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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
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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)

II. METHODS

Purpose: The purpose of this needs assessment was to guide planning for future activities to support medical homes for families, children and youth with special health care needs undertaken by the Medical Home Leadership Network (MHLN) and the Washington State Department of Health Title V Children with Special Health Care Needs (DOH-CSHCN). In 1993, the DOH-CSHCN Program explored physician attitudes, barriers and successful strategies for the provision of a medical home for the population of children with special health care needs. Findings from that set of interviews and subsequent statewide survey (pediatricians and a subset of family medicine physicians) were documented in the original Medical Home Project Report. Since that time activities to support medical homes have been pursued in the state of Washington with the development of ‘medical home resource teams’ in many communities in the state and the Medical Home Leadership Network (MHLN). Many of the local activities of these teams have focused on community linkages, parent linkages and practice tools for children and youth with special health care needs (CYSHCN). This year the DOH-CSHCN program decided to assess the MHLN team physicians’ current experience of serving children and youth with special health care needs and to see how care for children and youth with special health care needs has evolved for providers.

Respondents: Eleven of the 17 physicians active on MHLN community teams participated in the needs assessment. The MHLN consists of 21 volunteer, multi-disciplinary, community-based resource teams representing 25 of the 39 counties in Washington. Team structure is fairly consistent throughout the state with a physician (usually a pediatrician), a parent, a public health nurse Children with Special Health Care Needs Coordinator, and a Birth-to-Three Family Resources Coordinator. Some teams have also added additional members from other groups such as schools, Head Start, mental and/or oral health. Each year the teams identify one or more areas in which to improve medical homes (family-centered, coordinated, comprehensive primary health care) for children and youth with special health care needs in their communities. The teams also serve as resources and consultants for their community colleagues. The physicians for each team were selected to participate in the MHLN because of their expertise with children with special needs in their community. There has been very low turnover in team membership. At the time of this survey, each team physician had been active in the MHLN for between 3-10 years.

Survey Instrument: Kate Orville, MPH, Co-Director of the MHLN and Katherine TeKolste, MD, FAAP, and Medical Consultant to the MHLN, developed the design of the needs assessment, implemented the survey instrument and analyzed the findings. After review of previous MHLN team surveys, the 1993 Washington State Medical Home Needs Assessment, and current literature, a draft of survey questions was developed. This draft was reviewed by the DOH-CSHCN Program and their suggestions were incorporated into a final survey (See Appendix). In addition to the questions relating to medical homes, the survey covered the topics of nutrition services and adolescent health care transition. Both of these areas are of high interest to the DOH-CSHCN program which funds activities in these areas.

The initial plan to send a written survey to the team physicians was modified to a series of individual telephone interviews with the hope that MHLN staff would better capture details of what successes and difficulties physicians were currently experiencing, what strategies to support medical homes were working particularly well in their practice or their community, and their vision of the future of medical homes. The revised survey was piloted with one medical home team pediatrician and, as a result an additional question was added to the survey.

After the first few interviews, it became clear that more information was needed about how each practice was organized and whom they served because this affected the barriers and facilitators for medical homes in the practice. Further questions were added to ascertain the number of medical providers in the practice, support staff, and patient population characteristics (percentage of children and youth with special health care needs, Medicaid and other insurance coverage, and families for whom English was not a first language).

Survey Administration: Seventeen (17) active Medical Home Leadership Network physicians (including 1 family physician and 1 internist) were contacted by email and/or fax to schedule 45-60 minute interviews. Two or three requests were sent to physicians who did not initially respond. Eleven (11) physicians completed the interview (10 by phone and one in person) during November, December and March (2004-5). Three phone interviews were conducted with both MHLN interviewers; the remaining 8 interviews were completed by one or the other of the interviewers. Extensive notes (hand-written or computer-entered) were recorded during the interview, then reviewed and organized. Preliminary responses from the first six interviews were analyzed and shared with attendees at the November 19, 2004 Medical Home Summit.

This report contains the summary and analysis of the findings from the interviews with the 11 physician respondents from across the state. Kate Orville and Katherine TeKolste analyzed the data and wrote an initial draft paper. This paper was reviewed by Stacey DeFries and Maria Nardella from the DOH-CSHCN Program and Dr. Forrest C. Bennett, Director of the MHLN, and their suggestions incorporated into the final report.

III. ANALYSIS

A. Practice Characteristics

Eleven physicians participated in the interviews. Of these, two were from Eastern Washington, three were from Central Washington, and six were from throughout Western Washington. Ten of the respondents were pediatricians and one was a family physician.

Three (3) practices were multispecialty-clinic based, 2 were multispecialty Federally Qualified Health Centers (one operating as a private multispecialty clinic), 4 were pediatric practices with multiple practitioners, 1 was a public health clinic practice with several primary care providers, and 1 was a solo pediatric practice with a nurse practitioner. The majority of the physicians (8) interviewed represented rural practices serving primarily rural or small town populations.

The percentage of the children and youth seen by the physicians who had special needs ranged from estimates of 10% to more than 50%. The National Survey of Children with Special Health Care Needs (CSHCN) estimates that 14% of children have special needs in Washington State. Most of the providers interviewed see a higher percentage of these children. Three of the 11 physicians interviewed reported that between 30-50% of their patients were children and youth with special health care needs.

Many of the children served by the physicians interviewed were poor or low income. Medicaid was a big insurer for the children seen by these providers- for the 7 providers for whom insurance information was asked, the lowest percentage was 1/3 for Medicaid, military and uninsured—the rest of the providers saw 50-55% Medicaid, up to all Medicaid and/or uninsured. At least 7 of the 11 providers had a substantial number of families in their practice for whom English was not their first language.

B. Key Medical Home Components

The American Academy of Pediatrics defines a medical home as primary care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective.

A medical home is not a building, but rather a team approach to providing primary health care services in a high-quality and cost-effective manner.

In a medical home the child or youth, his or her family, primary care physician, and other health professionals develop a trusting partnership based on mutual responsibility and respect for each other's expertise. Partners share complete information with each other.

Together, families, health care professionals and community service providers identify and access all medical and non-medical services needed to help the child and family.

Medical homes are especially important for children with special health care needs and their families. However, all children benefit from coordinated, family-centered care.

--Washington State Medical Home Website
www.medicalhome.org

The definition of medical home is large and encompassing. We were interested in finding out how physicians prioritized, conceptualized and implemented the concept in practical ways.

What pieces of medical home do you consider most important, i.e. where do you put your efforts in your own practice?

While there was a range of answers to this question, every physician said that care coordination was a critical component of a medical homes and where they focused energy in their own practice. All of the physicians were personally involved in care coordination activities, usually with the help of office staff and often community services. Care

coordination was also seen a critical disincentive for other practices to serve children and youth with special needs and a frequently frustratingly time-consuming activity for the physicians. Funding to pay for care coordination for patients with special needs in general and for children and youth with mental and behavioral health in particular was cited as important for medical homes to thrive. A more detailed discussion of what care coordination services physicians and their practices provided, barriers to care coordination, and successful strategies to address these barriers can be found in the section on Care Coordination.

The second medical home area of focus for the physicians was the provider-family relationship.

Physicians described provider-family partnership as:

- Give and take
- Empowering, educating and supporting the family, including telling them about the medical home concept, and discussing have a care notebook
- Provider attitude of “healthy humility”- I don’t know “If you feel you know everything, it doesn’t work well. You need to be able to say to the patient and family—I don’t know about that but I’ll find out, or here’s a referral and come back so we can talk follow up”.

Several physicians also talked directly about the importance of having this provider-family partnership extend beyond the physician. There needed to be a philosophy and attitude of welcoming children and youth with special needs and their families by the entire practice and office staff, not just the individual primary care provider, for medical homes to work. The “office staff needs to be helpful and focused on meeting the needs of the family”, said one physician who was concerned that office staff sometimes seemed to be more concerned with “protecting” the physicians.

A final theme from the physician respondents was the need for infrastructure and funding at the practice and community-level to address the needs of families and practices make medical homes feasible. A physician whose practice used electronic medical records (EMRs) said that he thought EMRs were a key component of medical homes. Another physician reported that she believed the number one criteria for medical homes was having open access to health care services in the community. This physician said that the physicians in her community partner with each other. For example, children were accepted into any practice, regardless of the type of insurance they have, leads to Medicaid burden not disproportionately affecting any one practice. She said if community providers do not agree to provide open access, then the practice that welcomed children with Medicaid would be at a financial disadvantage. At least one other practice in a community where it was the only practice welcoming children who had special needs or Medicaid coverage, faced long-term financial vulnerability.

C. Quality Improvement Activities

Do you/your practice have a formal or informal mechanism for Quality Improvement? (not limited to a focus on children and youth with special health care needs)

There is a movement nationally and in Washington State to improve medical homes and healthcare generally through learning collaboratives and other quality improvement (QI) measures (for example, the National Initiative for Children's Healthcare Quality, the Institute for Health Improvement, and in Washington State Kids Get Care and the Diabetes Collaborative. Having a process in place to get input from families and improve services is increasingly considered an important piece nationally of medical homes). We were interested in finding out if physicians and their practices had mechanisms in place to improve the quality of their services and if so, what their experience with QI activities had been.

Most of the 11 physicians interviewed expressed substantial interest in healthcare QI. However, the current QI activities actually undertaken in the clinics ranged considerably. The majority of practices (8 of 11) reported having at least some sort of basic formal QI process.

Several clinics had extensive QI activities woven into the fabric of their regular operations. Of these, immunizations, asthma and Attention Deficit Hyperactivity Disorder (ADHD) were the most common areas of focus. For example, two practices had been involved in studies on vaccines and how well the whole community was doing at getting immunized. One practice looked at how to standardize ADHD treatments within the practice. Another adapted national guidelines for asthma and ADHD to the community. Other topics mentioned were obesity and eating disorders, well child visits, and newborn hearing loss. Two of these practices belong to large multidisciplinary groups that regularly participate in extensive quality improvement projects. One physician reported that the head of his department was interested in looking at care plans for children.

