




SUMMER 2008



Life in the Florida Keys for CYSHCN and their Families

In May of 2008, a group of dedicated professional, family, and community leaders gathered in Key West to discuss, develop, and promote a better way of serving children and youth with special health care needs in the Florida Keys. This effort was the climax of events to promote a medical home, family –professional partnership across the state for families and their children and youth with special health care needs through the Integrating Families, Communities, and Providers (IFCAP) project at the Florida Institute for Family Involvement (FIFI). This document captures their ideas and intentions to improve the lives of CYSHCN and their families throughout the Keys

Professional and Family Leaders Respond to the Challenge of Enhancing the Approach to Serving Children and Youth with Special Health Care Needs

Family-Professional Collaboration is an approach that:

- Promotes a relationship in which family members and professionals work together to ensure the best services for the child and the family
- Recognizes and respects the knowledge, skills, and experience that families and professionals bring to the relationship
- Acknowledges that the development of trust is an integral part of a collaborative relationship
- Facilitates open communication so that families and professionals feel free to express themselves
- Creates an atmosphere in which the cultural traditions, values, and diversity of families are acknowledged and honored
- Recognizes that negotiation is essential in a collaborative relationship
- Includes some acknowledgment of mutual respect for each others' culture, values, and traditions

Bishop KK, Woll J, Arango P. *Family/Professional Collaboration for Children with Special Health Care Needs and Their Families*. Burlington, VT: Family/Professional Collaboration



www.fifionline.org

The Medical Home Approach

In a medical home, a pediatric clinician works in partnership with the family/patient to assure that all of the medical and non-medical needs of the patient are met. Through this partnership, the pediatric clinician can help the family/patient access and coordinate specialty care, educational services, out-of-home care, family support, and other public and private community services that are important to the overall health of the child/youth and family.

A Medical Home is:

Accessible & Continuous

Care is provided in the community.

Changes in insurance providers or carriers are accommodated by the medical home practice.

Coordinated & Comprehensive

Preventive, acute care, specialty care, and hospital care needs are addressed.

When needed, a plan of care is developed with the patient, family, and other involved care providers and agencies.

Care is accessible 24 hours a day, 7 days a week.

The patient's medical record is accessible, but confidentiality is maintained.

Family-Centered

Families and individual clients are involved at all levels of decision-making.

Compassionate and Culturally Effective

The patient's and family's cultural needs are recognized, valued, respected, and incorporated into the care provided.

Efforts are made to understand and empathize with the patient's and family's feelings and perspectives.

Adapted from the AAP Medical Home Fact Sheet and the Washington State Medical Home Key Messages

A medical home is not a building, house, or hospital. It is an approach to providing comprehensive primary care for children and youth with special health care needs, including those with behavioral, emotional, and mental health care needs.



FAMILIES AND PROFESSIONALS RESPOND

Our Intent

- Capitalize and build on current networking efforts
- Enhance family involvement at all levels
- Integrate medical home approaches and family-professional practices into existing curriculums
- Re-center services are the family and their children
- Facilitate advocacy for necessary change at multiple levels
- Promote awareness of CYSHCN across all systems of care
- Use history and experience as a mechanism for accountable change
- Re-design family involvement to match the family and community culture

Our Ideas

- Educate all service providers on the Medical Home Model for collaboration and partnership development.
- Develop a method of gathering the family and youth voice and sharing their regarding their needs and appropriate responses
- Encourage primary care practices to utilize innovative approaches that model family support, such as a designated day for special needs for exams.
- Guarantee the Compassionate Rule is followed and families and their children are treated with responsive respect.
- Ensure a responsible path of communication between systems, providers, and families at all levels.
- Develop and promote innovative ways of communicating with families, such as e-mail and electronic bulletin boards.
- Advocate for appropriate reimbursement for approaches that support a maximization of resources for families and their children, such as telemedicine.
- Develop a commonly accepted care plan that will be used across agencies and programs.
- Ensure that schools are included on the medical home team and as a critical partner in the development of care and policies for children and youth with special health care needs.
- Develop and disseminate easy to use tools for families, providers, and programs that will enhance partnerships and facilitate family and youth involvement at all levels.
- Create a strategic plan for the Key's that will map resource and program roles and responsibilities in implementing a medical home and family professional partnership approach to service planning and delivery.
- Develop a common method of collecting and aggregating data regarding CYSHCN, service needs, service encounters, and outcomes that is specific to the Keys and shared among all partners.