So they just watch him for a limited time.

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

When I work weekends sometimes my daughter watches my son. She comes home for the weekend but 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 baby-sitter. 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 I mean she was the worst baby-sitter I had. All she did was literally watch him. She took him off the bus and she watched him, if she wasn't watching TV.

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, you know. 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 my mom was the one holding her, you know. So I know my father would be able to handle the situation, because he has handled bad situations with my other daughter. But it is just unnerving to, you know, to just leave them and when you know you are the one that knows how to do everything.

A mother of a child with muscular dystrophy

PARENTS' VOICES

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 were not toilet trained. Some programs accepted these children but parents complained that they wouldn't change their children regularly. Still 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. 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

I had to pull my son out of child care because he wasn't being changed. The last day I saw him come home with a pretty yucky diaper rash I said, "We should pull him out, no ifs, ands or buts, pull him out." I thought this happened way too many times so no use going on because they were just going to keep doing it.

A mother of a child with Autism Spectrum Disorder

They don't change her. She is either in pull-ups or diapers in the school. She will be sitting there and she will get home at 3:30, 4:00 and there is a really bad mess. They won't change her, they won't clean her up. She goes to preschool, she's three years old. We are trying to do the potty thing. She goes to school from 11 a.m. to 3:15 p.m. During school hours if she gets snack or has lunch or something and she wets and the other kids go to the bathroom, they won't change her. 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' VOICES

Toilet training, medication and medical issues

The school my son goes to now—he started there just after he turned two and he wasn't potty trained. But they do an awesome job of keeping him dry and for maybe two years after he started maybe even more, I had him wear pull ups and I always let them know. We had a communications book. I said I am trying to train him and he doesn't always do it, but he has never, ever come home dirty and he has even had episodes when I tried to move him out of pull ups into training pants. He would have accidents in his pants and they put on somebody else's. They have pants they keep at school and they would put a dry one on him. It would probably be short, but it would be dry. They did ask if he was potty trained or not. They don't refuse them if they're not. They do an excellent job, they really do. I can't say enough about how attentive they are in the school system. It is a totally different ball game from day care.

A mother of a child with developmental delays

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

My son is on 19 pills a day and has been on them for over three years. That was another thing when you are looking for someone or places to help you and you tell them, he takes medication. I learned when I first came to Connecticut. There are only two people in the area who are what they call medication licensed. 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 reason I had to have my sister care for my daughter is because I could not find appropriate child care for her. I searched and I searched because I had to go back to work. I searched around and every place I called—because when she was younger she had a lot of medical needs. She had a feeding tube, you know, she couldn't get around, basically she was like in a coma all the time. My sister came then and she could watch her. Luckily, I have a really flexible work schedule so I can work around all the Birth to Three therapies and doctor's appointments and all that kind of stuff. But when I need to leave the house and I can't

take her, my sister is able to watch her for me for a couple of hours. The reason we chose that option was because I couldn't find appropriate child care. They would just tell me we're maxed out with children with special needs. First of all to find day cares that had the experience of dealing with children with special needs, there are very few of them. A lot of them were not close to me and some of them were very expensive, you know, the specialized ones are very expensive. Some of them you just couldn't get into because of waiting lists, and the majority of them just said that they could not take [her].

A mother of a child with Prader-Willi Syndrome

She 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

I tell them if you see him turn blue, or if he starts spitting you have to know he needs oxygen. You have to know, you have to do CPR, you have to know all these things. They [child care providers] are not going to tell you they can't take the child because of this. They will tell you, "Well no, we don't have a space right now." I have not seen a place yet that would welcome children with special needs. We were so lucky that through my job we were able to get a lot of equipment for my son. Because if they put him on a bed, he would be there for eight hours. He will not ask to be fed, he will not ask to be changed and you know I mean he is three and he is blind. You want to sit him, you want to stand him, you want to bring a little world to him. When you bring children to these places, they can't—it is a place where you bring children to play but they don't have it.

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

PARENTS' VOICES

Toilet training, medication and medical issues

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, whose hours got 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

PARENTS' VOICES

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 bring him in the morning and I sit him on this big area rug and I give him a big bucket of toys. When I come back to pick him up, he is sitting there in the same spot and nobody around him, the kids aren't playing with him, he just sits in the corner all day. 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. But I mean all of the other kids are outside. I just don't think it is fair. So I don't leave him there a lot.

A mother of a child with developmental delays

I don't have child care providers turning me away—they just stick him in the corner. [My son] was at the day care and he wasn't as active as the other kids and he would sit in a corner and they would just put him in the corner. He had to go outside for—I don't know, whatever the rule is—he had to be outside for 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 started looking out for stuff and I noticed they would put him in like a stroller and strapped him, a kind of restraint, strap him down and just leave him there. They had what you call circle. If they knew that the Birth to Three person was coming, they put him in the circle. They knew when he was coming because they knew the dates. So then he would be with the other kids. But if they weren't expecting us or if I showed up unexpectedly, he would be alone. Like one day it was his birthday, so I brought in some cupcakes for the other kids. He was in the corner, like so pitiful, you know. (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' VOICES
Lack of inclusion

Every time they have a nap time, my child is behind this bulletin board, by himself in a corner. All of the other kids are lined up in a row and I am like, "Why is that?" I asked questions, you know, to the teachers and they said, "He chose to do it." My child is a very outgoing child, very outgoing. I don't think there is difficulty finding child care. I think the difficulty is finding the right people to deal with the child.

A mother of a child with speech delays

My kid is special needs and as he has gotten older he has become way more independent but when he was one or two he didn't walk, he didn't speak and I'd go get him and he'd be in a stroller or something in the back of the room and they had a report each day "he ate this, he ate that." He never ate any of it because it was what they fed him but they put it in front of him and then they picked it up. So he would come home, I'd drop him off at 6:30 a.m. or 6:45 a.m. and I picked him up at 4:30 p.m. and all he would have all day was probably a glass of milk. When I found out, I decided to bring my own, you know, what I thought he would eat. They didn't have the patience to feed him, so it was just a mess.

A mother of a child with developmental delays

PARENTS' VOICES

Communication with child care providers

When asked about their communication with 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. I will write and tell them 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

He has been there two weeks. I go over every day instead of taking my lunch. I go there every day at different hours. I try my best to be involved in everything. I want to know everything he does. Send me a book every day that has notes of what he does. What time he ate, what did he eat? I want to know everything. His life depends on them. I watch that very closely as much as I can.

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

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

At school they think it's all right that I don't have the same things at home as at school. If he is not doing the same things that he is doing at school at home, he's thinking, "Well, I'm supposed to do it here, but at home I can do whatever." I think they are really good but they don't really tell me much. So I don't know what to do at home that they are doing at school.

A mother of a child with developmental delays

PARENTS' VOICES

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. She is like, okay do what you got to do and come back. I was bringing him to OT here, preschool, plus speech and after I bring him to all of those, I have to go back to work. It took me an hour to get focused again. Then I would have to stay overtime to make up my hours.

A mother of a child with Autism Spectrum Disorder

I think the bus ride is too long. Maybe now that he is getting older it is not as bad. But when he was just two, two and a half—like there is an 18-month-old (on the bus)—I think that is a long bus ride for these babies. It is a long time for them to be on that bus, strapped into a car seat. It is not like you are going on a trip, it is an every day thing. When you are potty training them, that is an impossible task, bus rides you know. They can't let them off to go to the bathroom if they have to go. I was a nervous wreck over potty training him. What is going to happen if he has to go and he is on the bus? He is not going to last that hour or hour and a half. He is going to end up wetting himself.

A grandmother/guardian 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 a.m. 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 20-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

Well if somebody paid me to stay home with my kids, I would. 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 when you think of it. I am still struggling with my car and all of my bills, just because for the last month I have been struggling trying to work.

A mother of a child with a cleft lip and palate

He has had so many appointments; we used to have an appointment every day of the week. You know, whether it was somebody coming to the house or usually it was us going somewhere.

A mother of a child with Pulmonary Stenosis

I am having a problem with the transportation situation with my youngest son. He needs certain things with the transportation. He gets sick very easily. He seems just to pick up everything because of his prematurity. I had a problem with the bus driver. She always had the bus freezing since school started. Raining, pouring rain out, and the bus is so cold that the kids are like shivering, they are all wet and I was getting nowhere with the bus driver. One day I said, you can't keep it so cold in here, this kid is going to get pneumonia and she just kind of rolled her eyes at me and didn't say anything. When you heard her speak to the kids it was like she didn't take into consideration that most of the kids on the bus were developmentally delayed. She would talk to them like they were fifth graders, "Sit down and be quiet" and just really rude, you know. I called the supervisor of the bus system. I said, "Look these are special needs kids, they can't be treated like that." Finally, after school has been how many weeks now, I have called three times a week since school started trying to get this straightened out.

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

PARENTS' VOICES

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.

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

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.

I think they do a great job. I think the teacher is very, very strict, sometimes to the extreme, but in a lot of ways it is what they [the kids] need. It is extremely structured, more structured than I can make it at home. Maybe because it's not their kids—you know, it is a program, there is just one of them, and you know, not just wanting the teacher, one person to deal with them. I think they have done a really good job.

A grandmother/guardian 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. Talking to my doctors and therapists everybody felt the [integrated] 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 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

He goes to school full days. They have what we call regular kids and kids with special needs in this mainstreaming program. He has just been there two weeks. It is hard putting him in a place where he is going to be there for six hours a day. It takes a life to know these kids and I just think what are they going to do with him? The other side of it is it's exciting. It doesn't matter what you do, you never could do the things the same way they do it for the kids. So it's exciting. It's too early to tell if it's wonderful but I think he is getting a lot. He seems good; there are a lot of good people there and he seems to like the children.