A couple of clinics with electronic medical records used them to generate reports for QI purposes. Reports included well child visits, immunizations, abnormal newborn screens and hearing screens, and lead levels.

Two clinics started Parent Advisory Groups in the past year or two. One of these groups had parents who had children with special needs as well as parents who had typically developing children.

At least three clinics had regular meetings (weekly, biweekly or monthly) of clinical and/or other staff to discuss and address issues as they arose. Two of the clinics had a notebook or whiteboard for any staff member to record issues to be brought up at the regular meetings.

A couple of other practices met with community partners on a monthly basis to review and develop care for individual children with especially complicated needs. This serves as both a quality improvement and care coordination activity. One of these practices also did chart reviews for all their children with special needs. A nurse and one staff member went

through all the charts on a regular basis and sent reminders for upcoming appointments. However, this generated so much work that they had to back off for a while.

Several other physicians reported that the primary quality improvement activity in their clinics were provider chart audits. Physicians had a certain percentage of their charts audited with the emphasis on the quality of overall charting and coding.

- One physician reported that the provider chart audits done by her clinics were helpful to her. Once a month the clinic selected one or two providers to have their charts audited. All the doctors had to be part of the audit team 3 times a year. The teams looked at quality of care, especially around coding. This physician reported finding it very helpful to see what others are doing. The teams looked at the medical record—was there a history and physical? Was treatment appropriate? The physicians looked at that part and then other members of the 3- person team looked at whether the chart notes indications of the patients’ smoking and other details. The process looked at the quality of overall charting coding, and then the provider was given feedback. “It’s hard to get the feedback but good”.
- Another physician reported that each doctor had a certain percent of charts that were audited by the internal QI Department, to see whether dictations were signed, etc. “You see your results on your performance review”.
- A physician at a large practice reported that there was a “whole arm” of the clinic that focused on QI. However, the QI focus might be on coding or documentation (not discussed) because this physician also said that quality assurance for following practice parameters etc. happened more informally, including through the regular influence of new, recently trained pediatricians joining the practice.

Insurance companies and hospitals provided an additional source of quality improvement activities for several practices.

- One physician reported that in addition to internal chart audits, that once in a while insurance companies would look at immunization rates or do an audit—this was sometimes helpful, especially with the immunization information. However, she said that she might only have one person insured by that company which limited the usefulness of the information.
- Another physician noted that insurance companies did chart audits to check on things like whether the doctors were counseling patients to quit smoking, recording allergies etc. She said that the local hospital also went through the charts, but that they were checking more on competency than actively improving care.
- A couple other physicians mentioned the Healthy Options consumer surveys but said that these were less useful to the practice as a means of improving services.

D. Identification and Tracking of CSHCN

How do you know WHO in your practice is a CSHCN? How do you identify them or track their charts?

(Note: The federal government and healthcare quality improvement groups promote the use of electronic clinical systems to support and improve patient care. However, the use of electronic information systems in health care still lags behind other sectors due to high costs of implementing these systems and the lack of national standards. A recent study found that only 17% of physician offices nationally use electronic medical records (CDC, March 2004). This did not vary significantly by region of the US. Seventy-three percent of physician offices had electronic billing systems.)

Physicians reported a variety of ways to identify their patients who had special needs. This ranged from using electronic databases to informal lists. One physician said that the practice did not have a good way to identify children and youth with special needs.

At least four MHLN team physician practices had electronic medical records (EMR) (this question was not explicitly asked). Of these four, three practices used their EMR system to identify their children with special needs.

- As one physician reported, the practice could identify children by diagnoses. All the medical charts were now on electronic records -- “this came in handy with flu immunizations”. They were able to stratify patients by cardiac, respiratory problems, and different types of developmental delay. This allowed them to come into compliance with the Centers for Disease Control guidelines very quickly and send out notification letters to all the patients who should come in and get their flu vaccine.
- Another physician reported that their practice could pull up a list of children with special needs either through the EMR or by hand. “Everyone remembers their 10 <medically fragile> or so”. When a new pediatrician joined the practice they were able to make her a binder with care sheets for all the children in the practice who were medically fragile.
- Another physician with EMRs reported that every time a child with special needs was seen, that special need was updated and entered into the EMR problem list.
- One physician reported having EMRs in the clinic and internet access for the computers. However, they learned they did not have a good way to identify the children through the database when they were trying to identify high risk children who need flu shots this year. This physician made a list of her children with special needs – about 25—so that the other doctors knew about them in her absence.

One practice reported that they did not formally identify or flag their children with special health care needs, although it was unclear if they possess the ability electronically.

Another practice did identify their children and youth with special health care needs although it was not specified how.

Billing Systems

One practice reported that they could identify patients by diagnosis through their billing system. They had a box on their fee slips where a chronic diagnosis could be recorded. The practice found this very helpful when they needed to identify groups of people. For example, for flu shots, they pulled out all the premature babies, children with diabetes etc. The staff would then take the list and ask the doctors if there was anyone else who should be added to it. The doctor called this system “a nice tool.”

Chart Flagging

Only two practices mentioned flagging charts for children and youth with special needs. One practice which used a billing system to identify special needs put a special needs flag on charts for immunosuppressed patients (such as a child with a liver transplant) in order to get them quickly out of the waiting room and into an exam room. This was done for a limited number of patients. Another physician put stickers on some of his charts, but the other physicians in the practice did not.

Problem lists

In one practice all the doctors had problem lists inside the chart cover for their informally identified children and youth with special health care needs. Many of the practice’s physicians had lists of “frequent users” for the front desk staff and tell them to only make appointments with their main doctor.

Informal lists

Several practices used informal lists of children and youth with special health care needs based on the patients who the clinic knows from their frequent visits.

Staffing Meetings

Sometimes children were identified as having special needs through staffing meetings to address children with more complex care needs. At least three practices had a process in place to hold a meeting with the family and all the important care providers, from the clinic and the community, to collaboratively address the needs of a child with particularly complex needs.

FAMILY INPUT

How does your practice get input from parents/patients?

Most of the physicians interviewed said that their primary means of getting input from patients and parents was informal and occurred usually during the patient visit. A number of physicians noted that they did not assume that this meant they knew for certain how patients felt about services. As one physician reported, the clinic relies on informal customer feedback- patients/families telling the clinic when they are dissatisfied and want something done differently. This physicians said that from a medical point of view the quality of

services in the clinic were demonstrably outstanding, but noted that the quality of medicine and customer satisfaction are not always the same thing. Another physician who had many families transfer to her because of the care coordination she provided, noted that she usually only hears if families are unhappy about something. There is not a lot of transferring from the practice which would be a sign of dissatisfaction she said, but there also are not a lot of other alternatives in the area either. Only one physician reported preferring family input that happened within the individual patient encounter.

Several practices have more formal means for parent input. Two practices had recently started family advisory groups. One of these practices also had a consumer on its Board of Directors. A multispecialty practice held patient focus groups practice-wide, but did not have an ongoing patient feedback loop. A couple of practices with a large number of Spanish-speaking families said it had been hard for them to get parental feedback – one wondered if culturally it was hard for these patients to give input, at least in the ways they had been asked so far. Another practice tried parent support groups through the clinic, but said the groups did not last, perhaps because the perceived need felt by families for the groups varied such much over time.

One physician mentioned a paper patient survey that the practice did 1-2 times a year, as well as a patient survey that a health care plan did of patients in the practice.

In addition to informal input, some physicians received parent feedback through other health care providers, including the local Family Resources Coordinator (FRC), the public health nurse Children with Special Health Care Needs Coordinator, and nurse aides in the clinic (one of whom was a parent of a child with special needs).

A couple of physicians with large Spanish-speaking populations said it was hard for their clinics to get family input, although the physicians would like more. Another health care organization in one of the counties has a Parent-to-Parent group and so they get a lot of parent input.

CARE COORDINATION

How does your office coordinate care for CSHCN?

"**Care Coordination** is a collaborative process that links children and families to services and resources in a coordinated manner to maximize the potential of children and provide them optimal health care." [AAP Policy Statement - Care Coordination: Integrating Health and Related Systems of Care for Children With Special Health Care Needs](#)

Care coordination can include a wide array of activities to help patients and families understand their health needs and to access and use medical and community services in an

efficient manner. Examples of care coordination activities cited by the physician respondents included:

- Helping families access equipment and specialty services
- Helping families access emotional and social services support
- “Trying to arrange what’s needed”
- Reminders/recall for regular chronic appointments or flu shots
- Responding to phone calls from families with questions
- Providing continuity of care—one place to call where someone knows them
- Coordinating services with mental health professionals and schools
- Referring patients to other providers
- Helping patients and families understand the importance of coming back after seeing the specialist
- Providing follow up to make sure patients make it into other providers and facilities
- Attending staffing meetings called by outside providers such as the speech therapist
- Developing a care plan for the patient
- Filling out paperwork for insurance preauthorizations, medicines at school, durable medical equipment (DME) requests, insurance documentation
- Sending reminder letters for well child visits
- Following up for flu shots or Synagis with families of high risk patients

Care coordination activities may or may not be called by this name within the practice. For example, one physician reported that in his practice they described these activities as “care management”, and another physician reported that they used a different description as well.

All of the MHLN team physicians were personally very involved in care coordination activities. Ten of the 11 respondents worked closely as a team with their office nurse or medical assistant to provide care coordination. Some of the clinics provided the physicians and families with assistance from designated care coordinator positions. Most of the physicians worked closely with external care coordinators as well, especially Family Resources Coordinators and public health nurse Children with Special Health Care Needs Coordinators.

Internal Care Coordination

Typically physicians had help from whoever worked closely with them in the office. This was usually a nurse, but sometimes a medical assistant. Some offices divided tasks with for example, the physician developing a care plan, filling out prior authorizations forms and durable medical equipment (DME) requests, and the nurse making phone calls to insurance companies, community services and schools. One physician gave an example of the physician and nurse working as a care coordination team when the physician called the school and the office nurse talked to the home nurse. A couple of physicians said that they felt it was important that the person providing care coordination had some clinical training, e.g. a nurse, in order to fully understand what they were trying to coordinate.

