



Promoting Medical Homes for Children and Youth with Special Health Care Needs and Their Families:

A Needs Assessment of Washington State Medical Home Physicians

September, 2005

**Written by: Katherine TeKolste, MD, FAAP, University of Washington
Kate Orville, MPH, University of Washington**

**Reviewed by: Stacey DeFries, MSW, Washington State Department of Health
Maria Nardella, MA, RD, CD, Washington State Department of Health
Forrest C. Bennett, MD, FAAP, University of Washington**



Funding for this report provided by:

Washington State Department of Health, Children with Special Health Care Needs Program through their Medical Home Partnerships contract with the Clinical Training Unit, Center on Human Development and Disability, University of Washington.

Additional copies of the report can be accessed online through the Washington State Medical Home Website, www.medicalhome.org.

TABLE OF CONTENTS

	Page
I. Executive Summary.....	1
II. Methods.....	10
III. Analysis	
A. Medical Home in Your Practice	11
1. Practice Characteristics	11
2. Key Medical Home Components	12
3. Quality Improvement Activities	14
4. Identifying and Tracking Children and Youth with Special Health Care Needs	16
5. Family Input	17
6. Care Coordination	18
B. Nutrition Services	25
C. Adolescent Healthcare Transition in Your Practice	29
D. Envisioning a Future Practice with Children and Youth with Special Health Care Needs, Collaboration and Medical Homeness	33
1. Wish List for New Services	33
2. Uses for Extra Reimbursement	35
3. Additional Practice Partners	37
4. Other Tools or Devices	38
5. What Could be Better Handled Outside the Medical Office?	40
E. Implementing Change and Collaborating	40
1. Medical Home Message to Other Physicians.....	40
2. How the MHLN Can Help	41
3. How State Agencies Can Help	43
4. How State Medical Professional Organizations Can Help	44
IV. Limitations	45
V. Recommendations	45
VI. Appendix	
A. Interview Questions	
B. Map of Medical Home Teams	

EXECUTIVE SUMMARY

MEDICAL HOME PHYSICIAN NEEDS ASSESSMENT

WASHINGTON STATE

PURPOSE

To identify:

- How to **support** experienced medical home physicians who are currently active on Medical Home Leadership Network (MHLN) teams in Washington State
- How to expand the number of physicians providing medical homes in Washington State
 - How to **recruit** additional MHLN team physicians,
 - How to **prioritize** effective medical home messages and tools to recruit new physicians

In order to understand these issues, staff from the Washington State Department of Health-Children with Special Health Care Needs Program and the Washington State Medical Home Leadership Network looked to expert physicians to find out about their current experiences providing medical homes for children and youth with special health care needs and their families.

METHODOLOGY

A telephone interview survey was developed. Questions covered the following topics: primary care practice patient and staffing characteristics, physician and practice efforts to promote “medical homeness,” barriers faced, successful strategies developed and suggestions for how to promote medical homes statewide. During the winter of 2004-05 interviews were completed by two Medical Home Leadership Network staff with 11 physicians active on MHLN county teams. The interviewers transcribed their notes and analyzed the data together.

PRACTICE CHARACTERISTICS

Ten pediatricians and one family physician were interviewed. Five practices were located in Eastern or Central Washington and six practices were in Western Washington. The majority were located in small towns and rural communities. The percentage of children and youth with special health care needs in these practices ranged from 10% to 50%. The majority of the physicians reported that the single largest source of medical insurance for their patients was public insurance (e.g. Medicaid, SSI, military insurance). Many physicians reported a substantial population of non-English speaking patients/families in their practices.

KEY FINDINGS

Key Components of Medical Homes for MHLN Physicians

Physicians stated that they viewed medical homes as good primary care with additional care coordination support for families. Physicians identified three key Medical Home components:

- Care coordination
- Provider-family relationship
- Infrastructure at both the practice and community levels
 - Funding
 - Medical record keeping
 - Community resources and collaboration
- Other Issues

Care coordination was needed but was time-consuming and difficult to fund according to physicians. Lack of reimbursement for care coordination was a huge frustration and barrier. Physicians do not currently identify cost savings from their care coordination efforts and identify a high need for additional help in providing care coordination. Some physicians utilize electronic medical records to streamline problem lists, care plans, justifications, etc. This also supports care coordination practices. All of the physicians stated that they provide care coordination for patients, usually as a team with their office nurse or medical assistant. However, many of the physicians identified a need for personnel assigned the specific role of care coordinator. Physicians with nurse or other care coordinators in their clinics reported this individual to be critical to the provision of a medical home for their patients and families.