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

PARENTS' VOICES

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, 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 will be so much simpler if they just made it a full day and I know where he is at all day at school 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

One of the reasons why I don't have this special ed program [a part-day, part-week therapeutic program for children with special needs which provides speech and PT on site] for her is that I like to have those special ed services like her speech and the PT and the things I know she will need. But because it is a Monday through Thursday program I wouldn't be able to work. I don't work full-time, I work part-time but still, you know, she would go Monday through Thursday from 8 a.m. to 11:30 a.m. Which means during that time every single day I can't go anywhere or do anything. Sometimes my job requires me to be at meetings and things like that. I won't be able to do anything with that time frame. Whereas if she was in a regular preschool program two full days a week I can work, I can work around that.

A mother of a child with Prader-Willi Syndrome

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

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.

PARENTS' VOICES

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 employers were 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. 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

When I found out he was autistic he was around two and a half. So it took me a year to get all of the services. And I couldn't get all of them in one spot. They couldn't provide him with the therapies in one place. They didn't have openings. I was working full-time and I would have to tell my boss, I have to leave for a little while. My boss was very flexible about it. She was just really great. So I would drive him to appointments and then come back in the evening to make up the hours. My mom would meet me and pick up my son so I could get right back to work. But then my Mom moved out of state and I had to quit my job because I couldn't make up the hours anymore. I couldn't find a sitter for him, you know, because I ain't trusting just anybody the way he doesn't talk so I was stuck. Now my mother is back in Maine but I am still unemployed because I can't find a job that is going to work around his schedule.

A mother of a child with Autism Spectrum Disorder

I almost lost it because of the job I had which was a factory, 40 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

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 can never get an appointment for my son that works with my schedule so I 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 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 were 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 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

PARENTS' VOICES

Work disruptions

I just finished school. I almost didn't finish because of the day care. They were calling me and 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

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 was 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

My daughter needs more of my attention. I manage the restaurant. Sometimes it is hard because she will call me on the phone when she's home with her Dad and I am in the middle of rush hour. It is very frustrating. It stops the business basically. I have to put everything aside and say, "Okay, I will call you later and hang up the phone." I just have time to see if it is a legitimate reason. This happens usually twice a day. Then three or four times a week I get a call from my daughter's school and I finally had to put a stop to that. "Stop calling me at work. Call home and if I'm not there leave a message. They haven't really stopped. They keep trying to call. I still get three or four calls a week sometimes.

A mother of a child with Oppositional Defiant Disorder

Last year he was in a home day care setting, a licensed day care provider, and she knew everything to begin with, but now we had a real problem, his seizures weren't being controlled properly. The medication just was not settled. So he would have a seizure at the day care. And she couldn't handle it. She would call me. But his seizures weren't, I mean he was fine. She was just afraid. I guess you can't blame her, you know, it is not her kid. She is worried about liability or whatever. It just wouldn't work out and there didn't seem to be any day cares that specialized in special needs kids.

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

PARENTS' VOICES

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 son was on a long waiting list for child care and so my wife had to work nights so one of us could be home with our children. My wife went in at 4 p.m. and got off at midnight and boy that was not good. That was absolutely horrible. A typical day was that I was up at 6:00 or 6:30 in the morning and I went to work. Everybody in the house was asleep so I didn't get to see anybody and at about 4 p.m. she would drop both of the boys off with me at the office and she would leave for work. Then I would take the boys home and feed them, get them ready for bed, do our evening stuff and then we would go to bed. She would come home around 12:30, 1:00 and everybody was asleep and she would sit up for a few minutes and then she would go to sleep. Then she had Friday nights off, but then she would work on Saturday, and then she had Sunday off. That was for a year. Any little thing that wasn't just so in the beginning of the week, you spent an entire week thinking this person doesn't care about me. I don't care about her. This would go on for a whole week. It would escalate.

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

My wife and I work different shifts because of who is going to watch the kids. 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 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 don't like to leave him there a lot [because she felt the child care program wasn't including her child in activities]. 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 p.m. 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

When I first went back to work, my daughter went to day care and caught a cold almost immediately. It turned into Respiratory Syncytial Virus (RSV) and she ended up in the hospital. She was sick for two whole months. It was really scary. After she was finally cured from the RSV her cardiologist told us that she would have to remain in quarantine until we were out of RSV season and until we could set her up for heart surgery. They didn't want us to put her back in day care because they wanted her in optimum health and to gain as much weight as possible before her surgery. We could have put her in day care but we opted not to because we didn't want to take a chance that she would get sick again, lose weight and we would have to postpone the surgery. So she came to work with me. My boss was wonderful about that because she is small and could be tucked in the corner, that wasn't an issue. It was an all-girl office—there were mommies all over the place. Over the course of six months, she probably came to work with me forty days on and off—she was there three straight weeks at one point. I think part of it is that at the time the business I'm in, they were having a really hard time just finding people to fill positions. I've been there 13 years. I got a raise during that time period and I was thinking, man, I have missed three days a week for the last three months and I brought my daughter in the days that I wasn't out. So I think obviously I had a baby at a very good time.

A mother of a child with Down Syndrome

PARENTS' VOICES
Work strategies

My job has been really good. I am a school bus driver and when my son turned two months he came down with RSV, then pneumonia, then a worse pneumonia. We intubated for a week and a half, and it took them another week and a half to wean him off the medication, so we had to keep him trached for that week and a half and everything else. I missed my job. I had started two weeks before this all happened. I had only put in two weeks. I am still working there. They have no problem whatsoever. And my son can come on the bus, I don't have to put him in day care, I can take him with me. It is great, it really is.

A mother of a child with Epilepsy and developmental delays

PARENTS' VOICES

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 I had a responsibility 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 a.m. 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 work I was 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 40 hours and the pay is good and I have benefits so I can't quit.

A mother of a child with Down Syndrome

PARENTS' VOICES

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 18 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 40-minute drive—because my daughter's trach fell out. They had to find someone to come in and replace me. I worked 7 p.m. to 7 a.m. 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 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

PARENTS' VOICES

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 hope that somewhere down the line, 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 40 hours a week instead of 60. 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

PARENTS' VOICES

Welfare reform

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.

When you are a single parent, you don't have any other options. Okay, this is my option. I either put her in this day care 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 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 day care. 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

Now, I can't say we've [ASPIRE caseworker] been fighting, I have just really been trying to push, hold off. They want me to go back to work, really they told me I have to, but I had to put it off.... July was coming up and my son was going to be [out of school] and that was going to be close to impossible.... You say you'll try him in day cares, I don't know, he might be better now, but he gets really aggressive sometimes and he will bite or scratch and he couldn't go to a day care because he's doing

PARENTS' VOICES

Welfare reform

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.

those things. He has a lot of days off [from school] as many if not more than the kids in elementary school. What do I do on those days? Do I constantly miss work and get fired and then have a bad employment record? What do I do? Last winter came and he had pneumonia five times. That would have been a lot of work time missed. What do I do? The caseworker keeps telling me "You have to do something, you have to do something. He's not a baby anymore." Being a baby has nothing to do with this, it's about what we can and what we can't do.

A grandmother/guardian of a child with Autism Spectrum Disorder

ASPIRE has been great working with me and giving me leeway as far as how many hours [I need to work] and really counting [toward my work requirements] a lot of stuff that I do at the group home, like counseling hours [and volunteer work].

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

[The ASPIRE caseworker] called me and said I have to be working by the 19th of [August]. I am like, "OK, it's not going to happen, but all right. I don't know what they expect me to do." I explained that I have my son coming out of preschool going into kindergarten and a year and a half old [daughter], I need to find a day care placement [for both of them]. [They] act like it is just, go drop your kids off at somebody's house and there you go, they are fine. That is not as easy as it looks. This will be taken care of today because I'll explain to them the situation and let them know they can contact Child Development Services if they want to confirm what I'm saying [about my son's special needs]. And they will.

A mother of a child with AD/HD and speech delays

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.

PARENTS' VOICES

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 out-of-pocket expenses. The need for transportation to services and even to out-of-state facilities was another.

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

Because... his neurological care is taken care of in Baltimore, we have to travel there... we went in April for two weeks... then we went back in June and July and now we are going back for follow up in October. Where we used to live we were driving five hours to see a neurologist and we were going at least once, mostly twice or three times a month and that would take me out of work for three days at least.

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

I try my best to stay away from the system, asking for stuff. So I don't really get anything from the system, but in his case, if you are labeling him mentally retarded and you are saying that he is slower than other kids, help him get up to par. Don't hand money to me, just get the services that I can take him to. I will take him anywhere I have to get him the help he needs [but]... it is so expensive it is unreal.

A mother of a child with developmental delays

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.

Because my son receives SSI and with my wages, we make enough that [I don't qualify] for cash assistance. But we are still considered poverty, which in my mind I don't understand. With my parents helping me out, we are fine but if I were living on my own, I couldn't make it.

A father of a child with AD/HD, learning disabilities, Post Traumatic Stress Disorder and Auditory Processing Deficit Disorder

It is so funny, if you work, you are not entitled to anything because of that money. I actually had to spend half of my paycheck for the past two years for his medical insurance because the money I made, to them it was above the limit even though it wasn't enough for us. So... they want you to work, but when you work and you pass the line, you can't get it.

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

My daughter gets SSI, she is totally disabled. I worked for four months... they came to me and told me they were going to withdraw for SSI, so now she gets maybe \$150 a month. "How do you expect me to support her on that kind of money?" I said, "Are you asking me to go out and get a job under the table?" I don't want to do anything I am not supposed to do, but how do I survive? If I work, you are going to deduct it from the SSI. You are chasing your tail.... I don't understand what they expect you to do.

A mother of a child with Cerebral Palsy

PARENTS' VOICES

Special 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.

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

A mother of a child with asthma and a seizure disorder

Once CDS gets involved and they help you, it takes so long to get it done because the workers change so often. The workers change every few months. They have such a huge caseload that each child ends up slipping through the cracks.