In one small practice it was just the physician who provided care coordination services. However, the physician reported that she might have the office nurse start taking on more of this responsibility after this recently-hired nurse had been in her position longer.

In several of the larger pediatric practices, there were specific care coordination positions and sometimes departments to provide care coordination services. The physicians who worked in these settings said that the structure made a huge difference in their ability to serve their patients.

- One pediatric practice with several offices had hired nurses to do most of the care coordination for patients. The 3 clinics have 5 full-time nurses between them who do care coordination, working 10 hours each. The nurses took care of medicine refills, contacted specialists, coordinated with parents, the school district, etc. In addition there were two full-time referral people between the 3 clinics. The doctors also spent time linking with the schools or letters for durable medical equipment etc. The physician from this practice reported that having the office nurse case managers provided an invaluable service with care coordination and made a huge difference for the work he did. He thought that the clinic would have to modify its patient population if the nurse case management services were cut.
- Another similarly sized pediatric practice also had a large care coordination system. A bachelor level Registered Nurse (RN) administrator managed the whole nursing team. In addition, they had a Department of Care Coordination with two aide-level employees with the skills to understand the system. These two employees were paid \$12 per hour to provide two functions for all the children, regardless of insurance—obtain authorization for insurance and obtain referral appointments and consultation. In addition, the clinic had a half time person whose only function was to provide patient recall to the practice. For example, if a child with special needs had a chronic illness, e.g. moderate persistent asthma, they would have a review appointment every 3 months. Children with Attention Deficit Hyperactivity Disorder (ADHD) who are taking medications for their ADHD were treated the same. **All** children were on the well child recall system. According to the physician interviewee, this system “ensures that well child and chronic illness paradigms are followed”.

Of particular interest, this clinic has successfully negotiated with one of their Medicaid health care plans for increased funding to provide care coordination and a follow up and recall system. This increased funding for care coordination and follow up was seen by the physician as a critical piece of medical homes.

- One physician in a large multiclinic setting reported a very successful use of referral coordination that had since been replicated throughout the system. One of the clinics had a referral coordinator who was “indispensable” to the smooth functioning of the clinic. This referral coordinator was a very detail oriented high school graduate who handled transportation, interpreter services etc. for patients. She did not handle clinic questions, but she would find out where someone could get into service earliest by calling around. She was “good at not losing people” and freed up the RNs to do

nursing again. The physicians at the clinic really liked what she was able to do too. This coordinator meticulously kept data which proved that the RNs saved time because of the work she did. As a result, all of the clinics in the system now had the same referral coordinator position in their clinics too. This coordinator also kept data on referrals that were denied after the changes in undocumented clients came out which was very helpful for the clinic.

- Another physician provided care coordination through what he called his team—himself as the physician, his RN, the Birth-to-Three Family Resources Coordinator, the local public health nurse CSHCN Coordinator and the clinic's utilization department (which makes referrals to specialists). Each clinic site had one utilization person.

Care coordination for children and youth with behavioral and mental health issues was an area of huge interest for many of the physicians. Two physicians provided examples of strategies that they believed addressed the mental and behavioral health care coordination needs of patients:

- One physician reported that her clinic had a Primary Care Mental Health worker at the clinic. This person worked 3 days a week and when she was there, her door was always open. Physicians could walk a family down the hall to her office – sometimes the mental health worker could meet with the family right then. But even if the family had to make an appointment, the reporting physician said that onsite care was better tolerated by the patients than going to a mental health clinic. The mental health worker did triage and assessment but also follow up appointments (as well as some independent individual and family counseling in practice outside the clinic). She served adults as well as children. If the family was experiencing an emergency, the worker would call the emergency response team and wait with the family or individual. The worker was good at recognizing if the mental health problem was too big for her and she would get the family to other services. She saw people for follow up appointments but seemed to be able to keep number of visits shorter to keep her open. The physician called this worker a “valuable extender for the practice”.
- Another physician reported that she saw funding for mental health needs as one of three critical components of a medical home. She said “we need our partners to develop funded collaborative models that include primary care nurse managers.” She went on to highlight good studies of collaboration where the diagnosis and medication were started and then the nurse manager did the medication management and family education in partnership with the primary care provider. The nurse taught the family and patient “about what mental health illness is, why they needed a diagnosis – this helps ensure the family will follow through with diagnosis, counseling, and medication”. Without this indepth education and support for families of the 5-7% of school age children with moderate to severe mental health needs/illness, she said the families would not follow up with the medical management, school attendance etc. and the children were much more likely to hit a crisis- suicide, run away.

External Help with Care Coordination

Several physicians said that the care coordination help they were able to provide their patients through the Family Resources Coordinator (FRC) and the public health nurse Children with Special Health Care Needs (CSHCN) Coordinator was invaluable. These public resources were credited as being able to keep up-to-date and knowledgeable about community resources and thus more effectively link patients to services than the practices were able to do. A couple physicians reported that they also provided the physician with important feedback on patient needs and community services – one physician said it was his most important source of getting real family feedback.

Two physicians specifically said that they used FRCs to help coordinate care for their younger patients and that they missed not having access for their older children to the relatively organized world of services for children birth to three.

One provider said that in addition to care coordination services provided by the doctor and nurse in the clinic, that the health insurance company had been very helpful for the children with special needs that they assigned case managers to. These case managers had “really helped to find resources that we would not have been easily able to find otherwise.”

One physician said that in addition to the other care coordination services the clinic provides, that a close relationship with a dependable home health service company was a big help in providing coordinated care for their patients. For example, the home health service company stocked nebulizers in the clinic that the clinic could hand out directly to patients who need them. Billing for the nebulizers was handled by the home health service company.

Care Coordination Tools

Several physicians identified tools they used to help keep care coordinated between providers within their office. This included:

- Problem lists in the front of the chart for all patients but which were updated frequently for children and youth with special health care needs. The problem lists served as a communication tool between providers. If another provider covered for that child, s/he would know what the most current issues and medications were. It saved the doctor from rifling through the chart and the family from having to explain everything all over again. For well children, the notes might just say “well child” or if there are more typical issues, “constipation” etc.
- One practice used time at the monthly staffing meeting to discuss care for patients with ongoing needs. The main purpose was so that the doctor on call knows what is needed. The meeting was 2 hours, once a month and the pediatricians advocated strongly for the meeting. It was also the time to put questions out to the broad multidisciplinary group that participated in these well attended meetings -- Indian Health Service, public health, sometimes Head Start, FRC etc.
- Special meetings called for individual children. In one practice the school nurse would come to the practice for a staff or medical education (“med ed”) staffing that the physician attended twice a year. The medical education staffing was for the parents, primary care provider, school nurse, social worker, etc. It was not an

individualized Education Plan (IEP) but rather for the child with seizures, asthma, severe food allergies etc. and looked at the medical component. Another practice held meetings they called meetings of the “Board of Review”. The family and all of the people involved in the care of the child met in the same place to address a broad plan for a specific child.

- Reminders for follow up visits, well child visits, flu shots etc. generated either electronically or through RN chart reviews.

Barriers to Care Coordination

There were several barriers to care coordination that stood out in the discussion of what physicians and their practices do for their patients and families.

- The paperwork and insurance phone calls involved in some care coordination activities were a huge frustration for the physicians. Specific examples cited were the time it took for durable medical equipment (DME) forms, prior authorizations for procedures, equipment, starting up some new medicines, and billing paperwork.
- Coding for correct reimbursement involved increased account tallying. Clinic visits with patients who had special needs often took longer than for other patients. However, it was difficult to be reimbursed for the time spent, even if theoretically the time was reimburseable. For example, one physician reported that he would bill according to the time spent and complexity of the patient’s problem. However, he said that the amount of time it took his clinic to resubmit the bill to the insurance company each time it was denied took too much time. They did studies within the clinic to look at the cost of this process. Now, even if this physician spent an hour with a patient, he only billed for 30 minutes because the clinic so rarely get paid for the full hour and wasted too much time arguing about it. He reported frustration that the insurance companies said you needed detailed documentation and time in and out with notes, but then when you did this, “they fight you”.
- Care coordination was harder for older children because of the more fragmented system of care for children older than three and the ending of Birth-to-Three Family Resources Coordinator services for that population.
- Physicians also cited as a big problem the increasing amounts of time required for care management for patients with mental health or behavioral problems who were seeing the primary care provider because they could not get in to see a child and adolescent psychiatrist.

Care Coordination Discussion and Models

Public clinics that function as a Community Health Center or a Federally Qualified Health Center have an advantage over a private practice in both reimbursement and staffing that can serve to make provision of staffing for care coordination easier in this setting. However private practices can make this work, though there is more worry about the time and reimbursement issues in this setting. As one physician from a private practice with many children with special needs said, “(It) would be great if time spent coordinating was paid for – realistically, we lose money on children with special health care needs. That’s what scares me...Doctors go into medicine to help people, but you also need to keep your clinic open – you need to make good business decisions.’

What seems to be key is that someone needs to be in charge who is known to the family and provides consistency for them. Care coordination ranges from ‘easy’ to provide and facilitate to ‘overwhelming’ to provide for children and youth with special health care needs and their families who have complex and wide-ranging needs. “If patients and families need survival help it’s bigger than typical care coordination”. Practices need links to outside resources or subsidies. Services and solutions need to be different for these differing levels of complexity.

Examples of Models that are Working in Washington:

Model A

- Part-time Medical Director Position
 - Care plan creation and implementation
 - Managing practice partner collaboration, education and decision-making
 - Grant-writing
 - Collaboration with community partners

Model B

- Multispecialty clinic (30% CSHCN; 40-50% Medicaid) with each pediatrician assigned a nurse and 2 MAs between the 3 pediatricians. Many specialists available on site. RN and MAs spend a lot of time on the phone, physician helps too; They also coordinate with schools and behavioral counselors and teachers; Work with case managers in insurance plans.
- ‘Most dramatic improvement of medical homes came from hiring developmentalist ... (he) has the ability to deal with bureaucracy...navigate all the acronyms. (He) was hired to be a 50%+ developmentalist but role has expanded exponentially. Once he came here we got a lot more special needs children. (He) is doing a lot of outreach to neighboring communities north of our county ...providing help with ADHD, coordination of care for medically-challenged children...doing outstation clinics which are primarily developmentally focused. They will be doing telemedicine in <outlying regions>... – allows us to be consulting physicians.”

