

ABSTRACT

Project Title:	National Center for Inclusive Community-Integrated Services for Children with Special Health Care Needs		
Applicant Name:	Early Intervention Research Institute, Utah State University		
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Problem: 1. *Approximately 25% of Families of CSHCN report that services are not organized so they can use them easily (National Health Survey, CSHCN supplement). A closer look at the data suggests problems in three areas: **Racial disparities** (percent of families with CSHCN who reported difficulties: white 22.6%, Hispanic 33.6%, black 34.7%). **Access to health insurance** (percent of families with some form of insurance 46.7% vs. those without- 24.6%); and **Complexity of the special health care need itself** (Rx meds and services use- 23%). (Functional limitations -37%), (Above routine use of medication- 38 %).*

Problem 2. *Solutions that attempt to target any one of these problems by itself have a high likelihood of failure. All three are inter-related and must be addressed at multiple levels and integrated both horizontally at any one level; and, vertically across levels.*

Problem 3. *Cookbook solutions to achieving inclusive community integrated services for CYSHCN at the individual family and systems levels tend to be ineffective. Models of transferring knowledge and action through purposeful learning communities are more likely to affect change in the long run with maximum inclusion of CYSHCN in community life.*

Goals and Objectives: The Center for Inclusive Community Integrated Services (CICIS) staff will work with DSCHCN and its other national centers, state systems, community based programs and family organizations to:

1. Identify and work with major national public and private community development initiatives
2. Facilitate linkages between community development initiatives and State Programs.
3. Develop and maintain a website linked to relevant community development initiatives,
4. Develop and disseminate materials on inclusion of CYSHCN,
5. Develop and implement a community recognition program; and
6. Collect, analyze, expand and **apply** evidence-based data to integrating community systems.

Methodology: CICIS will base its work on participatory action research (PAR), federal legislation, vertical and horizontal integration, implementation and sustainability.

Coordination: CICIS will work in a collaborative and coordinated manner with the other 5 MCHB-CSHCN Centers as well as national and community based advocacy and service provider organizations to identify and address the systems change strategies that rise above these problems.

Evaluation: A continuous quality improvement (CQI) evaluation plan will guide both the activities of this Center and the evaluation of its effectiveness of achieving the six objectives.