A grandmother/guardian of a child with Autism Spectrum Disorder

The ones up here coordinate with each other, but Boston really kind of sticks to themselves and I have to coordinate information between [all of] them. I had Boston send his test results to me and in turn I sent it to his pediatrician. Sometimes I will suggest that they do a joint visit if I think that they need to talk to each other instead of me just passing things back and forth. Sometimes they will voice mail each other back and forth and then for a week one person doesn't check their voice mail. They don't go into their office very much because they have so many clients. [My county] is just overwhelmed with clients right now. Sometimes they are just on the go all of the time, going from patient to patient and they don't get time to go into their office and check all of that. So sometimes I have to go back and forth between them, and that goes a long ways.

A mother of a child with Muscular Dystrophy

The parents that said that their children's specialists were in contact with each other were generally satisfied with the situation. While some parents voiced frustration with the lack of coordination of services, others expressed satisfaction with the therapeutic services their children received.

The social worker said she couldn't find anybody. Well, I called around and I found somebody (OT and speech therapists) and my social worker is like, "Wow, really? I never knew they were open." And I am like it is because you didn't look, you know. It was like I was on the end of the pile, she has so much work that she couldn't handle finding somebody or she wasn't looking. So my son — within that month — just being home and having his services at home increased more than the last two years that he has been at school.

A mother of child with developmental delays

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

I just wanted to say, Birth to Three was awesome with me. I had close relationships to my workers, because they thought my son was going to die. This is what they told me after I left the program. ... they said they were sent to support me. I work with the school system and they are awesome with my kid. They give him everything he needs, all his medical things.

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

PARENTS' VOICES

Special services

I think our Birth to Three Program worked really well for us because I was a stay at home mom and I had the time and energy to devote to research things like respite and all those other things. And also because of the support that I got from our physical therapist. If it had not been for the outside support and the support from our physical therapist, there would be a lot that we would have lacked. I don't think I would have been prepared for the transition. Because Birth to Three is like a cushion. A lot of parents don't know when they cross to go to the school system, it is a whole different ballgame, there is nobody to hold your hand all the time. So a lot of parents aren't aware that they can ask questions and they can learn about this. So that is the reason why I think it has worked.

A mother of a child with Prader-Willi Syndrome

I think overall we are doing wonderfully. I think PT-wise, she is doing great. The physical therapist was wonderful in that while she was in quarantine and technically couldn't have PT, the therapist still came to our house, so that my daughter—she was getting into the fear of stranger age—so she would still know who the physical therapist was.

A mother of a child with Down Syndrome

PARENTS' VOICES

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 knew that there was something wrong with my son at 15 months because he started doing strange things and I told the doctor and she said, "No, it is just a typical kid." I said, "Listen to me, something is wrong." She kept saying "No, no, no." and finally I just lashed out one day at the doctor and I said, "Something is wrong with my kid!" Then my mother says, "No kid has ever done this, I have never seen a kid do this." That is when I started bawling. Finally we found out he was autistic.

A mother of a child with Autism Spectrum Disorder

Every day I was on the phone, and nobody believed that there was a problem. [They just said,] "She is young, she'll talk when she's ready" and I had to prove to them that there was something wrong. I just kept bugging them. They kept sending me to the wrong people.

A mother of a child with Oppositional Defiant Disorder

I was telling all of the counselors and psychiatrists 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. 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 them there every three to six months. It's hard enough being a single parent.

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

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

PARENTS' VOICES

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, 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 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

PARENTS' VOICES

Accessibility issues for children with physical special needs

Parents of children with physical special needs described the challenges faced by 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.

You know, [a child with special needs] is not something that you expect to have. You build a three-story house and you expect, oh I will be able to walk to the top floor and enjoy the view, but no, it doesn't happen that way. You buy a four-door car, and you say, "Oh yeah, that will be perfect." Then a four-door car really means you need to have a van, and then a wheelchair accessible van. You have to buy a new van because they don't want to convert an old van and the conversion is \$5,000. Who is going to pay for that? Insurance won't cover it, because it is a convenience item. Then you have a house with a shower and not a bathtub because you think everybody will take a shower. Well, we need a bathtub, because he is three and a half years old and he needs to have a bath, not a shower, because he doesn't stand.

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

I have a three-bedroom handicapped accessible unit, which is subsidized—it goes by my income. You know, first of all it is not really handicapped accessible. We are on top of a hill. My son, if he goes outside in his wheelchair, he is rolling down the hill. They don't think. It is like, they are making it accessible, because it is a ranch style, but other than that, what is accessible about it? Do you have some bars in the bathroom? Well, where's the roll in the shower?

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

I asked my social service 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

PARENTS' VOICES
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.

PARENTS' VOICES

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.

I honestly believe that having a child or children with special needs, you will never be able to meet all of your needs. There is always something that comes up when you meet one need.

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

This summer we started having the seizures, it scared the daylights out of me. She was not responding. I had to lift her up while she was in this catatonic state and I didn't know what to make of it. I just kept praying, "Please Jesus, don't let her time be up." And we went to the emergency room.

A mother of a child with asthma and seizures

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? 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

[Caring for my son] is stressful, really stressful. It is a *lot* of work. It stops you from doing some of the things you want to do because you know of his actions and his behavior and what he is going to do. It isn't easy and there is a lot of stress, a lot of aggravation, a lot of time. I just hope that I can set an example for people who have children with AD/HD that they just keep going at it. Don't stop. Keep going. It's a hell of a ride so hold on!

A mother of a child with AD/HD and speech delays

Parents seemed to be burdened with frightening “what ifs?” and worries about their child’s future along with their more immediate 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.

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 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

He was never a good sleeper, but it got worse, a lot worse, and I couldn’t sleep an hour or two each night and then go to work, be up all day and then up all night again with him. I was really 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. I am more tired than I have ever been in my life and still go through every day. I just didn’t know anybody could be this tired and function every day.

A grandmother/guardian of a child with Autism Spectrum Disorder

My children — my two healthy children — there are times they think it would be great to pick up and go, but 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

I didn’t know how to take care of her [behavioral] special needs. I think she felt that and I think she knew in a way that I wasn’t very good with consistency and limit setting. Then one day I just broke down and said I can’t do this anymore, I can’t take care of her the way she needs anymore. I felt awful.

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

PARENTS' VOICES

Caregiver stress

Sometimes it feels like you are losing power as the parent because this child pretty much rules your whole life. Your world revolves around how he wakes up that day, what kind of morning he will have.

A mother of a child with speech delays

He had been hospitalized for breathing difficulties. I thought at one time when I was taking him to the hospital I didn't think we were going to make it and that is scary to think you are to going to make it to a hospital and your child is going to die in your arms. I am at work, I wasn't providing his care, so I had a hard time trusting people—that they were going to look for these things. When my other boys were younger and there were so many appointments for my son, my whole week was run around him and getting here and getting him there and trips to Bangor—more medical appointments than the average child. It was hard to coordinate services so that everybody was on the same page or try to get this child a consistent schedule and that has been difficult. We all have our schedules and he is not the only child out there, but try telling that to him. And you know, a parent is trying to fit in their life, too, with everything.

A mother of a child with Down Syndrome

I would try to grab a nap for two hours, actually I just dozed. I knew I couldn't do it anymore [work nights to care for him during the day because of a lack of appropriate child care] because I was falling asleep on the way to work, falling asleep coming home. Sometimes in the mornings, I would stop in traffic and when I realized there [are no cars] in front of me—I don't know how long I have been there—it was really bad.

A mother of a child with developmental delays

It is hard. I can't go to the store by myself with my son to do groceries because in order to get him in the cart and be able to get groceries, more than two or three things, I need a second person to be able to help me put his legs in the car. He has a wheelchair, but I can't get it in my car. I think it's hard because if you don't have anybody [to help you], you never get time to yourself.

A mother of a child with developmental delays

PARENTS' VOICES

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

My mother is the most active. My dad will do transportation, he will do meals. But a lot of it, because he is older and he has gone through a lot, during the evening he will shut himself in his room and my mom takes an active role. She is doing more the paperwork end of it now, more of the background, the checking into what needs to be gotten and I with the school and everything I always say, "Okay, what would you like me to do to help you out to take some of that off of you?" I, on the other hand, I get home, I deal with taking care of them from when I get home to when they go to bed.

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

[My mother] has no problems with it [caring for the child with special needs]. She raised four children and she actually took a fifth foster child in, so she has no qualms with this. She actually does a very good job. She is very meticulous. "He had a seizure from this time to this time. He ate this." She documents everything and gives it to us, "Here, this is what happened."

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

No, I don't talk to any of my family very much about it. I have a friend who has been a friend for, well a friend of both mine and my fiancé's. He kind of fixed us up together and he has been around a lot this time with my daughter. He is her godfather as well. He was one of the people that was our best friend and never came around [when they had their first daughter], you know, even being the godfather. I think he was

PARENTS' VOICES

Extended family can be a help or a source of tension and hurt

scared of the situation. He has talked to me since and said that the reason why he couldn't come over was because he felt bad for us. Then he felt bad for feeling bad for us, because he knew that we didn't want him to feel that way. You know, he would feel bad for the baby and, you know, he just, he said that he hurt inside to see her like that. But he will come over and get right down and play with my daughter for like a half-hour before he will even acknowledge that my fiancé and I are in the room.

A mother of a child with Muscular Dystrophy

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. Hospitals have 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

You know, even though she has Downs, she is still a baby and I think that is the hardest issue as far as his family goes—seeing her as a baby before seeing her as a baby with Downs. They are seeing her as a Downs baby whereas I am seeing *her*.

A mother of a child with Down Syndrome

All of the family will readily take care of our child without special needs, but they are kind of 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

It is hard a lot of times. I don't know when he is going to live till, but I want him to live the happiest life he can until whenever. It is hard sometimes because a lot of people don't understand because they don't have a kid with special needs, even my sister. This is your nephew, but as a mother, you don't know what it feels like to go through things, the feelings sometimes. Like, am I going to wake up and he is going to still be there and things like that.