Model C

- To promote a medical home, tell other physicians “it can save time and prevent long term complications, or can increase reimbursement. It can work within a busy practice. But as it stands right now, there are really no cost savings. It takes time to coordinate which works OK in a Community Health Clinic but would take a lot of resources in a private practice.”
 - The clinic is a FQHC/CHC but operates as a private practice. MHLN physician spends 1 day plus 2 mornings per week in clinic at 3 sites (and 2 afternoons a week as medical director of the clinics. Clinic has about 10-15% (rough estimate) CSHCN. FRC is located at the clinic.
 - Care coordination is by the team – MD, 2 nurses, the FRC, PHN and a ‘utilization person’ making referrals to specialists (one at each of the three clinic sites). But care coordination could be improved. There is not a specific

person to do this and it is a financial issue as to how to pay for that position. FRC and PHN do lots of home visits and that helps.

Model D

- Difficulty with mix of mental health, behavioral and cultural issues with lots of poverty, domestic violence, and abuse. But all providers in community are willing to take Medicaid. Specialty care is available through neurodevelopmental center, outreach clinics, and tertiary care centers in Seattle and Spokane.
 - o A primary care mental health worker is in the clinic 3 days a week (generally with an open door policy) who manages some patients and will call an emergency response team when needed. Sees a need for an infrastructure to provide families with what they need – SLP, OT, etc.
 - o Referral coordinator is available who handles transportation, interpreter services, etc. This position saved the RN time making it cost efficient to fund. The position was introduced into other clinics in the system.
 - o Other care coordination comes from FRC at the neurodevelopmental center for the 0-3 population and from nurse-physician team for older children.
 - o Would like to have money to put toward a resource/care coordination piece internally (not referrals) to make calls to schools, be part FRC and part parent advocate; would also like to hire a social worker.

NUTRITION SERVICES

Now I'd like to ask you about Nutrition Services in your county. Who do you use if you have a child who needs nutrition services—(prompt for Feeding Team and Nutrition Network nutritionists if it doesn't come up)—Please describe any barriers to using nutrition services.

All of the 11 physicians interviewed described multiple nutrition services that they used in their community for children who needed nutrition services. The most common pattern was for physicians to refer to:

- the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) nutritionist (typically located in the local health department but sometimes within the physician's own clinic),
- the interdisciplinary community feeding team (local or in one case, tertiary-care based outreach feeding team)
- and at least one other dietician or nutritionist, often based in the local hospital.

Feeding Teams

Washington State has a network of community-based interdisciplinary feeding teams who can address feeding and nutrition concerns for children with special health care needs. The teams address all issues of food and feeding and identify any subsequent services/therapies needed by the child/family.

Most of the 11 physicians were aware of and had used their local feeding team. However, this ranged from regularly referring to the feeding team to one physician not being aware that there was a feeding team in the county. Another physician said that the feeding team in her county was underutilized and thought it was because providers in the community did not know how to use the team.

- One physician reported regularly using the local feeding team that included the local public health nurse CSHCN Coordinator he works with regularly. He noted that the team mostly provided services to infants and preschool children but that some of the same people are also involved with older children. For example, there was a swallowing study that was done with a 6-7 year old child who had cerebral palsy.
- In one county there was a child with Failure to Thrive who was hospitalized. The parents thought the feeding team was over involved. The public health nurse had done a home visit and identified a concern. The public health nurse CSHCN Coordinator called the physician and Child Protective Services (CPS). The physician had recommended the feeding team services and CPS mandated them.
- Another physician expressed satisfaction with the Feeding Team from Sacred Heart Medical Center that visited his county every 3 months.

WIC

Some of the bigger community clinics had WIC nutritionists stationed in them. Most physicians expressed satisfaction with the WIC services and used them as a main resource for their children who needed nutrition services. One physician reported that WIC was an enormous resource for her, at least for babies and that she did not know what she would do without it. Another physician said that most of her pediatric patients were already hooked into nutrition services when they saw her, but that she referred patients to a nutritionist if there were a form that needed to be filled out with something she did not have like Body Mass Index (BMI).

- While most physicians appeared very satisfied with the quality of care given by the WIC personnel, two physicians said they had concerns about some of the WIC services in their communities. One physician said that children under 5 years were referred to WIC, but that the WIC personnel were not comfortable with children with special health care needs, even in the under 5 age group. As a result, a lot of the families took their children to the local tertiary care center. However, many families could not afford to do this, since they were struggling to pay for basic needs, including diapers. Another physician commended the local health department for the excellent nutrition and nursing services for older children they provided through home health visits where they could address weight and feeding issues. However this physician also expressed dissatisfaction with the quality of some of the advice given to parents by the WIC clinic.

Other nutritionists who provided nutrition services to children who did not have access to WIC services.

Dieticians in the Clinic

Some of the larger clinics, or clinics that belonged to bigger groups, had access to in-house dietitians. One physician said he was especially likely to refer children to this person for obesity.

Community Hospital-based dietitians, nutritionists and lactation specialists.

Half of the physicians mentioned referring to local hospital services. These services were often open to people of all ages although limited in scope (e.g. focusing on diabetes or obesity). One physician noted the high quality lactation consultation available at the local hospital and that these were also billable services. One hospital had a nutritionist who was also available to help with children with Failure to Thrive (FTT). The respondent noted that although the formal FTT work up was usually done through Mary Bridge or Children's Hospital and Regional Medical Center (where they can do calorie counts), that patients with g-tubes who were not gaining weight could be taken care of in their home county.

Nutritionists who do home-visits

Two physicians mentioned having access to nutritionists in their counties who could do home visits (but did not say where these nutritionists were housed). They considered these home visits very valuable.

Tertiary care center services

Physicians who were geographically closer to the tertiary care centers or whose communities were visited by tertiary care center teams on a regular basis tended to view these services more favorably than those whose families had to travel far to access care.

Nursing services

One physician cited the nursing services available by prescription, for example supplement and services for g-tubes etc, to help with nutrition and feeding problems.

Barriers

Insurance coverage (Medicaid or private) was the most frequently mentioned barrier – six of the 11 respondents cited it as the biggest barrier for nutrition services locally. Most of these physicians specifically mentioned lack of insurance coverage for obesity, despite the health complications that were likely for the child in the future.

- “Obesity is not considered a medical problem either through Medicaid or most private insurances, even though the kids could benefit from a nutrition consultation.”
- One respondent who reported that nutrition services for obesity is hard to get paid for, added that if coded as a growth disorder or insulin resistance, the child could get one consultation but not follow up.
- Another physician who was frustrated by the lack of access to nutrition services, noted that some nutrition services are covered for diabetes, but not for much else. This doctor said that it was a big problem with obese children with hypertension--- “kids who WILL need medicine for the hypertension but can't get the nutrition counseling covered that would prevent it.” This physician's clinic did do some counseling and follow up visits (including weigh ins) so parents did not have to pay for it.

- A family physician said that insurance is a barrier for nutrition services, but that it was not as bad for children as it was for adults. “Nutrition services often can get paid for by alternative funding sources like Child Protective Services or Birth to Three. The family usually doesn’t get stuck with the bill. With adults the problem is obesity which insurance won’t cover.” This physician also noted that in her rural community the nutrition resources for children were pretty much the same as the ones for adults.

Lack of effectiveness of some approaches to obesity which may be why insurance doesn’t want to pay (mentioned by one physician)

Lack of access to local services: One rural physician said that she “somewhat” uses nutrition services but wishes she had better access. Despite having several dietitians/nutritionists in the community including the local hospital, insurance barriers prevented many of her patients from accessing them. Some of the children she saw who had failure to thrive with intake issues had also had problems with the distant tertiary care center’s gastroenterology department. This physician noted that if her clinic could provide one thing they had not been able to to-date, it would be better dietary/nutrition support -- either a nutritionist who could come to the office or to have really good access to nutrition services at the local hospital.

Innovative approaches

- One county came up with an innovative approach to addressing the problem of childhood and adolescent obesity. This county has a structure in place and a track record of addressing pediatric health issues. A representative from each pediatric practice, the health department, school nurses and then representatives specific to the topic come together, choose a topic to address, meet for six months develop an approach to addressing the problem, get funding and do it. The county used this structure to bring together a coalition that included school nurses, psychologists, pediatricians, health department and others. They worked together to write a grant that funded using the “Shape Down” program (<http://www.shapedown.com/>) in their community to address obesity. According to the physician interviewed, this approach is the oldest and the most statistically successful in addressing the issues involved in overweight and obesity. A pediatric nurse practitioner and a community nutritionist became certified as Shape Down trainers and the county now has four more people going through the training. The Shape Down services are not covered by insurance, but are offered on a sliding scale and scholarship from the grant dollars. In addition, as a group they worked out what from a physician viewpoint was the optimal evaluation of an extremely obese child and mailed their recommendations to all the clinics in the community. As of winter 2004-05, they have had 91 children referred and are working with them. The classes are offered with 6-10 children per section—they are currently holding their fifth session.
- One clinic contracted with the county health department to meet the nutritional needs of their patients with special needs. A nutritionist came to the clinic 1-2 times a month to do a review of the nutrition needs of children with special needs. She provided an annual nutrition review, especially for those kids on feeding tubes and supplement.

- One physician reported that a local pediatric clinic affiliated with his larger multidisciplinary clinic had done some quality improvement work on pediatric obesity and overeating.

ADOLESCENT TRANSITION

Do you currently work with your adolescents with special health care needs to help them assume more of their care and transition to adult health care providers? What sorts of things are you doing?

Population Characteristics in Primary Care Provider Practices:

Most of the providers had adolescents and youth with special health care needs in their practice. None of the pediatricians interviewed accepted new patients above a certain age, either 18 or 21 years. Many providers had at least a few patients with special needs who were older than 21 years of age whom they had not yet transitioned to adult health care providers.

