

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

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***Talking Points***

- Mixed method study conducted in Maine of challenges of low income families in finding child care, working and balancing work and family
- Involves a focus on several policy arenas at once: welfare reform, child care, workplace policies and early intervention (PartC)/ preschool special education (Sec 619, Part B) services under IDEA
- Began with exploratory phase speaking with parents, then designed our methodology, research questions based on that qualitative data.
- Required a textual, qualitative as well as quantitative look because we suspected the “devil was in the details” for these families.
- The part of our study which may be most intriguing is our examination of the places where these systems intersected and the ways in which programs, policies and funding streams seemed to conflict causing families to be pulled in so many directions at once.

**CROSS-SYSTEM ISSUES:  
EMERGING THEMES FROM RESEARCH TO DATE**

Part C, Sec 619 Part B of IDEA Early Intervention/Preschool Special Ed	CCDF/TANF Welfare to Work
<p><b>Mission/Service Plans</b></p> <ul style="list-style-type: none"> <li>➤ Focused solely on special needs of the child, not need of parents to work</li> <li>➤ IFSPs and IEPs don't address families' child care and work issues.</li> <li>➤ Assumes and often encourages availability of parents during work day to support delivery of services, attend meetings, facilitate communication,</li> </ul>	<p><b>Mission/Service Plans</b></p> <ul style="list-style-type: none"> <li>➤ Encouraging and supporting work</li> <li>➤ Pressure of work requirements and time limits</li> <li>➤ Emphasize importance of being reliable workers, limiting work disruptions.</li> <li>➤ Family contracts for TANF don't adequately address special needs of child.</li> <li>➤ Lack of knowledge about disabilities among TANF case workers.</li> </ul>

deal with paperwork.

### **Service Delivery**

- Therapeutic programs –hours based on child’s special needs as determined by team, not parents’ need to work, so part day, part week, lack of coverage in summer.
- Depending on severity of S.N. may not be able to access wraparound care or that care doesn’t meet needs of child.
- Even if mainstreamed in full-day child care, IDEA will only approve supports child may need to attend (e.g. one-on-one aide, deaf interpreter) for part of the day based on needs of child, not need of parents to work.
- In rural Maine, lack of center based care, shortage of specialists, particularly mental health, lack of reimbursement for travel time of therapists means program depends on availability of parents to deliver services at home or transport child to therapists’ offices. Undermines inclusion and parents’ ability to work.
- Reimbursement policies, transportation issues caused work disruptions (e.g. school buses won’t cross district lines, regional transportation authorities raise safety, reliability concerns, children suffer from too many transitions)
- Varying local interpretations of eligibility for IDEA services meant that in some areas social/emotional difficulties were ignored as long as child was reaching “academic” milestones on time. Child care providers reported need for support to care for growing number of children with undiagnosed behavioral issues yet couldn’t get services for children.

- Varying interpretation of appropriateness of child care to determine work exemptions. e.g. If special services not offered on site at child care is that considered an inappropriate setting?
- Provision of child care assistance to enable access to child care is based on parent working, not children’s need for social interaction.
- Quality enhancements but lack of funding for “extras” needed to serve special needs

### **Service Delivery**

- Access to formal child care system limited for SN and concerns over ability of providers to meet child’s needs. Incidents of lack of inclusion among the most painful stories parents told about their child care experiences.
- Reliance on informal arrangements more difficult for these families particularly for kids with behavioral problems or complex medical needs. Hurt feelings, tensions when family reluctant to help or is perceived to favor a non-disabled sibling.
- Access to family child care also more difficult because provider operates alone. Even the addition of one more caregiver greatly increases the chances that a child with SN would be accepted.
- Parents whose children were in comprehensive programs (particularly full-day Head Start) where staff knowledgeable about disabilities and inclusion, special services delivered on site and full time care provided had fewer work disruptions, more success in employment, less stress.

Research Question: What are the work experiences of these families given these conflicts? How were these conflicts affecting hours worked, what strategies they employed, stress levels.

### **Strategies used by Families:**

If could gain access to full day child care arrangements, some parents would pick that over part-day therapeutic programs with special services so they were able to work. If transportation to therapists' offices could not be provided or home-based delivery of services was not possible because of Mom's work schedule, child would go without the therapies.

Parents did everything they could to avoid child care problems and still work. These strategies included:

- Working nights (though for these parents sleep deprivation and caring for a child with challenging behaviors all day caused work problems, stress, health and safety concerns.)
- Taking children with them to work, with or without the knowledge of the employer.
- In two parent families, working split shifts or having one parent work 2 or 3 jobs so the other could stay at home causing strains on marriages on top of the strains of caring for a child with special needs.

Parents who had to work traditional hours and whose children were not in comprehensive programs, reported many work disruptions resulting in issues with their employers and even job losses. Even when employers were understanding, parents would need to make up the hours causing additional child care challenges.

### **Conclusion:**

Low income parents of children with special needs share the same child care/work challenges as low income parents without children with special needs: fragmented system, lack of quality child care, inflexible work place policies except that these are ratcheted that much higher for these families. Child Care Plus Me staff (who provide support to providers in Maine serving children with special needs) said when they go in at the request of a provider they are more likely to see global issues of quality affecting all the children than they are difficulties related to one particular child. As a result they call kids with special needs "canaries in the coal mine" that alert them to more general problems because these kids are the first to fall apart. Similarly, low income families of children with special needs are the "canaries in a coal mine" for a system that lacks a coherent mission and coordinated approach to serving all families in the dual roles of providing for the economic and emotional needs of their children.

## **Broad Research Questions**

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

## **Study population:**

Families under 225% of poverty with at least one child with special needs under age seven. Special needs defined very broadly to mean any mental or physical condition, diagnosed or undiagnosed, that may make it difficult to find or keep child care.

## **Methodology:**

Mixed methods, multi-level approach

Qualitative:

- Parent focus groups and interviews in six communities in Maine and Connecticut (n 39)
- Field Study in three communities in Maine to interview TANF welfare to work case workers, case workers from the multi-barrier agencies, child care R&Rs, child care providers, therapists (OT, speech/language, PT) Child Care Plus Me. (Center for Community Inclusion) staff and case managers from the early intervention/preschool special education program. (36 out of 45 interviews completed)
- Follow-up parent interviews in three Maine communities (ongoing)

Quantitative:

- Statewide parent survey of 500 parents drawn from early intervention/preschool special education and Maine Care lists) (ongoing)
- Child Care provider survey of sample of child care providers
- Analysis of data from National Survey of American Families and Longitudinal Survey of Youth