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

They just wanted my child with less severe special needs all of the time. His [father's] parents were the same way. They didn't want our child with severe special needs.

A mother of a child with learning disabilities

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

There's even some friction with my sister and I. If I have a really bad day, I am having a bad week and he is not sleeping, I am exhausted, I start to cry or whatever. Her answer is, "Well, you are the one who asked for it, you are the one who took this on, it is your problem." Be a little supportive, you don't have to throw this at me, you know. It can cause a lot of stress and I end up resenting her for saying that. How can you say that, you won't even baby-sit because of the way he is. I asked for this, so I deserve not to sleep, not to get a break? I had to be at the hospital, I was supposed to have surgery and I had to leave because my sister wouldn't watch the baby any longer. I had to cancel the surgery and put it off, until my daughter could come up. It is really hard. And that is a huge fear, getting sick. Who is going to take care of him if anything happens to me? That is such a big thing and it's always in the back of my mind. If something happens, who is going to do this, when nobody wants to baby-sit, nobody wants to do anything.

A grandmother/guardian of a child with Autism Spectrum Disorder

PARENTS' VOICES

Extended family can be a help or a source of tension and hurt

It was odd at her funeral [of her first child] there were a lot of people there. I think it was the second biggest one that this funeral home up there had seen. There were 500 people there. It was good that everybody came to support us, but for some of the people, or for a lot of people, it was the first time that they had seen her, you know, was when she had passed away. That was really hard for us because we could have used their support while she was alive, you know, and it would have been so much easier. The people that did get to know her, and were able to be comfortable around her, would come to us and say she is an angel. It felt really good to have that feedback, you know, how the outside world kind of sees you. But you have best friends that you grew up with that distance themselves because they feel bad for you. They will come out and tell other people and you kind of hear it through the grapevine that, you know, they feel uncomfortable being there. It makes me feel uncomfortable that they are uncomfortable. But I don't want to have to stop my life and stop the way I am living, just to make them feel comfortable.

A mother of a child with Muscular Dystrophy

PARENTS' VOICES

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. 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

When he is screaming you can't get through to him, you just have to pick him up and he is screaming and kicking and pulling my hair and scratching my face so I have to restrain him as I am walking out of the store. He is strong. It takes two of us. People are looking at you like you are abusing this child and [I] fear that somebody is going to call the police on me while I am going out to the car. Public awareness [is needed] that you are not always hurting your child, sometimes these things have to be done.

A grandmother/guardian of a child with Autism Spectrum Disorder

PARENTS' VOICES

A lack of understanding in the community

He kept having fractures [as a result of his special needs] and I would bring him to the emergency room and they would say, “Someone is abusing him. We might have to get family services involved.” I said, “I don’t care what you do. It [his history] is documented in your hospital so go check it out.” They just look at me like I am this bad mother.

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

They had the school call the police because my daughter was truant. She goes to school but she is late [because of problems getting her ready on time due to behavioral issues], or sometimes I couldn’t bring her [at all] because she is flipping out. Then the truant officer, they call the police, they call the judge. [Now] you’ve got to go to court because child welfare is involved.

A mother of a child with Oppositional Defiant Disorder

[Leaving the hospital after my son was born], one of the nurses came in and asked if I was going to get the pictures done. I had already talked about this with my fiancé. At Wal-Mart, they are a lot cheaper. So I said, “No, I am not getting the pictures done here.” She said, “Are you going to wait until after the surgery?” I just really felt like getting up out of that bed and just smacking her in the face. It was just such a hit to me, her thinking that I didn’t want pictures of my son because he was born with something different. That just really hit me so hard. That is one of the reasons why I want to be a nurse.

A mother of a child with a cleft lip and palate

Because people see him screaming and biting me and having a fit on the floor—we call it the Wal-Mart fit—they think that there might be more to it than they are seeing. It is a spoiled brat and I am a bad parent. There is more than you can actually see. It is not, “Well, if you didn’t spoil him so much.” If I didn’t have to listen to that from people! [I wish] that people would be more understanding, but that isn’t going to happen. It just doesn’t happen that way.

A grandmother/guardian of a child with Autism Spectrum Disorder

PARENTS' VOICES

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.

I've got to do what I've got to do. 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 who knows, not getting the services they need, because there are so many doors slamming right in front of you.

A mother of a child with speech delays

There is so much going on we don't have enough time to check into all of the avenues [for services]. I'm sure there are other families going through the same thing.

A father of a child with AD/HD, learning disabilities, Post Traumatic Stress Disorder and Auditory Processing Deficit Disorder

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 [my caseworker] 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

So basically I have told them I know the law states that she is supposed to be in the least restrictive environment, which this one is not. And I've started to explore other schools and put in a couple of applications into those schools, but I know already the battle, and I hate to call it a battle, but it has already begun and we are not even [in elementary school] yet.

A mother of a child with Prader-Willi Syndrome

They make you [sign up for transportation services] monthly. So with this coming month, with a holiday, that Monday she won't receive therapy because it is a holiday for everybody so they are going to substitute Thursday. The transportation company said, "You can't call us until after the ninth." I said we are registering for the month,

PARENTS' VOICES

The stresses of navigating the system

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 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.

just switch that one day. “No, you have to call after the ninth.” If I remember. If you don’t give them 48 hours notice, they don’t come anyway. So if you don’t remember, you are out of luck and your child doesn’t receive services. So this is constant. You need a secretary for this work. It is crazy.

A mother of a child with Cerebral Palsy

It is my job to see that my son can be a productive citizen when he is an adult, so I need to give him these tools now for him to succeed. It is tough because one agency throws it to another agency and then this one throws it to another one and when I get frustrated with it and call to see what is going on, they say, “Well, you need to contact your case manager.” If they would just give me a straightforward answer!

A mother of a child with Down Syndrome

It is a full-time job taking care of all of this [paperwork]. With my son, you are dealing with Social Security. Somehow or other they manage to mess [income statements] up so we’ve got to go back and fix everything for them. We give them the income, we give them my white slips so they know exactly what is going on, but they still manage to mess it up. I am puzzled by all of this.

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

You have to stay on top of things. I try not to argue but I try to make a plan. You can’t stop his [special services] for two months, he’s going to regress, go right back where he started. You can’t put this kid in with [only children with special needs] all the time, you are making him worse. Sometimes they agree but sometimes they don’t. I have a real issue with this but it’s the system. What can you do?

A mother of a child with developmental delays

When we were in Birth to Three, they ask what your goals and dreams are. One of our goals for our daughter at the age of three was to get into a preschool program with typical children. The way it is supposed to be, fully integrated. So now for the school system to turn our goal around and say there is only one [special needs preschool program], we have to settle for this and we don't want to because it goes against everything we worked so hard to achieve when she was in Birth to Three. I just wish it wasn't such a struggle all the time. I wish the systems could change. I wish it could become more family friendly.

A mother of a child with Prader-Willi Syndrome

PARENTS' VOICES

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.

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

Their father, he blamed himself for what happened [our child being born with a special need] and he started using drugs and then he became violent. He was never there for appointments or things. I used to tell him, "It's hard because everything—your problem, the kids' problems—are on my shoulders. Sometimes I just want to take it off and put it on you for a minute." He couldn't understand that. He was very controlling. Nobody could touch the kids because he didn't want anything to happen to them. I had to do everything alone.

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

We were always together and then we were not together. I think it [her daughter's special needs] was just too much responsibility on him.

A mother of a child with developmental delays

Honestly, it [having a child with special needs] basically destroyed us. We are still married and everything. Hopefully when the kids grow up they will understand. AD/HD destroys a family; it breaks them apart if they're not careful.

A father of a child with AD/HD

On his days off, we might rotate sleeping [to watch our child], you know, “You sleep two hours, I will sleep two hours.” We pretty much stayed up as long as we could and then we would wake the other one up. That was really stressful on our relationship, not only on our family. It almost didn’t seem like a family.

A mother of a child with Muscular Dystrophy

My significant other was wonderful when my daughter was in the hospital and sick. [But when she came home] there is a lot of work. It got to the point where I had three kids and I don’t need four. You either got to make up your mind that you’re my partner in this or if this is too much, you can go. He said “I am here.” We continue to work and go to doctor’s appointments together. I can’t take anymore than what I have and if you are not helping, you are hurting. So my relationship is in the gutter.

A mother of a child with Cerebral Palsy

PARENTS' VOICES

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

With both my kids, it is the small victories; it is the little stuff, the little things that they do.

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

After I had my second child and we started to realize that she would have [the same illness], I kind of felt like I was an angel bearer, like God kind of put you on the spot. You are going to be the perfect parent for this baby and I totally think that all of us have been chosen in some way or another. I feel like it makes you more special than an average mom or an average dad.

A mother of a child with Muscular Dystrophy

My son is my definition of unconditional love. Right from day one he just has had a quality about him that is non-judgmental. He is not manipulative. It is strictly from the heart. He is the apple of our family

and I have watched all his struggles. Everything he has worked to accomplish and I don't take anything for granted anymore. Life wouldn't be the same. With everything, my son would be largely missed.

A mother of a child with Down Syndrome

I have to say having my daughter has really changed our family's life for the better. It has just brought us so much closer as a couple, as a family. I hate to say it, but it has been one of the best things that has happened to me personally, because now I am doing exactly what I dreamed of doing [for work]. I always knew that I wanted to work with families and children and help other families and you know, boom, it fell into my lap. It was a blessing. It wouldn't have happened if I hadn't had her. I feel like I have so much to give and learn. So it has been one of the best things—as hard as it has been—it has been one of the best things that has ever happened to us.

A mother of a child with Prader-Willi Syndrome

My oldest son has learned a lot from having brothers with disabilities. He is very caring. When somebody has a problem, he is the first one to help them. It teaches you to take one day at a time. It teaches you how to see the good in anything and appreciate things.