Providers without adolescents in the practice identified the following reasons:

- (1) The presence of Internal Medicine- Pediatrics (Med-Peds) specialists in the community. These are physicians who have done a combined medical residency program in Internal Medicine and Pediatrics and passed the qualifying boards in both. When Med-Peds are available in the community they can take on the care of adolescents and young adults with special needs.
- (2) The availability of family medicine specialists in the same clinic or in the community, combined with the lack of pediatricians, led to adolescents generally being in the care of the family medicine providers.

Are there patients you have difficulty transitioning to adult providers? If yes, what are the barriers to that transition?

Four of nine physicians seeing adolescents with special needs indicated transition to adult health care was *very* difficult, with one physician indicated this as the *biggest* problem faced by the clinic. Adolescents with some diagnoses experience more difficulty finding an adult provider than those with other diagnoses. Individuals with mental or behavioral health needs, with very complicated medical needs, or on Medicaid or Social Security Supplemental Insurance (SSI) were the most challenging to transfer. As one pediatrician reported, “internists are closed to new Medicaid patients. If I plead I can get them in. SSI is even worse.” Depending on the community, some youth with other health or developmental conditions sometimes had problems transitioning.

Physicians reported that occasionally the largest barrier to effective transition was with the family or youth rather than the pediatric provider. The adolescent has to be ready and able to be a partner in their health management, including self-management of medications.

Characteristics of the practices experiencing *greater difficulty* with adolescent transition were:

- Clinics without a formal link to adult care providers such as clinics providing pediatric care only who are not part of a multi-specialty clinic
- Located in communities where adult providers were not accepting new patients with Medicaid or SSI (because of reimbursement levels)

Characteristics of practices experiencing *fewer* problems with adolescent transition:

- Family medicine providers (rather than pediatric providers) who took care of the adolescent with special needs
- Pediatricians practicing in a multi-specialty clinic or in a clinic with family medicine physicians
 - Also allowed for easy transfer of medical record, consultation with the pediatrician after transfer, and helping the adolescent find an internist or family medicine specialist who will be a good match
 - If there is an Obstetrician-Gynecologist specialist, other elements of adolescent and adult preventive care are also easier to obtain – as one physician reported, this can be the “beauty of a multi-specialty group”.
- Communities where all practices saw all patients regardless of source of payment for care – usually a conscious decision of all the practices in a community which resulted in no one practice being over-burdened by low reimbursement rates and care management requirements for high-needs patients

Conditions present in youth with special needs who had difficulty transitioning (as mentioned by surveyed primary care providers):

- Behavioral and mental health problems –
 - Bipolar disorder, oppositional disorder, and sometimes attention deficit hyperactivity disorder (ADHD)
 - On many medications, frequently medications the internists were unfamiliar with and were likely to discontinue
 - One clinic indicated psychiatry services were being cut at the local tertiary care center and they know of no one to take on the psychiatric care; preventive services and adult care were otherwise being provided for this clinic by the family medicine specialist on site, but because of the volume of patients being referred, this physician was at risk of being over-burdened
- Complicated medical problems, including cystic fibrosis
- Children on palliative care for whom ‘there would be no point in making the family transfer’
- Autism was identified by one physician as an “emerging issue”

- *Specialty care of any kind* for adults with disabilities was a problem according to one clinic serving a very high risk/high needs population

One pediatrician said that his biggest transition struggle was with patients with behavioral problems and that he had a lot – patients with bipolar, oppositional, ADHD. These patients were on lots of medicines. He said that the internists would just take the patients and take them off the meds because they are not comfortable with the psychotropic meds. He called this a “MAJOR” problem area. This same physician noted that youth with Type II diabetes, asthma, or Down syndrome were easier to get local adult providers to take.

A physician with large transition concerns cited psychiatry concerns as a huge problem. The outpatient psychiatry clinic at the nearby tertiary care center was dropping some patients and transferring care to primary care providers. “These kids are scary when not stable”, this physician said, noting that pediatricians are not comfortable with the psychotropic drugs and the rationale for treatment decisions and how to follow the medications.

Conditions present in youth with special needs physicians considered easier to transition:

- Type II diabetes
- Asthma
- Down syndrome
- Youth with some limitations in activities of daily living as main issue

Systems needs and ‘things that work’:

- Streamlined methods for transfer of information to new providers. One physician reported the example of an 19 year old youth whose diabetes was in terrible control. This youth ended up transferring to the University of Washington for care, but the UW clinic had no information from the tertiary care center. Since the patient was a very poor historian, the adult providers did not have the information they needed.
- An assisted living house where a nurse visits regularly and most of kids live somewhat independently
- The Adolescent Health Transition Notebook was spontaneously mentioned by several physicians who said how helpful they found the materials and that they used them regularly with their adolescents with special needs. One of these physicians also specifically mentioned sharing the Adolescent Health Transition Project Timelines with families.
- Have hospital recruit Internal Medicine-Pediatrics (2 currently in one community) in a hospital-based pediatrics practice and send all adolescents to them. This has been both good and bad. Good because there is a physician to take youth with special needs, bad because med-peds specialists had a different approach to hospital pediatrics and there were too many inpatient requirements. If the hospital become dissatisfied, they would ask the med-peds specialist to leave (which the Med-Peds specialists would do).

- Clinical guidelines for special health care needs for adult providers would be helpful.
- Practice community-wide collaborative medicine so as to not over-burden any practice subset.

Can you give an example of a youth/family with special needs who has transitioned out of your practice to an adult provider? How did that work?

Strategies providers used to transition youth included:

- Often practitioners pushed age limits in the practice and just continued to see some youth into early adulthood and/or beyond.
- Pediatricians personally asked adult providers to take on an individual patient
 - One pediatric provider indicated he has had to, in most cases, personally speak to adult providers to get youth into adult services.
 - Two providers indicated this rarely worked for them
- Families found an adult physician on their own, often through their own family physician

Examples of Successful Transitions to Adult Health Care Providers

- A 24 year old patient, quadriplegic from birth, required a home ventilator, tracheotomy, and wheelchair - The family shopped around and found a practice that would take their child.
- Young woman, age 27 years, with Down syndrome and diabetes experienced a successful transition after the pediatrician connected her with a female internist. This young woman lived at home with her parents, who already had guardian status. Even though the young woman had developmental problems, she did not have any emotional problems and came from a stable, supportive family. These factors facilitated the transition according to the physician.
- One adolescent with kidney failure was awaiting transplant and trying to transition to group of family physicians. The pediatricians had the family physicians come meet her, then start seeing her. The pediatricians were available to the family medicine providers for medical consultation after the transfer.
- Starting at age 15 years, a youth with asthma experienced an ICU admissions which included consultation with pulmonary during hospitalizations. The various hospitalizations were used as way to transition the youth. Now at 23 years of age, the patient has transitioned to adult care and the pediatrician takes care of the former patient's two children who also have asthma.

Non-Medical Transition Needs

Three physicians stated their concerns for transition issues beyond the medical issues. One physician called the biggest problem faced by the clinic was “transition across the board—medical care, getting equipment, everything!” This physician gave an example of a non-medical need that was no longer paid for when children officially become adults. The

physician said that the day a teenager who cannot move and was not growing turns 18, the state will no longer pay for care for this person through the clinic's daycare and respite care center and the youth had to get out.

Two physicians who did not have problems transitioning youth with special needs, did cite concern for the lack of availability non-medical resources. "What isn't working so well in transition is meeting educational and vocational transition needs. There is no mechanism when a child turns 14 or 18 to look at their vocational or educational needs. It is mostly just left up to the school." This physician gave an example of a 17 year old with special needs who joined the clinic recently from another county. The physician was asked to see what she could do to help. She looked through the patient's file and realized she had no transitional plan documented. The physician was able to use the Adolescent Health Transition book to take out the elements of a transition plan." Another pediatrician said that while she had not been in practice long enough to have experienced much adolescent transition, and worked with family physicians who were willing to take those patients who did transition, she suspected that there were not many resources in her community like youth group living homes to support other aspects of transition.

Envisioning a Future Practice with CSHCN, Collaboration and Medical Homeness

What have you wished you or your office staff could provide to your patients/families with special health care needs that you have not been able to provide to date in your practice?

- Care coordination provision by the practice or linkage to care coordination services
 - Most of the physicians indicated the desire for more care coordination, provided on site or linked in the community. Care coordination would make the physician more efficient and 'less would be thrown onto the parents than now'.
 - Many of the information, financial, paperwork and similar needs could (and should) be dealt with at the current visit so there was 'no wrong door' to get needed assistance.
 - More Family Resource Coordinators and Division of Developmental Disabilities case managers were needed (linked with primary care practices).
 - Case managers with ability to serve ESL families were needed – Spanish-speaking, in particular, was mentioned
 - Many children with special health care needs miss well-child and other scheduled disease-management visits. A care coordinator would be very helpful to work with the family on this.
 - One practice would like a nurse to help coordinate care, but also to provide patient and family education to children and youth with severe mental health problems
- Care coordination tools for the families and the primary care provider
 - Electronic medical records and other record-keeping assists to give 'a bird's-eye view of what is happening with the patient' (perhaps listing the five most

- active problems to aid in prioritizing care and focus on needs when working with the patient and family)
 - Care plans
 - Flow sheets
 - Problem lists – one physician particularly mentioned a streamlined Medical Home problem list
- Financial support/Insurance that covered all the needs
 - Universal health insurance
 - Streamline financial eligibility process – ‘Doesn’t always work to get the child classified as disabled (e.g. SSI); some parents cannot make it through the process.’
 - Reimbursement rates: Medicaid reimbursement rates were affecting the number of family physicians seeing pediatric age patients with special health care needs. Transition to adult care was difficult because of Medicaid reimbursement and SSI reimbursement rates
 - One physician indicated that from speaking with the community’s physicians at local medical meetings he knew that physicians tend to like the medical challenge of complicated patients. The barriers to care were not the complexity but the 1) low reimbursement and 2) high amount of un-billable time involved in the care of special needs patients.
 - Thirty minutes of face-to-face time with a child and family with special health care needs leads to an hour of justification letters and communication with specialists and others involved with the patient’s care.
- Good developmental surveillance within the community – at least one physician wanted to get out to community providers with tools to address this. (Additionally, two MHLN teams contacted MHLN staff in spring 2005 and indicated this is a local team priority for this year)
- More time with patients
 - Physicians were finding the need to spend more time for less compensation in their medical practices, across their patient population. They would like to spend more time with patients and families but were uncertain how to do more than they are already doing.
 - Patient education was a priority, but needed more time to deliver this. Some physicians indicated they would like the nursing staff to be able to do more basic patient health, developmental and safety/prevention education.
- More feedback from families
 - Would like an organized group to track parent needs and feedback.
- Resources to aid in management
 - Dietary and Nutrition support such as a nutritionist who could come to the office or easy access to nutrition services at the local hospital
 - More resources in the local community – in many communities there were no providers of needed services. Children and families may need to travel a significant distance for services. In general, it was cheaper to bring a

specialist to the community than to send 10 children and families to a specialist. Services specifically mentioned included occupational therapy and speech services.

