Who are the Children and Youth With Special Health Care Needs in Your Practice?

All physicians who care for children will have patients and families with special health care needs in their practice. Children and youth with special health care needs are recognized to be those from birth to 21 years old who:

- ☐ Have a chronic physical, developmental, behavioral or emotional condition expected to last 12 months or more, and
- ☐ Need health and related services more than most children,
- ☐ May receive these services from various public and private agencies and providers in the areas of health, education, and social services,
- ☐ And, as a result of complex conditions and many different providers, may need help in coordinating their care.

This includes children and youth with chronic medical conditions such as diabetes, sickle cell anemia, cystic fibrosis, and heart disease; developmental disabilities such as cognitive or intellectual disabilities, sensory impairments and autism spectrum disorders; emotional or behavioral health needs including ADHD and mental health conditions; as well as physical disabilities such as cerebral palsy, spina bifida, or muscular dystrophy. Recent survey data from the National Center for Health Statistics, Centers for Disease Control and Prevention estimate that 13% of children nationwide have special health care needs that meet this definition.

Resources for Building Your Medical Home

National
- www.aap.org
- www.afp.org
- www.medicalhomeinfo.org
- www.pcpcc.org
- www.familyvoices.org

New Jersey
- www.aapnj.org
- www.njafp.org
- www.njha.com
- www.njcth.org
- www.spannj.org

What is a Medical Home Partnership?

A Medical Home is more than just a building, house or hospital. It is an approach to providing health care services in a high-quality and cost-effective manner.

The American Academy of Pediatrics, the American Academy of Family Physicians and the national Maternal & Child Health Bureau are promoting Medical Home partnerships between families caring for children with special health care needs and the physicians they trust. In a Medical Home, families and physicians work together to identify and access all the medical and non-medical services needed to help children with special health care needs reach their maximum potential.

A Medical Home Partnership enhances the effectiveness of the patient-family-doctor relationship, not by working harder and faster, but by doing things differently. A medical home is defined as primary care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective.

- ☐ Medical Home is as much an attitude as it is a way of delivering care: families are recognized as the principal caregivers and the center of strength and support for children.
- ☐ Medical Home is another way of describing a physician's office when it helps families access the full range of services and supports needed to care for a child with special needs.

"All children benefit from a medical home, especially those with special health care needs. Parent/professional partnerships and care coordination provide support for families while helping children maximize their potential" (**Fran Gallagher, MEd, Executive Director, AAP NJ, PCORE, SPAN Board of Trustees**).

Why Invest in Building a Medical Home Partnership?

- ☐ The number of children and youth with chronic or disabling conditions is rising. Advances make it possible for persons of all ages to be cared for in the home and community, but this requires new approaches to care and new systems of supports.
- ☐ All primary care physicians who care for children have some patients with special health care needs in their practices.
- ☐ Linking all children with special health care needs to a comprehensive medical home has become a priority of the Healthy People 2010 objectives of the AAP, ACP, AAFP and AOA (Joint Principles of the Patient Centered Medical Home, 2007).
- ☐ "Recognizing the importance of quality health care, appropriate payment for medical home activities is imperative. A high-performance health care system requires appropriate financing to support and sustain medical homes that promote system-wide quality care with optimal health outcomes, family satisfaction and cost efficiency." (University of Illinois at Chicago, the Division of Specialized Care for Children). Purchasers are increasingly using patient satisfaction measures as an indicator of quality care.
- ☐ Breakdown in communications and connections between patients and their physicians are among the primary reasons why consumers change providers and, in severe cases, take legal action.
- ☐ AAP NJ Chapter & PCORE, in collaboration with partners, are offering supported technical assistance to primary care practices working to strengthen their medical homes (e.g., phone consultation, workshops/conferences, online resources).

"Participating in the medical home project at Kent Plaza Pediatrics has been very rewarding, as it is a step in the right direction to bring together the resources that have proven invaluable in meeting my daughter's needs, and those of other children with special health care needs, now and in the future." **(Janet Gundling, Parent Partner, Kent Plaza Pediatrics, Howell, NJ)**

These materials have been adapted from Small Steps…Big Differences", a medical home partnership brochure developed by New England SERVE, Boston, Massachusetts. www.neserve.org

New Jersey's Medical Home Program

For Children and Youth With Special Health Care Needs

The American Academy of Pediatrics, New Jersey Chapter (AAP NJ)

New Jersey Pediatric Council on Research & Education (NJ PCORE)

Statewide Parent Advocacy Network (SPAN)

NJ Department of Health and Senior Services (NJDHSS)

Medical Home team:
NJ PCORE at (609) 588-9988
SPAN at (800) 654-SPAN
NJDHSS at (609) 777-7778

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™
New Jersey Chapter

You are already a Medical Home...
This brochure will provide you with small, simple steps your office can take to strengthen your Medical Home.