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

He has just taught me so much about life and that some of those things that people think are perfectly normal aren't important. There are so many little things that are just so special, that I took for granted with my other kids. They just pick things up so quickly and with my son, it's just a discovery, little things are just so big. Those little things can take all of the [hardship] away just for those few minutes.

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

My son [without special needs] is wonderful. He has a very caring, nurturing way, I think, because of his sister [and her special needs].

A mother of a child with Cerebral Palsy

PARENTS' VOICES
Suggestions

We asked the parents we interviewed to share with us what changes could be made in order to make their lives easier. Their suggestions ranged from changes in government policies and programs to an appeal for greater understanding of their children's special needs in their communities.

PARENTS' VOICES

Access and inclusion in the child care system

Many parents wished that the child care system was more able and willing to accept children with special needs and that the care provided allowed for children with special needs to be cared for with other children in an integrated setting.

Any child with AD/HD needs to have the option where they can go to a day care and get their needs met and not just go to a day care and play with blocks all day. Sending a child that has AD/HD to a regular ordinary old day care is not healthy. You never see an ad in the paper for a day care that specifies children with AD/HD. You would think the Department of Human Services would put something in the paper.

A mother of a child with AD/HD

My dream is to have a day care for children with any disability. I mean it is hard enough trying to work and make ends meet and taking care of the rest of your kids. I think parents need a place where they can bring their children in the morning and know that there are specially trained people to deal with their medical, developmental and social needs.

A mother of a child with Down Syndrome

They definitely need to get programs like day care that do accept special needs children and where they could be one-on-one with the child. There is nothing for special needs children in our day care.

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

I think if there was one thing I could change I would probably change that spot where “regular” kids and disabled kids stand. There is a lot of discrimination against kids with special needs. The minute they are sick, the minute they use meds, the minute they have a diagnosis, that puts them apart from the real world. If that could be changed to the point where you can go to a day care center or anywhere and you tell them that “This is what my son has” and they say, “This is what we could do for you” instead of saying “We can’t do that.”

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

PARENTS' VOICES

Easier access to information

The lack of centralized information or a comprehensive list of resources for parents of children with special needs was a source of frustration for many parents. They felt that they were missing out on critical services for their children simply because they weren't aware of them. It was especially frustrating when parents felt that even the agencies helping them were unaware of services in their area. Suggestions included a national system of services for children with disabilities and a special needs version of the yellow pages.

I think that there should be a national system in place to work with these kids. It is just so piecemeal depending on where you live, depending on how determined you are to figure out the different resources. If you are not a person with the resources to read all you can, find out all you can, it just seems there should be one system so that from the beginning, you're helped. Not depending on where you live and who you talk to and who your doctor is.

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

There are things that are there, but you don't know about them until somebody, until you start making phone calls. Nobody makes this knowledge [available] to anybody.

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

I just think the system has to be easier for us and to let us know what resources are there. A lot of times you don't know unless you talk to somebody else and even CDS, sometimes they just assume I know things. I don't know and I wouldn't, how would I know? There are a lot of resources out there that we need to be made aware of. Some of us are really stuck in limbo and we don't know where to go.

A grandmother/guardian of a child with Autism Spectrum Disorder

There really should be a yellow pages that these are resources [for children with special needs] in our community. I have always considered myself to be a resource person. I try to connect with all of these different things if I can find out about them, but you can't even find out about them because one is not telling the other.

A mother of a child with seizures and asthma

They need to work on the Board of Education. Whoever is there doesn't know what is going on or what it is to have a child with special needs. We are knocking on doors and they are closing all of the time. I am not asking for door-to-door service or for you to cater to me, but I mean, sit down and relate to me and see what I am going through.

PARENTS' VOICES

Easier access to information

If they can't give us the help, refer us to other people that should be helping. If we would stop every time we get our door closed, our kids would be home and not getting the services they need. It is ridiculous that you would have to call for three months straight for them to return your call. Even if they are not going to give me the service, treat me like a human being.

A mother of a child with speech delays

We need more vision on the part of the agencies for families in terms of the children. In the government agencies there should be more specialized doctors because they are the ones who could say how the children could be helped and what resources are necessary for the child. I would like to see a panel assigned that would identify what are the most pressing needs for children. Once that group puts out a study we can see where the resources should go.

A father of a child with asthma

The problem with all of these programs is that there is not one resource to coordinate. You have got all of these different places that offer this, this and this and I wish they would just tie it together, make it one huge building.

A mother of a child with AD/HD

I wish the systems could change. It all becomes about dollars and cents and not about the child. I wish it could become more family friendly.

A mother of a child with Prader-Willi Syndrome

I would like to have the tools to help him learn. He doesn't know his ABC's or his numbers. If I had the right information I could help him.

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

PARENTS' VOICES

Changes in policies and programs

A number of parents cited changes in specific government policies and programs or additional services which they felt would be beneficial to families with children with special needs.

My big thing is the ASPIRE program. They should be cutting people a little bit more slack. It is not that I enjoy sitting home constantly. I want to go to work, but I also don't want to go get a job and then have [my son] in day care and then him getting sick and me having to take time off all of the time or getting fired because he gets sick. [Her child is highly susceptible to illnesses because of his condition.] I have got to leave because nobody knows how to deal with it. I want to go to work, but due to him being like he is, I can't. I just wish they would understand that.

A mother of a child with Pulmonary Stenosis

I wish the maternity leave law was four months long and I wish that it was mandatory for all workers. I know that it is probably a hardship on employers, but you know, 12 weeks is not enough and it is unpaid.

A mother of a child with Down Syndrome

I think there needs to be more equipment. We don't have anything at home for him. He just sits and plays with his toys and stuff. We can't put him in a walker because he weighs too much to be in a walker now. So it would be great to have a walker and things that are equipped for older children, not just for small toddlers.

A mother of a child with developmental delays

PARENTS' VOICES

Social support

Parents cited the need for more social support to relieve the stresses of caring for children with special needs. Some wanted more respite care to allow them to take some time away from the responsibility of caring for their children. Others, particularly in rural areas, were eager for opportunities to speak to other families facing similar challenges and seemed grateful for the chance to do that through our focus group sessions. Still others wished that their communities, friends and families were more knowledgeable and understanding about the nature of their children's special needs and the challenges they faced as parents.

I just wish there would be times where someone would be able to come in on the weekends to watch the kids and I could get away.

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

I wish there was someone who would come over and just watch him, even if it was for two hours. I just want a break. Maybe if there was some place where we could go with all our special needs kids and have fun with the kids and the parents can share some of our feelings. Not always just having the bitter end from all of the stress from the day.

A grandmother/guardian of a child with AD/HD and developmental delays

Maybe some parents groups; we don't have those up here. Maybe more meetings, forums. Parents or guardians with special needs can come and find out what's there for you, things like that. Or somebody who would run a resource place, you know, we are here, this is here, this is here.

A grandmother/guardian of a child with Autism Spectrum Disorder

If there could be something like this, [the focus group session] where all of the kids could come. You don't have to worry about the children, they could all be in there playing and they can relax and share emotions like this.

An uncle of a child with AD/HD and developmental delays

I wish that other people were more knowledgeable. I wish people were much more open minded and willing to learn about stuff.

A mother of a child with Muscular Dystrophy

I wish people were not so judging. You can't take your special needs child in the store, going grocery shopping without getting dirty looks.

A mother of a child with Autism Spectrum Disorder

I think that employers have to work with the parents. You know, you can't have to decide can I put food on my table or am I going to this appointment? I am not going to neglect my child for a job.

A mother of a child with Down Syndrome

I wish there was more public awareness. Sometimes, my child wants something, and sometimes telling him "no" just doesn't cut it. He will start screaming and throwing himself on the floor. The looks you get are terrible. We need more public awareness that sometimes these things have to be done.

A grandmother/guardian of a child with Autism Spectrum Disorder

Martha

Martha starts her day at the crack of dawn, when her only son, Matthew, wakes up and cries for food and attention. Her son was born with a condition which leaves him highly susceptible to infection. In addition, Matthew displays challenging behaviors which have sent his mom to the emergency room on more than one occasion.

A typical day for Martha involves driving over 30 minutes to take Matthew to any one of a number of developmental services. On Fridays, Martha feels fortunate that her mother is willing to care for her son so that she can have a few hours to herself. Although she would like nothing better than to get a job or go to college, Martha has been cautioned by her doctor not to place Matthew in day care because of his fragile health. While she loves her son, it is a challenge to care for him full-time, and she misses the satisfaction of working. She is anxious for Matthew to reach a level of medical stability so that he can attend Head Start.

Martha began working when she was 15 and continued right up to the day she went into labor with Matthew who was born four months prematurely. Once she learned of the intensive nature of Matthew's health issues, Martha applied for and received TANF assistance. This enabled her to care for Matthew full-time. Now, however, she has been told by her caseworker that she must find child care for him even though her pediatrician has warned her against it because of his susceptibility to infection. She has one month to begin the process of looking for a job. She doesn't know how she will meet that deadline.

2 To protect confidentiality, all names in this section have been changed and in some cases, the genders of the children have also been changed. For definitions and descriptions of the disabilities, medical terms and programs mentioned in these vignettes please see the Glossary.

Alice

Alice is the single mother of a five-year-old boy, Nathan, who is confined to a wheelchair, faces multiple health challenges and has significant developmental delays. In order to earn enough money to support herself and her child and avoid being on public assistance, Alice has to work three jobs. In between her hectic work schedule and taking care of Nathan, Alice is busy trying to track down services which will provide the adaptive equipment necessary to assist Nathan in gaining independence.