Extra Reimbursement

If you were to be given extra reimbursement for the care of children, youth and families with special health care needs, what would you be most likely to be able to provide to this population that you have not been able to provide to date?

Care coordination services - Overwhelmingly care coordination was the first thing physicians would invest extra reimbursement in (7 of the 11).

‘The best thing to increase the efficiency of our office would be to be able hire another RN. A lot of our work is on the phone arranging scheduling etc. Most offices don’t want to do this. We thought about giving up the school contract because they were down a nurse, but we couldn’t do that because they’d lose continuity of care. The RN sees the kids in school, then in the clinic, and eventually hopefully will be able to see them in their homes.’

“It would be great if time spent coordinating was paid for. Realistically, we lose money on children with special health care needs—that’s what scares me.”

- More time to do care coordination would make the biggest difference for the clinic.
- A dedicated person to do care coordination was preferred.
 - Trying to coordinate so there is one nurse regularly with each doctor so they can be the touch-person for the families.
 - Could get one person to do this fulltime.
 - There is not a specific person too do this. It is a financial issue as to how to pay for that position.
 - Someone who could do more of the resource coordination internally (not referrals)—someone who could make calls to the schools, etc. Someone who’d be part FRC, part parent advocate.
 - Give RN an extra half day to work on children and youth with special health care needs’ issues

Care plans - as part of care coordination services.

- To give a bird’s eye view of what is happening with the patient - with perhaps five highest priority problems on the list.
- Need a care plan in the electronic medical record (EMR), but it is difficult.
- Need a flow sheet
- Would encourage better use of care plans—out of care management approach would come a feedback or focus group to help direct the process of creating care plans.

Social Worker on site

Two physicians said that being able to hire a social worker for their clinic would make the biggest difference for them.

Provide behavioral/mental health help

Many patients see the physician monthly because they can't go anywhere else for mental health care. Primary care physicians are doing it more by default.

Coordination and consultation

Might be able to use more money to expand a fiber optic network which would let the group consult over a wider area.

Literature for patients

Parent and patient information handouts and 'Reach Out and Read' were given as examples.

"Extra reimbursement would not change what I do for children with special needs"

- Extra reimbursement wouldn't make a difference. I do what I need to do.
- Many patients get initial care but then don't follow up because they're afraid of the bills. One physician spearheaded an effort to create a clinic or care system for people who are uninsured – trying to pick up the bills- but it was hard to get enough funding.

Other

- Relieve practice burden by default - One practice indicated they would be relieved to see more reimbursement because it would mean other providers in the community who current do not serve this population would want them back. This would relieve a significant burden on their practice.
- Vision screening. - A photo screener in the office and training on its use and interpretation of results. It is hard to uncover vision problems unless the parent says there's a problem. This physician has specialists in the region to take vision referrals, but needs to know that there is a problem first.
- Occupational Therapy and Speech and Language Pathology(SLP). SLP is only through the school district. Patients and parents have to go out of town for services – parents might care most about these services.
- Spanish speakers in various clinic roles.
 - One clinic has a large population of Spanish speaking children and youth with special health care needs and their and families. They are hiring a staff member who speaks Spanish. They also have a receptionist who speaks Spanish and are sending her to classes to become an interpreter.
 - Children and Family Services have provided \$6000 to provide interpreter services (to the same clinic as above)—but interpreters have to be certified to pay them with from this grant. Clinic wants to hire Spanish speakers and then train them to be interpreters but have to wait until they take the first test, find out results, then go take second course, and wait for results. The end result is that the clinic cannot take advantage of the \$6000.

Who else would you want working closely with you or within your practice (e.g. care coordinators, volunteer parents, etc.)?

No response

Half of the physicians reported they already have active community collaborations and were not sure who else they would include if new partners were added.

Local health department nurses and FRCs

Several physicians discussed their active involvement with these folks and how beneficial these partnerships were. A couple of these physicians asked for even more interaction with the health department nurses.

- Could the local health department meet the needs of everyone who would benefit from greater access to the CSHCN coordinator and other nurses? Could a nurse from the local health department be stationed in a PCPs clinic half-time (perhaps through grant monies) to make it more likely that families would follow through when referred to those services? The advantage of having a person stationed part-time in the clinic and part-time in the health department is that they know what resources are current, can facilitate at a location the family is already familiar with, and the immediacy of dealing with the issue at the time of the health care visit.
- Another physician reported that “just getting our nurses in the office to have more training would be helpful”. Co-training with the public health nurses would be helpful.

Contacts with many other partners needed

Another physician who reported collaborating with many groups, noted that “there are always groups you never meet”. This practice is addressing this by inviting representatives from community programs to come to lunch at the office and introduce their program to the staff and physicians. For example, recently the local PAVE (Parents Are Vital in Education) representative talked with this practice group.

Volunteer parents

One PCP would like to have parents willing to talk to other parents. This physician already links people informally, asking a parent if she can have another parent call them. There is also a very active Parent to Parent group in the county. “People seem to be able to get support if they look”.

Care coordination

Several physicians said that the most important people they could have working with them provided or would provide care coordination and related services.

- One physician said that his office nurses provide an invaluable service with care coordination—the clinic would have to modify its patient population if it cut this office nursing service.
- Another physician indicated the office collaborated with enough people to meet their needs, but the practice would like to have a person dedicated to CSHCN.
- A physician with a large non-English-speaking population requested help from a variety of people to assist with the many needs of the clinic’s population:

- ◆ Financial consultants
- ◆ Interpreters – they are way too stretched
- ◆ Bilingual case managers
- ◆ Someone to write all the justification letters, DDD forms etc.
 - In addition, there is a need to make the forms simpler. For example, accept that some diagnoses (quadriplegia) are obvious in affecting capabilities and you don't need to ask for clarification of all 20 activities of daily living.
 - Allow someone other than MD to fill out the form – many times a nurse can do this, including times when a PHN is doing home visits and better knowledge of Activities of Daily Living than the physician.

Analyze office systems

Finally, one physician discussed how medical offices can develop a strong system to protect doctors which can result in difficulty for patients and others trying to access physicians.

“People helping me... I don't know—I'm so protected by the office staff. People can't get in to see me. If people take the initiative to get a note to my RN I know they need to see me. If I find out someone needs to see me, I can say I need to see them or they'll end up in the ER. I tell my patients – get a message to my RN and we'll figure out how to get you in. “

What other tools or devices (such as computer ports) would you want available to your office or your patients?

Note: This question was confusing for some of the interviewees.

Computer access for patients

- In some communities the local library has a nice computer with a high speed connection. It would be nice to have a couple of computers in the waiting room set to an appropriate website.
- A known website resource for the physician or the patients/families to go to or send patients to with information for patients on resources and other information. They like the idea of WA medical home website.
- Computer access for patients. In some clinics the patient population really doesn't have access to computers. It would be nice to have that available.

Patient education

(In addition to the points made above under 'computer access for patients')

- Patient education program on the EMR don't currently deal with CSHCN population. Would like more resources for this.
- Information videos to be viewed while patients are waiting in the exam room. Patients like the video format. (Note: there were a few presentations at the Sept 2004 AAP National Conference and Exhibition on the usefulness of this)

Care Plans

- Most family physicians and mid-level providers are not very familiar with care plans – Down, Muscular dystrophy, Premies – those kinds of tools would help. There is more need in those providers. Would recommend guidelines be introduced to these folks.

Personal Digital Assistants (PDAs) –Handheld computer or personal organizer device

- One self-described “non-techy” physician indicated a lot of physicians now use PDAs and perhaps the Medical Home website could list databases that are downloadable for PDAs.
- (Note: some practices have PDA’s provided through an Asthma and/or ADHD clinical improvement project through Children’s Hospital and Regional Medical Center.

Electronic Medical Records

Practices with electronic records (EMRs) were more enthusiastic about them than those without EMRs. Those without EMRs saw the theoretical benefits, but worried about the implementation. (Note: there were a number of presentations at the AAP National Conference and Exhibition (2004) about EMRs and several noted that most are currently created for adults and not pediatric-friendly; there was no one record to recommend at this time. Many sources are working on pediatric EMRs (but need to investigate how they are incorporating CSHCN, care plans, case management tools, etc.)

- Electronic medical record theoretically is good
- Part of one clinic has gone to electronic medical records. The internists are in a new building so they piloting. The main records are at the big clinic. ‘We’re working on getting EMR throughout the system but it will probably take 5 years. It’s a hard process.’
- Another clinic will be all electronic with terminals inside each room.
- One clinic has all the medical records in electronic form but the physician still has to dictate notes and then they get added. The software has patient profiles, problem lists, family history etc.—very good for children with special needs. ER department has access to all the clinic’s records. Really useful to families in the ER as well as to the ER staff. They thought a lot about having a database that the families could hold onto but it ended up seeming too difficult. Now have to go to the hospital at Central WA to get, but the system seems to be working well.

Other Tools or Needs

- Photoscreener in the office for vision screening
- Lab equipment to check hematocrits on site
- Spirometer- would be nice to do things in the clinic for our asthma and other respiratory patients
- Allergy testing in the clinic
- ‘X-Ray would be awesome but pretty unlikely.’