Physicians reported that some clinics had a designated care coordinators and/or referral coordinator. Several clinics have developed cost-effective care coordination systems with non-clinical personnel to handle referrals, follow-up appointments, and/or other non-medical care coordination services for patients. Most physicians worked closely with a public health nurse Children with Special Health Care Needs Coordinator and Family Resources Coordinators. One clinic negotiated a higher rate from a Medicaid-plan to cover the cost of the care coordination for a subset of children. Another clinic demonstrated cost savings resulting from a referral coordinator and then was able to use that data to hire a referral coordinator in all of the affiliated clinics.

Provider-Family relationship. Physicians reported that families need support and information. This includes a welcoming atmosphere in the office, basic patient health education available on site, patient handouts to take home, and assistance with insurance coverage. In clinics with large numbers of families living in poverty and/or for whom English was not their first language, interpreters and help with logistical needs such as transportation, housing and finances was identified as a need. Physicians would appreciate computer access for families in their offices – for linking to information websites and family resources, completing applications, etc. Many families do not have access to computers, or if they do have access, the connection is too slow to allow efficient downloading of materials.

Infrastructure in the clinic and community. A number of items - e.g. electronic medical records, local access to medical therapies, subspecialty consultation, social supports, and community collaboration in serving populations with unmet needs – were seen as necessary for physicians to be able to provide a medical home. At least one practice with a high percentage of patients who had special needs and/or Medicaid coverage indicated long-term financial vulnerability and a need for improved funding of services provided to ensure practice viability.

Other Issues

- **Mental Health Issues.** Physicians were spending increasing amounts of time treating and coordinating care for children and youth with mental health/behavioral problems who do not have access to a psychiatrist. They identified a severe shortage of mental health professionals as referral sources for this population of patients. Physicians stated that it was very stressful to be responsible for the diagnosis and treatment of complex mental health problems they feel inadequately trained to manage on their own.
- **Adolescent health care transition** to adult health care providers is difficult in many communities. When transitioning is a problem, it is a VERY BIG problem for the physician. Identifying adult care physicians to accept youth with special health care needs was the primary challenge reported by physicians. However, to a lesser degree the barrier lay with the family preferring to maintain the current pediatric health care arrangement. Another barrier identified by physicians was sometimes the adolescent's lack of readiness to assume their own health management. Transitioning for subspecialty care is at least as big a problem as transitioning to general adult preventive and acute care. Youth with mental health/behavioral issues, complex medical and care coordination needs, with multiple medication requirements, and/or funded by Medicaid or SSI insurance were the most difficult to transfer to adult care providers.

Expanding the Number of Physicians Providing Medical Homes

Physicians reported that there was no one message that would successfully recruit additional physicians to provide care through the medical home approach. Some physicians reported that one approach was to promote medical homes as an approach that can work effectively in a busy practice and that was financially feasible if you could show that it either improved health outcomes (decreases poor outcomes) for patients or increased reimbursement for the practice. Others suggested messages emphasizing that 1) community collaboration makes medical practice easier and 2) the benefits of medical homes as a way to improve communication and medical care for all patients. The MHLN was mentioned as a resource for bringing together involved people, team building, assisting with local grant applications and disseminating of ideas.

Physicians indicated taking care of children and youth with special health care needs involved more financial risk and increased work for practices. One provider stated that

unless the reimbursement/financial viability issues were addressed, nothing would bring more providers into the medical home efforts.

A number of tools were mentioned as helpful for providing medical homes, including electronic medical records, care plans, patient education materials, care guidelines for specific diagnoses and community resource lists.

Suggestions From Physicians for how State Agencies can promote medical homes

Advocacy is critical. Legislators and policymakers need to hear about the needs of children and youth with special health care needs and the need for increased funding to meet those needs - in particular, advocating for adequate reimbursement or funding for care coordination, Medicaid funding, universal health insurance and improving mental and behavioral health services.