A typical day for Alice begins at 5:00 a.m., when her son wakes up. Because she needs to be at work by 6:30, Alice must drop Nathan off at child care at 6:15. A bus comes to the child care program at 7:30 a.m. to take Nathan to school. Alice pays for her son to be in child care for 20 hours a week, and could easily have Nathan bused back to the center after school finishes. However, Alice is worried about the lack of attention paid to Nathan at the child care center. On several surprise visits, Alice found her son sitting in the exact same spot where she had left him, away from the other children who were enjoying activities together. In the summer, when the other children were taken outside, Nathan was left inside alone with one staff person watching him. Because he was unable to feed himself, Nathan didn't eat a snack because the program director said they didn't have the staff to feed him.

Frustrated by this lack of attention but knowing that this is the only program in town which would take her child, Alice has decided to leave Nathan there for as few hours as possible. She picks her son up from school at 1:30 p.m. and brings him along while she goes to her third job, cleaning commercial offices. She pushes Nathan's wheelchair while she does her work. Alice's employer is not aware that she is taking Nathan to these job sites. Although this is tiring for her, Alice feels this is a better situation for her son's well-being than child care. Alice's work obligations do not end until 7:30 p.m., a full 13-hour day.

Sarah

Sarah is a young mother of two who is currently attending school. While her daughter Kaitlin is a normal four-year-old, her 18-month-old, Elizabeth, was born with a cleft lip and palate. A typical day for Sarah involves waking at 7 a.m., preparing breakfast, and driving both of her children to their separate child care situations before going to one of many classes she is taking to complete her degree. In the afternoon, she picks her children up, drives them home, makes them dinner and gives them a bath. At 8:00 p.m., she finally has a few hours to work on her homework, which she tackles until midnight. Because her child needs to be seen by a number of specialists in different locations, Sarah also must devote time transporting her child to these appointments and ensuring that all of these professionals communicate with each other.

Sarah used to have a full-time job as a CNA. However, Elizabeth's many surgeries and therapeutic appointments have caused Sarah to miss a significant amount of work, and, subsequently, her hours were cut. Because of this loss of income, Sarah was forced to apply for public assistance. Knowing that her obligation to ensure that Elizabeth receives proper services would likely prevent her from future employment as a CNA, she opted to apply for a program that would enable her to attend school and still receive TANF in hopes of improving her job skills and securing a better life for herself and her children. But getting there has not been easy. Sarah's first case manager initially balked at the idea of Sarah entering the program, saying, "We got you off of welfare." Before she would approve Sarah entering the program, she insisted that Sarah work 20 hours a week in addition to attending school full-time. With two children to take care of, one with special needs, and a full class load, Sarah knew there was no way she could fulfill the 20 hours demanded of her. After educating herself about the system and talking to others who had done the very same thing, Sarah became convinced that state guidelines would permit her to go to school without working the 20 hours. She stood her ground with her caseworker. Eventually, a new person was assigned to her case who understood the constraints she was facing and assured her that she did not need to find employment for the time being.

Carol

Carol is the mother of Jason, a four-year-old boy with Autism Spectrum Disorder. Carol wants, above all, for Jason to reach his full potential once he is in school. But Jason's needs have been challenging. Carol must contend with all of the behaviors often associated with children who are diagnosed as autistic. Hitting, tantrums, and head banging are frequent occurrences which can happen without warning. Carol wishes she had someone who would be willing to watch her son for a couple of hours so that she could have some time alone. Unfortunately, because of the intense nature of his behaviors, no one in her family, or among her friends, is willing to help her and she is left caring for Jason by herself.

There have been financial challenges as well. Until recently, the only child care arrangements Carol could find did not offer special services such as speech and OT on-site. As a result, Carol lost several jobs because her employers were not willing to accommodate her hectic schedule driving Jason to these services three times a week. Determined not to give up she searched for and finally found a job with an employer willing to give her flexible hours to accommodate Jason's schedule. Still, juggling a 40-hour work schedule along with Jason's therapeutic appointments was very challenging for Carol. While her boss was willing to be flexible when Carol needed to leave for an appointment, he insisted that she return after the appointment to make up any lost time, which often meant working well into the evening. Fortunately, Carol was able to manage this because her mother was in the area to provide some help with child care. Before long, however, her mother moved away and Carol's own health took a turn for the worse. Although she enjoyed her work immensely, she was forced to leave the position. Because of the severity of Jason's disability, Carol had been receiving Social Security payments which eased some of the financial burden, but it is hardly enough to support her family's needs. Fortunately, Carol was finally able to enroll her child in a special preschool in her community where all of his services will be delivered on-site. She will no longer need to transport him. Her health is returning and she feels that now she can look for a job, at least during the hours that Jason is in school.

Andrea

Andrea is a single mother of four boys. Her son, Peter, one of twin boys, age five, was born with multiple disabilities including Spina Bifida, growth hormone deficiency, osteopenia, and asthma. When he was born, the doctors did not believe he would make it past the first week. Now, his mother describes him as her “little angel” because of his positive attitude and gentle demeanor. Before the twins were born, Andrea worked a full-time job, but because of Peter’s intensive medical needs, the hospital doctors insisted she quit work to take care of him. Once Peter turned five, she went back to work for between 40 and 50 hours, depending on the week. She would like to find proper child care for her sons, but as yet no facility has been willing to accept Peter because of the many medications he takes, and his need to be catheterized. Instead, Andrea pays her younger sister to look after her children. On the one hand, she is grateful to have someone she knows and trusts take care of her son. She has trained her sister in all of the necessary medical interventions, and knows that she will make sure they are executed properly. On the other hand, she feels badly that her sister, who is young with two children of her own, is burdened with caring for her son. Fortunately, for part of the day, Peter is in a preschool program which provides him with all of the PT, OT and speech and medical services he needs. This saves Andrea from having to coordinate transportation to these services.

While Andrea is happy to be back at work, she worries about how little time it leaves her to be with her children. In her previous job, she had to work many extra hours to make ends meet. She only got one weekend off a month. However, Andrea has recently acquired a new job which she is excited about because she will get out of work earlier and she will have the opportunity to request more weekends off.

However much better her work situation might be, Andrea still deals with the challenges and emotional ups and downs of having a child with multiple special needs. Because of his condition, Peter frequently sustains fractures which require Andrea to leave work to spend the day with him in the hospital. In addition to the strains these disruptions have caused with her employer, her stress has been made that much worse by the actions of the attending nurses at the hospital. On a number of occasions, out of ignorance about her son’s condition, they have raised suspicions that Peter’s injuries were the result of abuse. While Andrea understands that they are only trying to make sure children are safe, these incidents have been by far the most painful of any of her experiences associated with her son’s disabilities. She wishes that the medical staff were better educated about her son’s condition.

Judy

Judy is a mother of three. When Lisa, Judy's four-year-old daughter, was born her medical challenges were so great that the doctors in the hospital tried to convince her to give her daughter up to institutionalized care. Instead, Judy insisted on taking Lisa home and learning to care for her herself. For the first few years after her daughter was born, Judy owned her own tanning salon and also worked as a nurse. Judy's mother was watching Lisa. But as Lisa's needs intensified, Judy's mother no longer felt comfortable caring for her, and Judy was forced to quit her position at the hospital. At the same time, the tanning salon began losing money, since caring for Lisa left Judy with no time to manage business affairs. She ended up selling the business. To make matters worse, Judy's husband refused to take part in the care of their child and began to work long hours in the office. They are no longer together because of the strain Lisa's care imposed on the relationship.

In spite of severe Cerebral Palsy which makes her dependent on a wheelchair, trach, and G-tube, Judy's daughter has been able to attend a part-day preschool where she is integrated with typical four-year-olds. She is attended by a nurse, who oversees her medical care. Special services such as PT, OT, and speech therapy are all provided on-site both at the school and at home. Getting these services was no easy matter, however. In order to get her child into the school, Judy had to hire a lawyer to convince the state that requiring an RN to attend to her child solely at home was unrealistic given the shortage of nurses in the area. She could not accept that her child would be denied a normal school experience. As a result of her advocacy, Lisa was enrolled in the program.

Because the therapeutic services are split between school and home and there is no communication between the professionals who are treating Lisa, Judy must make phone calls to one or the other specialist to ensure continuity of care. Judy says if there was one thing she would do if she had the opportunity, it would be to go back to work. But while her daughter is in a preschool now, the hours are limited and there is no child care program willing to take Lisa the additional hours, or on school vacations. Judy hopes that some day these challenges can be resolved so that she can return to work.

Anne

Anne is the single mother of two children. Daniel, her youngest, has been diagnosed with developmental delays. Anne is fortunate to work in a hospital where her hours are fairly flexible. This has enabled her to leave, as needed, for any one of the many demands she must meet for her son's care, including transportation to weekly occupational, speech and physical therapy appointments. Anne works 60 hours a week in order to make ends meet, which has required that she find after school care for her son. Anne's experiences with child care have been grim. On surprise visits to the first child care center in which she enrolled Daniel, she discovered that he was being left in a corner by himself, while the other children were engaged in activities elsewhere. At one point, a staff member pulled her aside to tell her that Daniel was not eating lunch, and was only drinking the limited amount of milk allotted to each child at the center. Anne became so concerned about the program, that she switched her hours from day to evening shifts so that she could care for Daniel during the day and be sure he was receiving the attention he needed. Working during the night, however, and watching Daniel during the day, left Anne with no time to sleep, and she eventually found herself falling asleep at the wheel of her car. Knowing she could not continue with things as they were, she again tried to find child care, this time in a home-based care situation, part-time.

Anne was initially satisfied with the home. But then she discovered that her son was not being included in outings with the other children. So Anne took Daniel out of that home and, after many phone calls, eventually found another family child care home. This time all seemed to go well until the provider failed to arrive to pick her son up from the bus. Daniel ended up staying on the bus and traveling to its other destinations while the Board of Education scrambled to get in touch with Anne to pick him up. Repeated calls to the provider about the incident went unanswered. Anne was reluctant to look for yet another provider. However, knowing that she had to keep up her hours at work in order to pay her bills, she approached an older woman she knew through a girlfriend. She is now her current provider and the situation appears to be working out well for her and for Daniel.