What (if anything) have you or your office staff been asked to do for children and families with special health care needs that you feel could be better handled in a setting other than the medical office? (I.e. Of the hundreds of things the medical community, professional organizations, and patients/families ask us to do in our practices, what could really be handled by others to free up time to do things for which our medical expertise is essential?)

*Because of time constraints, this question was only directly discussed with five of the 11 physicians.

Help with social issues, especially mental health

- Taking care of many of the social issues—people having general problems such as transportation.
- WIC is an enormous resource, at least for babies- doesn't know what would do without it.
- Domestic violence, mental health—big issues. Wish the RN could screen for mental health and then wish she had a good place to send the patient/family. Some mental health needs aren't very big – e.g. just need some family counseling—but there is nowhere to send people. Most children with mental health needs she sees have Medicaid insurance
- Help with concrete issues like bus vouchers, heating bills etc.
- Financial assistance
 - ◆ Housing authority – e.g. have to write tons of letters to have a family move to a wheelchair accessible apartment

School medical forms

- They bring in forms that have a doctor component. Schools have 2 page forms for medications that are 'stupid' - have to fill out a different form for every medication. "I don't want to fill them out but no one should have to do it."

Home visitation

- Two physicians with large Spanish-speaking populations said that the local Family Resources Coordinator and CSCHN Coordinator already do a lot of home visits for patients and "that helps a lot".
- One of the physicians talked about the importance of meeting family outside the clinic saying that it helps with trust and hopefully helps with care coordination.

Medical Home Message to Other Doctors

What do you think would most help other PCPs to do medical homes? Your thoughts on what the most effective message to other primary care providers would be?

MHLN physicians recognized that taking care of children and youth with special health care needs involves more financial risk and work for practices. Doctors go into medicine to help people, but they also need to pay attention to make good financial decisions in order to stay in business. This recognition influenced two different approaches to promoting medical homes to additional physicians and other primary care providers (PCPs).

One approach is to promote the benefits of medical homes. This can be approached with the general message that medical homes are a way to improve communication and medicine for everyone. Children and youth with special needs may be helped the most by medical homes, but all children benefit. A Medical Home is really good primary care with care coordination and family-centered care given extra attention.

Other positive messages for physicians are the things physicians can do within a medical home that makes medical homes practical:

- Collaboration makes the biggest difference and makes things easier. Ask other people in the community to help take care of our community's fragile children.
- You need to know your resources and have interpreters if your patients speak other languages.
- Care coordination is critical. Families need to have someone in the office who's in charge and coordinating things so everyone isn't doing things differently. You need a case manager. It's frustrating for families if in a practice each provider does things differently for CSHCN.
- PCPs need to understand the medical home concept which means that PCPs stay involved, even when families see specialists (Many PCPs and some families still do not understand the concept.)
- The real key for the individual pediatrician is the medical home list – you need to memorize and make it happen. The key extra is CARE COORDINATION. The rest are just exactly what you are all about as a pediatrician in the first place.
- Electronic medical records are extremely helpful.

A second approach looked more directly at the finances of medical homes. A suggested message here was that medical homes can work within a busy practice and can either save and long-term complications OR can increase reimbursement. However, this physician believed that there currently there are no real cost savings to physicians. Providers in community clinics can take the time to coordinate, but this is more difficult in private practices (although there are models). Two physicians reported that money was the only effective message. Said one: there is no message that will encourage other doctors to see more children with special health care needs. If reimbursement is increased for taking care of CYSHCN to cover the cost of care coordination, other physicians will be eager to serve these patients. Otherwise, no message will make a difference.

Roles for the Washington State Medical Home Leadership Network

How can the MHLN help you?

This question was asked of 9 of the 11 interviewees.

Eight of the 9 physicians had suggestions for how we could provide them help in their medical home activities. The two biggest areas were:

- Facilitate conversations on important medical home topics including disseminating information about “how to get there from here”. As one physician said, Physicians can see what we need to do better- but how to get there -- how to get out of the trenches of seeing patients and dealing with underfunded services.
- Continue to do what the MHLN has been doing, including holding an annual statewide meeting.

Facilitating conversations and disseminating information:

Two physicians requested help specifically around **care coordination**:

- One physician said that the MHLN could play an important role by showing and publicizing studies that show care coordination saves time and money. He pointed out that it is hard to just have care plans which are only a small piece of care coordination. Care coordination requires manpower he said, which so far is underfunded. This physician cited the studies by Dr. Richard Antonelli from Massachusetts as being very helpful. He said that if you can show that having care coordination lets you see an extra patient a day and makes you more cost effective, that would help a lot.
- Another physician requested advice on which tools and resources are helpful for CSHCN, including integrating care plans into the electronic medical record. Which electronic medical record system to use? This physician’s dream/goal is to create a product or program which deals with CSHCN. According to him, it would not have to be already with an EMR, but it could integrate.

Another physician asked MHLN to consider tackling **children in foster care** and medical homes

- As stated by this physician, “these kids are notoriously disenfranchised”. She thought it would be great if the MHLN “could facilitate some talk on the state level—Dr. Abe Bergman, state initiatives going on like double reimbursement for EPSDT, Passport program”.

Already providing help-

- Already providing help. Most useful has been the big book with all the resources (Dr. Nickel’s book). VERY USEFUL. Just used the book to look up the Down syndrome charts. Great to have these resources- most family physician offices wouldn’t have these types of resources available.
- Being able to ask MHLN staff for help getting a child evaluated for autism (at the Center on Human Development and Disability). Helped get in whole family with autism and aspergers.
- Building the team. Providing a superstructure. We’re a team—we get together and do it. Creating a template for a team.
- Community resource lists kept up by MHLN team members helpful as a new physician- now knows all resources but important for other providers that they’re kept up. (which they are)

Hold yearly meetings for teams

- Meeting every year is good. Bring people together.
- I value the MHLN- attending meetings and meeting people who are very involved. Dr. Bennett has been a tremendous leader

Websites- a place to easily find reliable resources for our patients

Policy education:

- Get word out to policy makers and agencies about how these kids are different
- Lobby for reimbursement for time spent on phone coordination - would help more physicians do it—but really probably more the role of professional medical organizations.

Coordinate with other related activities

- Connect with work at CHRMC doing outreach to community clinics
- Know adult doctors for transition

Help teams with grants

How can state agencies help and other bigger systems help?

Because of time constraints, this question was only directly asked of 5 physicians.

Physicians asked for help with the primary unmet needs they face in their communities:

- Mental and behavioral health, including not having enough pediatric neurologists or pediatric psychiatrists and primary care providers struggling to address these needs. One physician asked for help getting funding for mental health needs, including partnerships with child psychiatrists.
- Help with developmental pediatric assessment, perhaps through the local health department – for rural counties it’s hard to even to send families to regional centers – much easier if someone could come to the local county to do additional testing. “can get testing through the schools but it is slow”.
- Oral health needs. ABCD Community dental Coalitions help, but more is needed.
- Adolescents and youth- help in dealing with children when they get older- including sheltered workshops and group homes, funding and insurance- what will happen to the children when they grow up?
- Having a good school system where you can get an evaluation. IEPs can be hard to get. Advocating in school systems for evaluations and coordination, not just mainstreaming.

Support for public health nurse Children with Special Health Care Needs Coordinators and Family Resources Coordinators

- Through MHLN and CSHCN statewide having FRCs and the CSHCN Coordinators is important to maintaining and strengthening components. Include the nutrition and screening components. Make sure these resources are supported at the state level.
- If could just have public health nurses get into clinics. But danger that if everyone accessed the services, they would be filled .

Medical home materials are out there but if there is not enough advocacy it isn't enough—state policymakers needs to hear that we need:

- increased funding for Medicaid,
- increased funding for care coordination
- increased funding for children and adolescents with mental and behavioral health problems
- Universal insurance – being insured and being able to access services

Coordination between different agencies- feds, state and professional medical organizations- energy is wasted in dysfunctional conflict. “if we all coordinate efforts it can be positive at a lower cost and more rapidly”. Let’s “be focused, get the job done, and move on”.

How can state medical professional organizations like the Washington Chapter of the American Academy of Pediatrics help?

Physicians reported that the Washington Chapter of the American Academy of Pediatrics (WCAAP) and other state medical professional organizations could help medical homes for children and youth with special needs by:

- Ongoing advocacy for funding and for systems that work
 - Includes lobbying for reimbursement for time spend coordinating care
 - Advocate for increased reimbursement
 - Need to get awareness of ongoing needs onto legislative agenda.
 - Decrease paperwork, excessive administrative expenses and roadblocks from of insurance companies contracted through MAA.
 - Advocate for cost benefits of preventive services.
- Identifying the needs and then where in the state the problems are “ No can afford to open a sheltered workshop in my area without getting funding for it”.
- Facilitate getting patient literature to physicians – Perhaps they could increase professional organization dues to do this – One physician who likes a lot of the national American Academy of Pediatrics materials said that it was hard for her to get her clinic to spend money for patient materials to give away, but that her clinic pays for her professional organization dues as do many clinics for their providers.
- “They have their own set of issues. Lots of MDs don’t take children with special health care needs.”
- One physician who has been both a primary care provider and a medical director reported seeing now seeing things from “the other side”. This physician said that one of the issues is the coordination between different agencies – feds, state and AAP. “We waste energy in dysfunction in conflicts. If we all coordinate efforts it can be positive at lower cost and done more rapidly”-- be focused get the job done and move on.

- “They already are helping”. The WCAAP is trying to provide assistance to communities seeking grants by setting up a foundation to help.

IV. NEEDS ASSESSMENT LIMITATIONS

The primary limitation to the needs assessment is the limited number (11) of interviews and the time constraints on each interview. At the time, 4 of the 21 teams were recruiting new physician members and one team was in inactive status. This left us with a response rate of 11 out of 16 active team physicians or 69%. We would have anticipated a higher return with brief written surveys but did not feel this would give us enough in depth information to creatively plan new activities. The 45 minutes we told physicians in advance that it would take was a barrier for some to participate. All of the interviews went at least 45 minutes and some longer. Still this was not enough time to cover each topic equally in depth.

