

PROJECT DESCRIPTION 2003

Objective:

Low income families with children with special needs face unique challenges in balancing work and family responsibilities. Faced with the difficult task of finding suitable, stable child care for their special needs child, many parents are nevertheless forced by economic necessity to join the labor force. Despite the higher incidence of disabilities and chronic health problems among low income children, to date, there has been surprisingly little research done about the experiences of these families.

The Institute for Child and Family Policy has been funded by the Child Care Bureau at the federal Department of Health and Human Services to learn more about the experiences of this sub population of low income families and develop policy recommendations to assist these families in gaining the support they need. While our primary focus is on access to child care, we are also looking at the challenges of work and caring for a child with special needs, and the issue of coordination of early intervention services with the child care system.

Background on the project:

Our project began on October 1, 2001 and will continue for three years. In our first year, we conducted qualitative research to learn directly from parents about their experiences, through focus groups and indepth interviews. We are focusing on families with children with special needs (disabilities and/or chronic health conditions) with incomes at or below 225% of the federal poverty level (for 2002, \$33,795 for a family of three.)

Why are we doing this research?

Our goal in conducting this research is not to examine how well any individual or agency is serving this population but instead to identify ways in which the system as a whole can better integrate services and be responsive to the particular needs of these families. We believe it is essential that we get the perspective of the individuals who serve these families. Our interest is in making it easier for the staff at agencies serving this population to do their jobs and provide low income parents with the support they need to care for their child with special needs and balance work and family. What we learn will have implications for policy making at the federal, state and local levels. In developing our policy recommendations we will look at initiatives in other states and examine whether those models might offer guidance to Maine in serving this population of low income families and children.

Advisory Committee:

An Advisory Committee made up of representatives of relevant state agencies, as well as independent organizations and individuals with an interest in the policy issues being examined, has met throughout the

project to advise us on our approach. They will also play an important advisory role as we analyze, report and disseminate our findings.

Our Research in Years Two and Three:

For the second and third years of our grant, we are conducting a mixed-method, multi-level study of low income families of children with special needs and the system which serves them, focusing primarily on child care, employment and balancing work and family. This approach includes analysis of existing national and state-level data sets, statewide surveys of parents and child care providers and a field study to look at these issues at the local level in three selected communities: Portland, Lewiston/Auburn and Presque Isle.

I. Quantitative Research:

- **A.** *Existing National and State Data Sets:* We are analyzing existing national and state-level data sets to supplement our findings from our research in Maine. The focus here would be on use of child care by low-income families with children with special needs, employment and financial well being, impact of welfare reform, tightening of eligibility requirements for SSI disability, etc.
- **B.** *Survey Data:* In order to obtain a big enough sample size to be able to reliably answer research questions about employment, TANF work requirements, availability of child care, and other related issues, we are conducting a telephone survey of a random sample of 500 families with children with special needs in Maine using client lists from the Child Development Services (CDS) Program. We are also conducting a mail-in survey of a statewide random sample of 200 child care providers to learn about the issues they face and the support they need to care for children with special needs. Survey questions are based on the information we have collected from our research with parents in our first year.

II. Qualitative Research

Field Study in Three Communities: We are conducting a field study focusing on the child care, TANF/Employment and early intervention/preschool special education systems in three communities in Maine: a rural community (the Presque Isle area), and two small city service centers (Portland and Lewiston/Auburn.) In this aspect of our research we are using interviews to gain a better understanding of the organizational and institutional processes which affect these families. This field study consists of:

A. A community/service and labor market analysis: For each community we have conducted an examination of child care availability, the existing agencies which serve low-income families with children with special needs, their roles and responsibilities, the rules and regulations that govern provision of services, the links that exist between agencies and the forms that are used with families. Critical to this analysis will also be a labor market audit to determine the status of the labor market in terms of wages, types of jobs available, unemployment rates, etc. This "mapping" exercise will provide us with key information on what programs and services are available to families and the process by which families can access this assistance. There will be a special emphasis here on child care issues and on how families on TANF, or who have recently been on TANF, are served.

- **B.** *Interviews/site visits with service providers/case workers:* We are conducting site visits and interviewing child care providers, Directors of local RDC offices (providing child care resource and referral) ASPIRE caseworkers, caseworkers at multi-barrier agencies under contract with ASPIRE, staff of the Center for Community Inclusion, Child Care Plus Me initiative, service providers such as speech/language therapists and OTs, and Child Development Services (C.D.S.) case managers to gain their perspective on the issues raised by parents, to supplement what we learn through our survey research and to address issues which may be unique to how programs and policies are implemented in that particular community. In a sense, we will be using what we learn from these site visits and interviews to create a "flow chart" of how families in different circumstances make their way through the system. We hope that this will enable us to identify points at which changes in policy might assist these families and the agencies which serve them.
- **C.** Additional in-depth interviews and/or focus groups with parents: We may supplement our quantitative research by conducting additional, follow-up in-depth interviews and/or focus groups with parents in these three communities. The protocol for these will be informed by what we learned in our first year, our statewide survey research and the community analysis and site visits/interviews we will conduct for the field study in our three communities.