Anne readily admits that the constant negotiating she must do between her work and her son's care has left her exhausted. In spite of the adjustments she has made to her schedule, she is lucky if she gets six hours of sleep a night. Sometimes she can rely on her 17-year-old daughter or her best friend to come through for her when she needs some personal time, but that is rare. Instead, more often than not, she is calling on them to help her when Daniel's child care falls through, or she is in need of transportation to services. She is not resentful of the sacrifices to her personal and professional life that she has had to make in order to get Daniel proper care. Her one desire is that Daniel grow up and be judged for his strengths, not for his disability.

Glossary

The following are definitions and descriptions of the particular disabilities, medical terms and programs mentioned in the focus groups and in-depth interviews with parents included in this report. Unless otherwise specified, the definitions of disabilities in this glossary are taken from a series of fact sheets published by the National Dissemination Center for Children with Disabilities, <http://www.nichcy.org/disabinf.asp>

ASPIRE-TANF is Maine's education, training and work component of TANF. In order to begin receiving benefits, a family must attend a TANF orientation and meet with their ASPIRE case manager. The case manager helps them create a Family Contract detailing which activities they will participate in and for how long. ASPIRE provides support services which can include child care subsidies. Maine has no time limits and allows assistance to continue past the federal five-year time limit.

There are no exemptions from the work requirements in Maine. However, based on family circumstances, the nature of the child's disability and other factors, the work requirements can be adjusted. Depending on the circumstances of the family, disability of the child and other factors, a family may be granted "good cause" for noncompliance which protects them from being sanctioned. "Good cause" can be granted for one day or for six months or more depending on the family's circumstances. Among the circumstances that may constitute "good cause" are two which affect families with children with special needs:

- illness or incapacitation of a dependent child
- inability to find "appropriate child care." The federal standard for this is lack of child care that is appropriate, affordable and within a reasonable distance.

Whether good cause is granted, however, depends on the caseworker's judgment about whether the family's circumstances meet these definitions.

Asthma is a respiratory condition caused by narrowing of the airways; symptoms include recurrent attacks of wheezing, coughing, shortness of breath, and labored breathing. Source: National Institutes of Health, www.nhlbi.nih.gov/health/public/lung/other/bpd/glossary.htm

Attention-Deficit Disorder (ADD) is a term used to describe a disorder characterized by inattention and distractability but without hyperactivity. The current term to describe Attention Deficit Disorder with or without impulsiveness/hyperactivity is Attention-Deficit/Hyperactivity Disorder (AD/HD) (See below.)

Attention-Deficit/Hyperactivity Disorder (AD/HD) is a condition that can make it hard for a person to sit still, control behavior, and pay attention. There are three main signs, or symptoms, of AD/HD: problems with paying attention, being very active (called hyperactivity), and acting before thinking (called impulsivity). Based on these symptoms, three types of AD/HD have been identified: AD/HD inattentive type, where the person can't seem to get focused or stay focused on a task or activity; AD/HD hyperactive-impulsive type, where the person is very active and often acts without thinking; and AD/HD combined type, where the person is inattentive, impulsive, and too active. These difficulties usually begin before the person is seven years old. However, these behaviors may not be noticed until the child is older. AD/HD is a neurobiological disorder that affects three to five percent of school-age children.

Autism Spectrum Disorder is sometimes used as an umbrella term for classic autism and related developmental disorders like Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) that share many of the same characteristics. Usually evident by age three, autism and PDD-NOS are neurological disorders that affect a child's ability to communicate, understand language, play, and relate to others. In the latest edition of the diagnostic manual used to classify psychiatric disorders, the DSM-IV (American Psychiatric Association, 2000), "autistic disorder" is listed as a category under the heading of "Pervasive Developmental Disorders." A diagnosis of autistic disorder is made when an individual displays six or more of 12 symptoms listed across three major areas: social interaction, communication, and behavior. When children display similar behaviors but do not meet the criteria for autistic disorder, they may receive a diagnosis of PDD-NOS.

Behavior Disorders/Emotional Disturbance. Many terms are used to describe emotional, behavioral or mental disorders. Currently, students with such disorders are categorized as having an emotional disturbance, which is defined under the Individuals with Disabilities Education Act (IDEA) as "...a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree that adversely affects a child's educational performance: (A) an inability to learn that cannot be explained by intellectual, sensory, or health factors; (B) an inability to build or maintain satisfactory interpersonal relationships with peers and teachers; (C) inappropriate types of behavior or feelings under normal circumstances; (D) a general pervasive mood of unhappiness or depression; and (E) a tendency to develop physical symptoms or fears associated with personal or school problems."

Birth to Three is Connecticut's statewide program funded under Part C of the Individuals with Disabilities Education Act (IDEA) designed to strengthen the capacity of families to meet the developmental and health-related needs of their infants and toddlers who have delays or disabilities. The Birth to Three program offers in-home evaluations, services delivered in a variety of settings and service coordination of early childhood teachers, physical therapists, speech pathologists, the child's doctor, or other professionals.

The Birth to Three System is funded through a combination of state, federal and commercial insurance funds. Referrals to the program come through Infoline which does intake for the program.

Families are referred to the Infoline number by a variety of sources including physicians and child care professionals. Children receive screenings and evaluations and if determined eligible an Individualized Family Service Plan (IFSP) is developed. Children are eligible for Birth to Three services if they have a diagnosed condition that has a high probability of resulting in developmental delay, or if they already have a “significant” developmental delay in cognitive, physical, communication, social/emotional or adaptive skills.

Catheterization is the placement of a catheter, usually through the urethra, into the bladder in order to drain urine from the bladder. Source: Hardy Diagnostics Micro-biology Terms and Abbreviations, <http://www.hardydiagnostics.com/Glossary-C.html>

Cerebral Palsy, also known as CP, is a condition caused by injury to the parts of the brain that control our ability to use our muscles and bodies. *Cerebral* means having to do with the brain. *Palsy* means weakness or problems with using the muscles. Often the injury happens before birth, sometimes during delivery, or, soon after being born. CP can be mild, moderate, or severe. Mild CP may mean a child is clumsy. Moderate CP may mean the child walks with a limp. He or she may need a special leg brace or a cane. More severe CP can affect all parts of a child’s physical abilities. A child with moderate or severe CP may have to use a wheelchair and other special equipment. Sometimes children with CP can also have learning problems, problems with hearing or seeing, or mental retardation. CP doesn’t get worse over time, and most children with CP have a normal life span.

Child Development Services (CDS) locates and coordinates services in Maine for children with special needs ages 0 to 5 under Parts B and C of IDEA. (See IDEA in this glossary.) There are 16 county-based CDS programs under the Department of Education. Unlike most other states, the pre-school component of IDEA in Maine is part of the same independent system—it is not run by the local school districts.

Children enter CDS through the program’s Child Find system of identifying, locating and evaluating children. Common referral sources include hospitals, physicians, parents, providers and social service agencies. Child Find refers the family to a regional site where they are then assigned an Administrative Case Manager. The child is briefly screened followed by a more in-depth evaluation which includes a review of their health, development and family. An Individualized Family Service Plan (IFSP) is then developed in conjunction with the Early Childhood Team (ECT). The ECT is made up of the parents, an agency rep, the child’s teacher or provider, the Administrative Case Manager, a member of the evaluation team and, if appropriate, the child’s regular education teacher. Services are coordinated by CDS case managers and delivered in a variety of settings.

Children are eligible if they have developmental delays or a diagnosed physical or mental condition that has a high probability of resulting in a developmental delay. Screening and evaluations for birth-five are at no cost to the family; early intervention services for birth to three are paid by the family on a sliding scale or third party, and children ages three to five receive special education and related services at no cost.

Cleft Palate is an opening in the roof of the mouth in which the two sides of the palate did not fuse, or join together, as the unborn baby was developing. Cleft lip and cleft palate can occur on one side (unilateral cleft lip and/or palate), or on both sides (bilateral cleft lip and/or palate). Because the lip and the palate develop separately, it is possible for the child to have a cleft lip, a cleft palate, or both. Cleft lip and cleft palate are congenital defects, or birth defects, which occur very early in pregnancy. Source: Cleft Palate Foundation, <http://www.cleftline.org/aboutclp/>

Developmental Disabilities are a diverse group of physical, cognitive, psychological, sensory, and speech impairments that begin anytime during development up to 18 years of age. They are attributable to mental retardation or related conditions which include cerebral palsy, epilepsy, autism or other neurological conditions when such conditions result in: impairment of general intellectual functioning or adaptive behavior similar to that of a person with mental retardation. In most instances, the cause of the disability is not known. That's why it's important to understand what factors increase the chance that a child will have a developmental disability and what can be done to prevent the condition. Source: National Center on Birth Defects and Developmental Disabilities <http://www.cdc.gov/ncbddd/dd/default.htm>

Developmental Delay is a term used to describe a child who has not attained normal development compared to the standard population. There may be a delay in physical development, or a delay in cognitive development, or a delay in speech. The term developmental delay is generally applied to children under the age of five but may in some instances be used in describing children over that age.