The needs assessment provides valuable insight into themes and models of medical homes across Washington from the perspective of primary care providers who take care of many of the children and youth with special needs in our state. This work can be built upon to promote medical homes, but does not try to represent a statistical picture of medical homes in general across Washington State.

V. RECOMMENDATIONS

The purpose of this needs assessment was 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 statewide
 - How to **recruit** additional MHLN team physicians,
 - How to **prioritize** effective medical home messages and tools

Physicians do not need to, and indeed cannot, provide a medical home through their efforts alone. The whole medical practice, other practices in the community, families, and a host of community resources need to be and should be involved.

The following areas of import/higher priority relative to providing and promoting a medical home were identified by the physicians participating in this needs assessment:

- Care Coordination
- Family-professional partnership in medical home
- Adolescent Transition
- Supporting the primary care practice – internally and externally

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
 - c. 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
 - d. Provide workshops on care coordination (*state and local agencies, family organizations, universities and other providers of training*)
 - e. 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*)
 - f. 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*)
 - g. 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:
 - a. Interpreters and information on culturally appropriate care
 - b. Mental health services and information on mental health/behavior problem identification and management
 - c. Subspecialty consultation – including possible outreach clinics
 - d. Transportation
 - e. Streamlined 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:
 - a. Care Notebook
 - b. Care Plans
 - c. Emergency plans
 - d. Transition plans
 - e. Medication management assistance(*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 videos, > 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:
 - a. Residency training programs in Family Medicine, Internal Medicine, and Internal Medicine – Pediatrics (Med-Peds),
 - b. Continuing medical education
 - c. Nursing education(*professional training programs, AHTP, professional organizations, state agencies*)
1. Increase awareness of Adolescent Transition Resource Notebook
 - a. Enhance health section of the notebook with family information and tools (*AHTP, DOH, CCSN, Family advocacy groups, Parent and youth consultants*)
 - b. Create a notebook for health care providers with tools and information to improve the health care of young adults with SHCN. Outline health care maintenance (e.g. oral health), special issues (such as menarche in women with DD, osteoporosis in CP, workplace accommodations, consent for care, etc.), tools (e.g. ER form, health history summary) and timelines for transition activities (*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*)

2. 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.*)
3. Provide youth and family education on the primary health issues (*clinics, professional organizations, family/self-advocate organizations, AHTP, diagnosis specific organizations, ...*)
 - a. Enhancing youth willingness and ability to partner on health issues, self-care, health care management
 - b. Wellness education
 - c. Health summary form
 - d. Anticipating and problem-solving health impacts on independence and employment

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)*
 - b. EMR tools specific to children and youth with special health care needs would be very helpful *(professional organizations, clinics, MHLN)*
 - c. 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)

APPENDIX A
Physician Needs Assessment for Medical Homes in Washington

Date:

Physician Interviewed:

Interviewer:

EXPLAIN purpose of interview and how info will be used

- How to **support** experienced medical home physicians who are currently active on Medical Home Leadership Network (MHLN) teams in Washington State by understanding what medical homes look like in your practice,
- How to **recruit** additional MHLN team physicians,
- How to prioritize **effective medical home messages and tools** in order to expand the number of primary care providers in Washington serving children and youth with special health care needs.

The information will be summarized and reported without names

Section I. Background on practice:

providers and support staff

% CSHCN etc.

Section II: Medical Home in Your Practice:

1. What pieces of medical home do they consider most important, i.e. where do you put your efforts in your own practice-

If no response, suggest

- identifying the CSHCN (data collection),
- family-centered care (parent input), and
- coordinated care (with the care plan part of the process).

2. Do you/your practice have a formal or informal mechanism for measuring quality improvement or care improvement (not specific to medical homes)? If it is measured, how?

3. (if not discussed above) How do you know WHO in your practice is a “child with special health care needs”? How do you identify them or track their charts?

4. How does your practice get input from parents/patients? Formal or informal mechanism? (CSHCN or all practice)

5. How does your office coordinate care for CSHCN? (if needed, prompt- suggest below) – the MD, the nurse. Is there someone hired for this role (e.g. social worker) (difference between medical vs. service coordination)

6. Now I'd like to ask you about Nutrition Services in your county—who do you use if you have a child who needs nutrition services—(prompt for Feeding Team and Nutrition Network nutritionists if it doesn't come up)—barriers to using nutrition services?

Section III: Adolescent to Adulthood with Special Needs

7.a. Do you currently work with your adolescents with special health care needs to help them assume more of their care and transition to adult health care providers? What sorts of things are you doing?

Following questions for pediatric providers:

- b. Are there patients you have difficulty transitioning to adult providers? If yes, what are the barriers to that transition?
- c. Can you give an example of a youth/family with special needs who has transitioned out of your practice to an adult provider? How did that work? (or, -how do you measure success?)
- d. are there adult health care providers in your community who take on the care of your special needs patients as they move into adulthood.

Section IV: Envisioning a Future Practice with CSHCN, Collaboration and Medical Homeness

8. What have you wished you or your office staff could provide to your patients/families with special health care needs that you have not been able to provide to date in your practice?

9. If your practice were to be given extra reimbursement for the care of children, youth and families with special health care needs, what would you be most likely to be able to provide to this population that you have not been able to provide to date?

10. Who else would you want working closely with you or within your practice (e.g. care coordinators, volunteer parents etc)?

11. What other tools or devices (like computer ports) would you want available to your office or patients?

12. What (if anything) have you or your office staff been asked to do for children and families with special health care needs that you feel could be better handled in a setting other than the medical office? (i.e. Of the hundreds of things the medical community, professional organizations, and patients/families ask us to do in our practices, what could really be handled by others to free up time to do things for which our medical expertise is essential?)

Section V: Implementing Change and Collaborating

13. What do you think would most help other PCPs to do medical homes? Your thoughts on what the most effective message to other primary care providers would be?

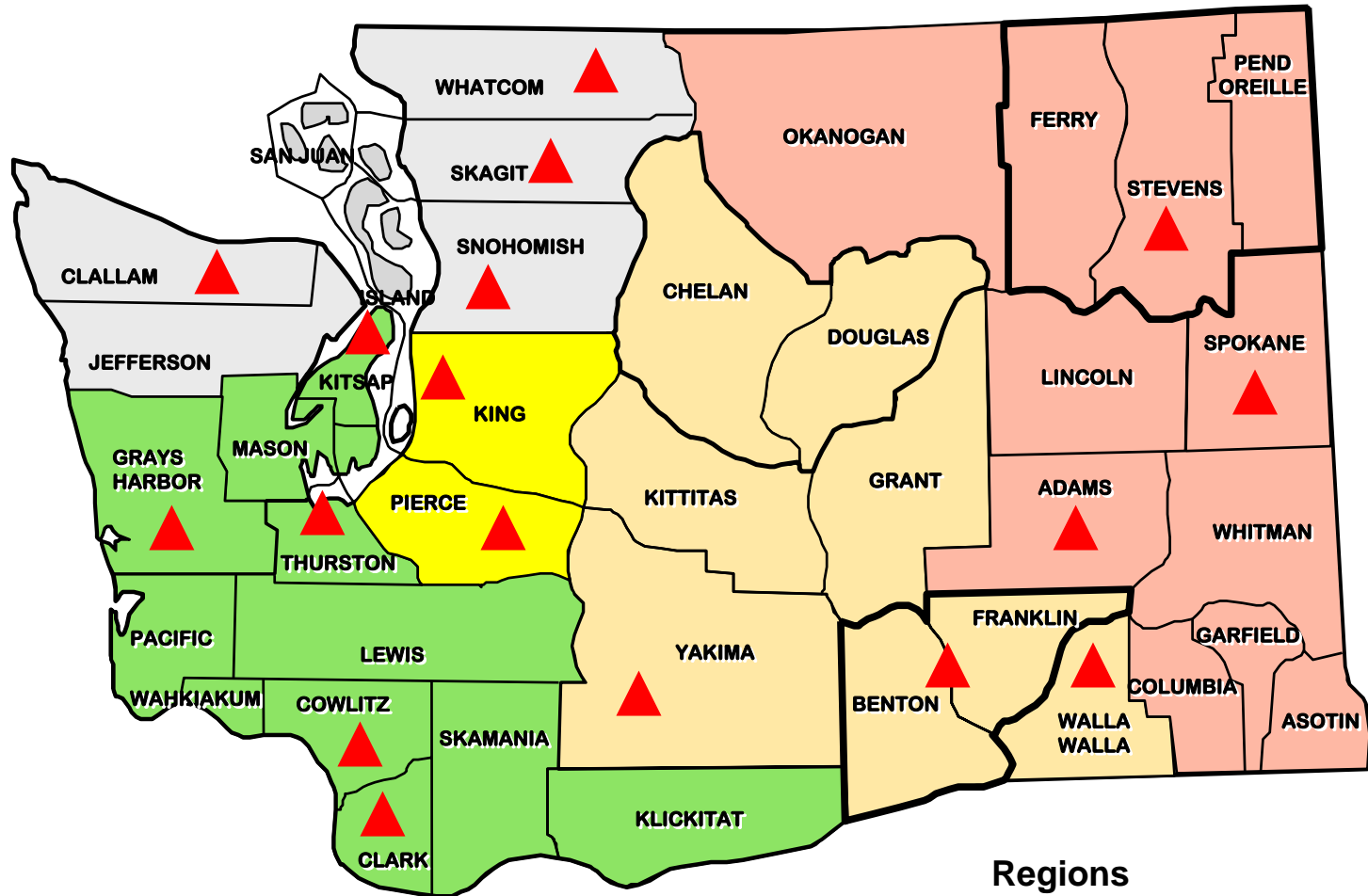
14. Do you have any ideas as to how the medical home leadership network can best help you target and achieve lasting change in your office practice or to other practices in your community. (on any issue you are motivated to change)?

15. How state medical professional organizations like the WCAAP can help?







Wrap-up:

16. Anything else you would like to share? Especially let us know if there are any tools or strategies they find especially helpful

Washington State Medical Home Leadership Network



Regions

- | | |
|---|---|
|  Northwest |  Central |
|  King & Pierce |  East |
|  Southwest |  Regional Resource Teams |