Address service provision at the community level of unmet health needs – including mental and behavioral health issues, developmental pediatric assessment, oral health needs, and adolescent transition, including non-medical aspects such as sheltered workshops and group homes.

Suggestions from Physician for how the Washington Chapter of the American Academy of Pediatrics (WCAAP) and other state professional organizations to promote medical homes:

- Continue to help communities and physicians obtain grants to address local problems.
- Facilitate provision of patient literature to physicians to share with their families
- Assist the identification of the needs of children and youth with special needs and identify areas of the state where these needs are being less adequately served
- Continue to provide advocacy for improved reimbursement, especially around care coordination, and for systems improvement

RECOMMENDATIONS

Based on analysis of the medical home needs assessment interviews with physicians, here are recommendations from the writers of this report about how to support experienced medical home physicians as well as effectively encourage additional physician to take care of children and youth with special health care needs and their families.

Suggestions for who might carry out these recommendations are listed in parentheses after each recommendation. (a key to the acronyms used is at the end of the recommendations)

RECOMMENDATION #1 - Support care coordination

Potential Activities

1. Care Coordinator within a practice
 - a. Address reimbursement for care coordination to enable physicians to hire care coordinators (e.g. health plans, insurance commissioner, Medicaid, grants, blended funding, etc) (*MAA, DOH, professional organizations, clinics, insurance commissioner, health plans,)*
 - b. Link public health or other personnel to a practice to provide care coordination activities (*DOH, ITEIP, DDD and MAA and other state and local agencies, FQHCs, etc.*)
2. Care Coordinator external to practice
 - a. Identify partners to provide care coordination activities. For example, CSHCN Coordinators potential to shift responsibilities to provide individualized care coordination, health plans, other community partners? (*DOH, ITEIP, state and local agencies, RSNs, DDD, Visiting Nurse Association, etc.*)
3. Educate and empower care coordinators
 - a. Provide workshops on care coordination (*state and local agencies, family organizations, universities and other providers of training*)
 - b. Link other community providers to care coordinators – resource lists, face-to-face meetings, eligibility guidelines for various services, ...(*DOH, local public health and other agencies, local service providers (private and public), etc*)
 - c. Provide care tools, care guidelines, physician information, family information, and links to resources for families, patients and physicians (*MHLN, CCSN, DOH, other state and local agencies, tertiary care centers, professional organizations, clinics*)
 - d. Share tools, information, models, etc. on the WA Medical Home website
4. Streamline paperwork and justifications (see recommendations in Rec. #5)
5. Increase access to other services in the community; identify and/or provide community resources and information such as interpreters, mental health services, subspecialty consultation (including potentially outreach clinics), transportation. Streamline eligibility and application for other services.

RECOMMENDATION #2 - Support Family-Professional Partnerships

Potential Activities

1. Promote wellness, not just diagnosis-related care (*GAP Guidelines, AAP/Bright Futures Guidelines, Community efforts to increase access to exercise, etc – e.g. YMCA/YWCA, Boys' and Girls' Clubs, Special Olympics, Local gyms, Community gardens, social and religious institutions, day activity programs, etc*)
2. Educate about and disseminate care tools, such as the Care Notebook, care plans, emergency plans and transition plans (*DOH and state agencies, MHLN, professional organizations, family organizations, AHTP*)

3. Support and facilitate family advisory groups and QI activities with families, such as focus groups (*DOH, MHLN, professional organizations, family organizations*)
4. Address barriers to patient and family education – personnel, time, reimbursement, materials, etc. (UW medical library, local libraries, local medical libraries, DOH, DDD, MAA, AAP, AAFP, Foundations, family organizations, diagnosis-specific organizations, etc – to look for support to increase materials such as brochures and vides, > personnel, time reimbursement issues – clinics, MAA, health insurers, health commissioner’s office, etc.)
5. Facilitate inexpensive access to patient education materials, including those in other languages
 - a. Onsite brochures, videotapes, computer linkage
 - b. Website information for families
6. Identify and utilize links in community for patient education and information, including medical librarians. (*clinics, community agencies, others*)
7. Linkage to family-to-family support organizations for emotional and practical support. (*clinics, DOH, family organizations*)
8. Promote Family Leadership activities and linkages including the Washington Family to Family Network (*DOH, MHLN, state and local agencies, family organizations*)