Down Syndrome is a genetic condition that causes delays in physical and intellectual development. It occurs in approximately one in every 800 live births. Individuals with Down syndrome have 47 chromosomes instead of the usual 46. It is the most frequently occurring chromosomal disorder. Source: National Association for Down Syndrome <http://www.nads.org/pages/facts.htm>

G-Tube is an insertion of a feeding tube into the stomach. This is often done through endoscopy (a long tube placed through the mouth into the stomach) by a gastroenterologist. It may also be done surgically. A small incision is made on the left side of the abdomen. A small, flexible, hollow tube (catheter) with a balloon or flared tip is inserted into the stomach. The stomach is stitched closed around the tube and the incision is closed. Source: Allrefer.Com <http://health.allrefer.com/health/stomach-tube-insertion-info.html>

Individuals with Disabilities Education Act (IDEA, PL 101-476) is a federal law passed in 1991 that reauthorizes and amends the Education for All Handicapped Children Act (PL 94-142). The purpose of IDEA is to ensure that all children with disabilities have available to them a free appropriate public education including an individually designed program (Individualized Education Plan – IEP). IDEA requires that a team of educators and specialists serving the child and the child's parent or guardian develop the IEP and make decisions regarding the child's special education program. These teams are called Pupil Education Teams (PETs) in Maine and Planning and Placement Teams (PPTs)

in Connecticut. Part C of IDEA focuses on services to infants and toddlers (ages 0 to 3) who are at-risk or have developmental disabilities and the service plan for children under Part C is called an Individualized Family Service Plan (IFSP). (See Child Development Services and Birth to Three in this glossary for more information about Part C of IDEA as it is administered in Connecticut and Maine.)

IFSP (Individualized Family Service Plan) is the individual plan for services for children 0 to 3 under Part C of IDEA (See IDEA in this glossary.)

Infoline. Child Care 2-1-1 Infoline is a statewide system in Connecticut that handles calls from parents looking for child care. Infoline staff keep an inventory of child care providers and assist parents by providing lists of providers who may match their needs. Connecticut also has a program called Care 4 Kids which includes an additional subsidy amount and an arrangement with Infoline to make helping parents of kids with special needs a priority, along with families receiving TANF. Infoline helps look for child care for these families and follows up to see how families did in their search. Families with children with special needs is one of ten target populations that Infoline staff follow up with after assisting them in finding child care.

Intubation - endotracheal. This procedure involves introducing a tube into the trachea to provide an open airway to administer gaseous medication, oxygen, or anesthetics. It may also be done to remove blockages, or to view the interior walls. Source: Health Central, General Health Encyclopedia <http://health.allrefer.com/health/endotracheal-intubation-info.html>

JOBS First is the work component of Connecticut's TANF Program which supports those making the transition from welfare to work. In order to receive benefits, potential participants are seen first by a Department of Social Services (DSS) Family Independence Representative (FI Rep) who does a service needs assessment to determine if the person should be exempt from the work requirements and time limits. Connecticut has a 21-month lifetime limit for receipt of TANF. Those found exempt from the work requirements continue on TFA (Temporary Family Assistance) benefits as "exempt" unless a biannual redetermination shows that the family is no longer exempt. One of the grounds for an exemption is "a family in which the caretaker relative is needed in the home because of the incapacity of another family member." This exemption is not automatic and depends on the family's circumstances, whether the child is in school and the nature of the child's disability, among other factors. Among other supports for those who are required to work, child care assistance is provided. It is available while the parent/guardian looks for work and also when he or she is working.

Learning Disability is a disorder in basic psychological processes involved in understanding or using language, spoken or written, that may manifest itself in difficulties with listening, thinking, speaking, reading, writing, spelling or using mathematical calculations. The term includes conditions such as perceptual disability, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. Source: National Child Abuse and Neglect Data System (NCANDS) Glossary <http://www.acf.hhs.gov/programs/cb/dis/ncands98/glossary/glossary.htm>

Mental retardation is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18. Source: American Association of Mental Retardation http://www.aamr.org/Policies/faq_mental_retardation.shtml

Muscular dystrophy (MD) refers to a group of genetic diseases characterized by progressive weakness and degeneration of the skeletal or voluntary muscles which control movement. The muscles of the heart and some other involuntary muscles are also affected in some forms of MD, and a few forms involve other organs as well. Although some forms first become apparent in infancy or childhood, others may not appear until middle age or later. Source: National Institute of Neurological Disorders and Stroke http://www.ninds.nih.gov/health_and_medical/disorders/md.htm

Nebulizer is a machine for getting medicine into the lungs, a nebulizer makes a mixture of liquid medicine and water into a mist that a person then inhales (through a mask or a mouthpiece). Nebulizers are often used for babies and children too small to be able to coordinate using a metered dose inhaler. They are also sometimes used for people having severe asthma symptoms, as many people find it easier to take in the medicine this way when they are having a lot of trouble breathing. Source: University of Chicago School of Medicine: asthma.bsdc.uchicago.edu/AboutAsthma/AAAGlossaryM.html

Oppositional-Defiant Disorder (ODD). In children with Oppositional Defiant Disorder (ODD), there is an ongoing pattern of uncooperative, defiant, and hostile behavior toward authority figures that seriously interferes with the child's day-to-day functioning. Source: American Academy of Child and Adolescent Psychiatry. <http://www.aacap.org/publications/factsfam/72.htm>

Osteopenia. Osteopenia of prematurity is a metabolic bone disease of premature infants, in which decreased bone mineral content occurs. This condition makes children more susceptible to fractures. Source: Neonatology on the Web, <http://www.neonatology.org/syllabus/osteopenia.html>

Pervasive Developmental Disorder/Not Otherwise Specified (PDD/NOS). See Autism

Post-Traumatic Stress Disorder (PTSD) is an anxiety disorder that can develop after exposure to a terrifying event or ordeal in which grave physical harm occurred or was threatened. Many people with PTSD repeatedly re-experience the ordeal in the form of flashback episodes, memories, nightmares, or frightening thoughts, especially when they are exposed to events or objects reminiscent of the trauma. People with PTSD also experience emotional numbness and sleep disorders, depression, anxiety, irritability or outbursts of anger. PTSD is diagnosed when symptoms last more than one month. Source: National Institute of Mental Health <http://www.nimh.nih.gov/publicat/ptsdfacts.cfm>

Prader-Willi Syndrome (PWS) is a congenital (present from birth) disease characterized by obesity, decreased muscle tone, decreased mental capacity, and hypogonadism. (Hypogonadism is a condition in which there is a reduced or absent secretion of hormones from the sex glands or gonads.) Prader-Willi is

caused by the deletion of a gene on chromosome 15. Signs of Prader-Willi may be seen at birth. New infants with the condition are often small and very floppy (hypotonic). The growing child exhibits slow mental and delayed motor development, increasing obesity, and characteristically small hands and feet. Mental development is slow, and the IQ seldom exceeds 80. However, children with Prader-Willi generally are very happy, smile frequently, and are pleasant to be around. Affected children have an intense craving for food which can result in uncontrollable weight gain. Source: MedLine Plus Medical Encyclopedia <http://www.nlm.nih.gov/medlineplus/ency/article/001605.htm>

Preschool Special Education in Connecticut is special education and related services provided to eligible three-, four- and five-year-old children with disabilities. Preschool special education falls under Part B of the federal Individuals with Disabilities Education Act (IDEA). In Connecticut, preschool special education services are provided by the local and regional school districts. Preschool special education services are provided in a variety of settings, including the school and community. Many school districts provide special-purpose preschools for children with special needs or integrated programs where children attend with children without special needs. The amount of time children can attend these programs and the level of services they receive while they are there depends on what the team, required under the Act, determines will meet the educational needs of the child. (For preschool special education under Part B of IDEA as it is administered in Maine, see Child Development Services in this glossary)

Pulmonary Valve Stenosis is a condition, usually present at birth (congenital), in which outflow of blood from the right ventricle (lower chamber) of the heart is obstructed at the level of the pulmonic valve (the valve which separates the heart from the pulmonary artery). Source: MedLine. <http://www.nlm.nih.gov/medlineplus/ency/article/001096.htm>

PET's Pupil Education Teams. See IDEA in this glossary.

Resource Development Centers. In Maine, ten Resource Development Centers (RDCs) throughout the state provide parents with information on child care providers in their area and providers who accept children with special needs. These are the equivalent to Resource & Referral Centers or R&Rs in other states. The RDCs are also the child care voucher managers. A family must make less than 85% state median income to be eligible. There is a sliding scale of parent fees with no more than 10% of income going to child care. There are also subsidized slots at about 60 child care programs contracted throughout the state.

Respiratory Syncytial Virus (RSV) is the most common respiratory virus in infants and young children, and infects virtually all infants by the age of two years. In most infants, the virus causes symptoms resembling those of the common cold. In infants born prematurely and/or with chronic lung disease, RSV can cause a severe or even life-threatening disease. Each year, RSV disease results in over 125,000 hospitalizations, and about 2% of these infants die. Source: RSV Prevention Information Center <http://www.rsvprotection.com>

Sanctions are actions taken against recipients who fail to comply with the requirements under TANF and cannot demonstrate good cause. The policies regarding when sanctions are warranted and the amount by which the grant is reduced when a sanction is imposed differ from state to state.

Spina Bifida affects approximately one out of every 1,000 newborns in the United States. Spina Bifida results from the failure of the spine to close properly during the first month of pregnancy. In severe cases, the spinal cord protrudes through the back and may be covered by skin or a thin membrane. Surgery to close a newborn's back is generally performed within 24 hours after birth to minimize the risk of infection and to preserve existing function in the spinal cord. Because of the paralysis resulting from the damage to the spinal cord, people born with Spina Bifida may need surgeries and other extensive medical care. The condition can also cause bowel and bladder complications. A large percentage of children born with Spina Bifida also have hydrocephalus, the accumulation of fluid in the brain. Hydrocephalus is controlled by a surgical procedure called "shunting" which relieves the fluid build up in the brain by redirecting it into the abdominal area. Most children born with spina bifida live well into adulthood as a result of today's sophisticated medical techniques. Source: Spina Bifida Association of America, <http://www.sbaa.org/index.shtml>

TANF Temporary Assistance to Needy Families replaced Aid to Families with Dependent Children as the federal program of public assistance for families with children when the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) was signed into law in 1996. The work requirements under TANF are administered under the JOBS First program in Connecticut and under the ASPIRE Program in Maine which are described earlier in this glossary.



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