

The Florida Institute for Family Involvement has successfully conducted an extensive exploration of ideas with key community leaders on services for children and youth with special health care needs, in three areas of the state; Jacksonville, Sarasota, and West Palm-Broward. The process used to obtain the views of the community leaders is called Concept Mapping.

The purpose of Concept Mapping is to gain understanding of the actions that the community believes are critical to the development, expansion and sustainability of a family-centered, community-based, culturally competent system of care for all children and youth with special health care needs and their families in your community. Concept Mapping uses a mixed approach of group interaction and research-based analyses of the responses to produce an unbiased report of the participants' views.

Approximately 30 key individuals whose diverse experience and expertise provided critical insight into the development and sustainability of systems of care was gathered. The process was led by two national consultants in Concept Mapping, Marty Hydaker and Lenore Behar.

Concept Mapping involves four tasks:

- Brainstorming action steps;
- Sorting those action steps into related groups;
- Prioritizing the action steps in terms of importance and feasibility; and
- Measuring progress by determining which action steps have been completed.

The brainstorming process was used to generate the action steps. It took approximately 3 hours on the first morning. On the second morning, participants were asked to participate in sorting and rating the action steps for importance and feasibility. This activity was completed within 2 to 2.5 hours. *Each individual was urged to come both days and complete the entire process.* In the three areas of the state, there was almost no attrition from the first to the second day.

After confirming the findings, the results will be used to determine the activities to be undertaken to foster the development and sustainability of a community based system of care for children and youth with special health care needs and their families that is built upon a medical home and parent professional partnerships. The Florida Institute for Family Involvement and other critical partners will develop a Project Report of findings, recommendations, and next steps. As a follow-up, in six to eight months, the participants will be invited to another 90 minute session. They will be asked to rate the action steps in terms of which ones have been completed.

It is important to invite individuals to participate who represent a broad spectrum of community leaders. In our sessions, most of those who participated were families, youth,

service providers, program managers, Children's Medical Service's staff, business leaders, pediatricians, home health staff, nurses, counselors, DME providers, therapists, public health, school representatives, and early intervention specialists, just to name a few.

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