RECOMMENDATION #3 - Support Adolescent Transition Activities

Potential Activities

1. Work to identify and assist adult providers willing and able to take on this population (*AHTP, professional organizations, DOH, MAA, DDD, Providers currently seeing this population, Adults and Elders Program, Group homes statewide, Advocacy groups, and other state agencies*)
 - a. Review and address reimbursement barriers
 - b. Partner with the Adults and Elders Program for Adults with disabilities, DDD, Rainier School, parents of youth with special health care needs, and others to identify helpful management hints and provide education for adult providers
2. Encourage outreach clinics or local hospital-based clinics (and perhaps provide subsidies) to work with populations that have extra equipment needs for health care access and/or behavioral/cognitive issues that are difficult to accommodate in a typical primary care practice setting. (*Insurers, state agencies, local hospitals, Local health jurisdictions, community clinics and FQHCs, group homes, etc.*)
3. Consider local learning collaboratives/community work-groups to assess and address health care needs of the local special needs population. Work with families, Adults and Elders Program and other community partners to identify these groups and plan services. (*state and local agencies, family/self-advocate organizations, etc*)
4. Enhance educational activities to increase knowledge and ability to manage youth and adults with special health care needs. Partner with residency training programs in Family Medicine, Internal Medicine, and Internal Medicine – Pediatrics (Med-Peds), continuing medical education, and nursing education (*professional training programs, AHTP, professional organizations, state agencies*)
5. Increase awareness of the Adolescent Transition Resource Notebook
 - c. Enhance health section of the notebook with family information and tools (*AHTP, DOH, CCSN, Family advocacy groups, Parent and youth consultants*)

- d. Create a notebook for health care providers with tools and information to improve the health care of young adults with special health care needs. *(AHTP, DOH, DDD, Rainier School, Fircrest School, CCSN, Med-Peds programs, UW Department of Internal Medicine, UW Department of Family Medicine, WWAMI Program, parents and youth)*
6. Examine electronic medical records (EMRs) for utility in managing emergency forms, transition timelines, health history summaries, medication management and other flow sheets, etc. Make recommendations on use of EMRs for each transitioning adolescent and for adults with Developmental Delay/Intellectual Disability or special health care needs. *(MAA, DDD, AAP section on EMR, Adults and Elders Project, Clinics and community hospitals, Whatcom County Pursuing Perfection Grant, etc.)*
7. Provide youth and family education on the primary health issues enhancing youth willingness and ability to partner on health issues, self-care, health care management and anticipating and problem-solving health impacts on independence and employment. *(clinics, professional organizations, family/self-advocate organizations, AHTP, diagnosis specific organizations, ...)*

RECOMMENDATION #4 - Support Medical Home Practices Internally
--

Potential Activities

1. Connect public health nurse and other services into local primary care provider offices on a regular basis. *(DOH and other state agencies, local health jurisdictions and other community agencies and private providers)*
 - a. Provide family-friendly services with timely access and service delivery at a familiar location
 - b. Provide education about local services to staff in the primary care office who will then be better able to facilitate access when the PHN is not on site
 - c. Market the CSHCN services and personnel; face-familiarity/personal contact enhances the referral process and the utilization of services; this also markets the medical home concept
2. Promote community resource awareness, including nutrition services
 - a. Community service representatives come talk to primary care practices at breakfast or lunch meetings *(local agencies, family organizations, clinics)*
 - b. Community resource presentations at local medical meetings *(local and state agencies, family organizations, professional organizations)*
 - c. Increase physician/primary care provider awareness of community nutrition and feeding resources locally and identify and promote successful community and primary care practice models to address unmet nutrition needs such as obesity. *(DOH, MHLN, local agencies and private resources)*
3. Promote systems and tools that streamline clinical efforts in the PCP office
 - a. Electronic medical records (EMRs), personal digital assistant (PDA) resources, care plans, care guidelines, problem lists, and other communication tools between providers on specific shared patients *(clinics, professional organizations, DOH, MHLN, state and local agencies, insurers, family organizations)*
 - d. EMR tools specific to children and youth with special health care needs would be very helpful *(professional organizations, clinics, MHLN)*