STEP 1: Before the Visit… Anticipate the Arrival of Your Patients with Special Needs

Identifying Children and Youth with Special Health Care Needs (CYSHCN)

Identifying children and youth with special health care needs in your practice can be a first step toward strengthening your medical home. Options include:

- ☐ Develop a method of identifying children with special health care needs in the scheduling system, if you are a paperless practice.
- ☐ Use a special sticker or marker to identify charts.
- ☐ Include a summary of medical issues or critical needs at the front of the medical record.

Reception and Waiting Area

- ☐ Schedule extended time if needed or consider scheduling CYSHCN for the first or last appointment of the day.
- ☐ Greet families and patients by name to increase confidence that their needs are recognized.
- ☐ Ask the family to complete a brief form to identify current concerns, new issues or pressing needs.
- ☐ Use the waiting room to share resources useful to families (e.g., services for children and youth with special health care needs).
- ☐ Be mindful of challenges faced in the waiting room due to equipment or infection concerns. Offer alternate space when waiting time may be extended.

Small, but significant steps that you can do.

STEP 2: During the Visit… Use Families as Experts

In The Exam Room

- ☐ Ask for advice before starting any procedure, "Is there anything I should know about your child or what works best for him/her at the office?"
- ☐ Delay more routine aspects of the exam until urgent parent concerns are addressed.
- ☐ In cases where a child is examined frequently, the physician may decide it is not necessary to weigh or undress the child at each visit. This can spare the parent and child difficulty or discomfort.

Assess Unmet Needs

- ☐ Review the "concern of the day" to facilitate conversation.
- ☐ Encourage the family to discuss other facets of their child's life including in-home care, education, recreation, and social/emotional concerns.
- ☐ Offer to help explain their child's medical needs to other health, education or community professionals, if needed.

Use Written Plan of Care

- ☐ Acknowledge the family's need to communicate medical plans and decisions to other providers outside the office.
- ☐ Set short-term (3-6 months) and long-term (12 month) goals with the family, always including non-medical goals (e.g., education plan).
- ☐ Provide information in writing on recommended medical treatments.
- ☐ Develop a written plan of care with the family and update the plan when regularly assessing progress.

These practical tips for physicians, nurses and office staff can help improve both family and provider satisfaction...

STEP 3: After The Visit… Help Coordinate Care

Help Find Resources

- ☐ Identify a staff member or community-based care coordinator to help families find needed services and implement care plans.
- ☐ Connect families to community resources, such as specialized transportation, durable medical equipment, respite and home care.
- ☐ Maintain telephone numbers of public agencies.

Maintain Linkages with Specialist(s)

- ☐ Ensure continuity of care and updated information by working to improve timely communication with medical specialists.
- ☐ Help families make sense of clinical recommendations they may receive from different providers.
- ☐ Organize or participate in team meetings with multiple providers and parents to achieve agreement on plans of care.

Paying the Bills

- ☐ Assign a staff member to help with referrals, payment issues and follow-up activities to assist families to coordinate financial benefits and increase timely reimbursement.
- ☐ Maintain contact information for the special case management programs within health plans and insurers that serve your area.
- ☐ Refer families to public programs such as Division of Developmental Disabilities, Social Security Administration and/or Catastrophic Illness in Children Relief Fund for financial assistance.

...Use them to review current office policies and for training staff. Start where you can; there is no special order for implementation.

STEP 4 In the Community… Work in Collaboration with Families

Family and Staff Participation

- ☐ Seek input from families in your practice to ensure your office is user-friendly and family centered.
- ☐ Identify potential parent leaders who may be interested in supporting other families.
- ☐ Invite staff members with interest and skills in working with families to help build the Medical Home partnership in your practice.
- ☐ Meet regularly with your staff (e.g., 10 minute weekly "huddle") to identify areas for care improvement and discuss specific family and patient concerns.

Parent-to-Parent Support

- ☐ Encourage families to connect with support groups in their community. In New Jersey, The Statewide Parent Advocacy Network offers a "one-stop" for families of children with special needs at 800-654-SPAN or www.spannj.org.
- ☐ Post notices about meetings and events in your waiting room.
- ☐ Offer your office facility for evening meetings.

Families as Advisors

- ☐ Include parents on existing practice-based committees that inform office policies and practices.
- ☐ Benefit from the expertise of parents in your practice by creating a Family Advisory Committee.
- ☐ Seek consultation from family leadership groups in your community when questions arise regarding family centered care.

...Build your Medical Home partnership one step at a time.