- e. Disseminate models that are working (state and nationally) (*MHLN, DOH and state agencies, professional organizations, residency programs*)
- 4. Work to meet equipment needs – ability to weigh a child in a wheel chair, examining tables that are accessible for the disabled, etc. and create and maintain a database of specialized equipment in local communities – such as weight scales. Post link to information on Medical Home website (*local agencies, clinics, professional organizations, DOH, MHLN*)
- 5. Data Management/Systems Planning - Assist practices in assessing and utilizing data resources for CSHCN identification, tracking of expenses for contract negotiations, care planning, resource allocation within practice and to target care coordination and follow-up activities (*professional organizations, insurers, state agencies*)
- 6. Promote parent advisory groups to identify family and patient needs and to assist practices in improving and streamlining services (*DOH, MHLN, family organizations, professional organizations, state and local agencies*)

RECOMMENDATION #5 - Support practices externally

Potential activities

- 1. Examine communities where health care providers are at financial risk and disproportionately serving the special needs population. Review reimbursement options to assist these practices. Consider subsidizing practices that take large numbers of CYSHCN in communities where practices don't 'share the burden' hence putting a practices at financial and burn-out risk. (*State agencies*)
- 2. Expand the support of public health department/districts in community problem solving and grant submission. Consider creating community learning collaboratives with primary care providers, public health and other health organizations, community resources and other partners to identify and address a problem. Include a review of best practices, grant funding, creative/successful solutions, creating community awareness and marketing of the agreed upon approach to the solution.) (*DOH*)
- 3. Identify community partners to assist in accessing and providing information on needs related to social services, mental health, systems/resource access (such as financial supports, transportation, cultural/language support, nutrition) (*State agencies, community agencies, clinics*)
- 4. Provide support for home visits – e.g. nutrition, nursing, behavioral health (*state agencies, insurers*)
- 5. Promote and fund outreach clinics/telemedicine – ease travel burden on families, supply missing expertise such as developmental pediatrics, nutrition, psychology, psychiatry, occupational therapy/physical therapy/speech and language pathology (*tertiary care centers, insurers*)
- 6. Create learning collaboratives around topics of particular interest to practices, teams and communities (*State agencies, community agencies, professional organizations, MHLN*)
- 7. Provide funding for and use the Medical Home Leadership Network to disseminate information, support local team activities, provide listserv, facilitate regular meetings of community teams (*DOH, MHLN*)

8. Continue to support and expand Washington State Medical Website, and keep it responsive to user-base needs (*DOH, MHLN*)
9. Examine ways to expand provider availability, such as pediatric training for adult occupational therapists – For example, provide pediatric occupational therapy training for adult occupational therapists in specific communities with shortages. Support training of local Spanish speakers to become interpreters, Family Resources Coordinators, etc (*Community agencies, university training programs, state agencies*)
10. Bring together insurers, schools, equipment providers, professional medical organizations and others to streamline paperwork and justifications. For example, consider allowing paperwork/phone justifications to be completed/signed off by non-MD. (*DOH, state agencies, professional organizations*)
11. Build on existing collaborations with health care plans, especially those contracting with Medicaid, to explore insurance issues for this population of patients, including excessive paperwork and rejected claims. Current collaborations include the Children with Special Health Care Needs Communication Network, EPSDT Meetings, and the Medicaid contractor meetings. (*DOH, state agencies, professional organizations*)
12. Encourage and develop grant applications to document care coordination activities/models and outcomes (*all*)

KEY to acronyms:

AHTP=Adolescent Health Transition Project, **CCSN**= Center for Children with Special Needs, **DDD**= Division of Developmental Disabilities, **DOH**=Department of Health, **Family/Parent organizations**= groups such as Parent to Parent, Fathers Network & PAVE, **FQHCs** = Federally Qualified Health Centers, **ITEIP**=Infant Toddler Early Intervention Program, **MHLN**=Medical Home Leadership Network, **MAA**=Medical Assistance Administration (Medicaid), **professional organizations**= Washington Chapter American Academy of Pediatrics (WCAAP), Washington Chapter, American Academy of Family Physicians, Washington State Medical Association etc., **RSNs**= Regional Service Networks (for public mental health services)