This is the first of two issues focusing on rural health, a topic of great importance throughout the Northwest region and Alaska. Articles in this issue describe systems and processes, demonstrating how connections within the maternal and child public health system support the health of individuals and families living in rural and frontier areas.

Articles by Mary Selecky, a long-time Washington State public health professional, and Shelly Gilman, the mother of children with special needs, describe how health professionals and families must work together in systems that are changing rapidly in order to achieve their goals. Administrators must preserve systems even though funding is shrinking, while families must learn how to access the services they need. Teri Thalhofer emphasizes how important partnerships and collaborations are for public health professionals serving families in rural and frontier areas. Carolyn Gleason explains the “safety net” of federally funded primary care programs. Sheri Hill discusses details of those services in Washington State school districts. Michael Neufeld describes the challenges of discharging infants from a Neonatal Intensive Care Unit to home when that home is in a isolated rural area. Medical homes are critical for helping these families care for their infants.

Reports from each of the states illustrate how maternal and child public health programs are meeting the needs of children living in rural areas. Yvonne Goldsmith describes research in which results are inconclusive as to the causes of high rates of iron deficiency and anemia in Alaska Native children. Dieuwke Dizney-Spencer explains that while children with special health care needs fair better by many measures in Idaho State than nationally, access to medical services in isolated areas of the state continues to be a challenge for families. Beth Gebstadt and Heather Morrow-Almeida showcase three maternal and child health initiatives to increase access to health care services for families living in rural areas of Oregon State. Carol Miller and Teresa Vollan describe a pilot campaign, Learn the Signs. Act Early, to raise awareness of developmental milestones of children. The campaign targets Spanish-speaking, Hispanic parents living in rural and frontier areas of Washington State.
We welcome Kate Besch and Carolyn Gleason to the editorial board. Kate provides support services for children with special health care needs at North Public Health Center, Public Health - Seattle & King County, Seattle, Washington. Her previous work experience includes case management and public health, home visiting, and school nursing.

Carolyn Gleason is regional maternal and child health consultant, Maternal and Child Health Bureau, Health Resources and Services Administration Region X, United States Department of Health and Human Services. Carolyn previously served on the editorial board from 1990 through 2002.

A special thanks to Jane Rees: this will be her last issue as faculty lead on the editorial board. Dr. Rees joined the board in 2006.

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Rural Public Health at a Crossroads

Mary Selecky

When I came to the Northwest in the 1970s I knew very little about rural health. I had been an assistant dean of students at an East Coast university when I decided to “go west” with some friends. By chance, that cross-country trek led me to Colville, Washington—a very rural area of the state that I still call home today.

Armed with my degree in history and political science, I lead the local Economic Development District for a few years. I was then hired by Dr. Ed Gray, a local physician and health officer, to administer Northeast Tri-County Health District in Colville and worked there for 20 years. Dr. Gray and another person from that community, Dr. Bill Foege, played major roles in my public health career. Dr. Foege ended up leading the Centers for Disease Control and Prevention and was instrumental in eradicating smallpox. While many of us fear change and try to avoid it, these two physicians are among the best at recognizing change on the horizon and preparing for it.

Rural Health Yesterday and Today

A lot has changed since the 1970s, and a lot has not. I don’t think there has ever been a time when funding was plentiful for rural public health. As long as I have been doing this work there has never been enough money for local health departments, hospitals, doctor’s offices, and clinics in rural areas—yet most communities somehow make it work. Providers and people who direct rural health facilities have to be extremely creative. A friend and colleague of mine was the administrator for a small rural hospital. Then as now, they struggled to keep the doors open. One of the things they were best known for was the great pizza they made in the hospital kitchen. There was no pizza place in town, so they started selling pizza pies out the back door to make ends meet. Now that is a creative solution to a funding challenge.

Rural communities, however, have changed, along with their needs and expectations for health care. Not that long ago, most people who lived in rural communities were long-time residents. In the last 20 years, many rural areas have seen an influx of people leaving...
cities to “get away from it all.” Many of these same folks bring their urban expectations with them. They want more than many rural health care facilities can deliver. In many cases the system has tried to grow and adapt to meet these new needs and expectations, but it takes a lot of appointments for a hospital or clinic to justify and afford state-of-the-art equipment common in city health care settings.

Today, we are at a critical crossroads. Government financial support on all levels is drying up and it is clear that many rural health care facilities, including local public health agencies, will not succeed unless they change. The decisions we make today will affect our public health system long after most of us have moved along. Today’s leaders stand on the shoulders of people like Dr. Gray and Dr. Foege. We must provide the same solid foundation, vision, and leadership for those who come after us.

**Agenda for Change**

In Washington State we have put together a workgroup of some of our most experienced local, state, and federal public health leaders, referred to as **Re-shaping Governmental Public Health in Washington State**, to develop what we call the **Agenda for Change**. The agenda sets three primary goals: sustain our past successes, confront emerging challenges, and use our resources most efficiently and effectively. Defending programs we have at all costs is not going to lead to future success. It will damage our credibility, which is among the most valuable assets we have.

Of course setting goals is just the start; real change requires much more. We have developed an “action agenda” that clearly identifies the areas we will focus on, and the steps we will take to assure our public health system of tomorrow is a result of critical thinking and focused actions. We cannot let luck, chance, and politics dictate what our system becomes.

The “action agenda” focuses on protecting people from diseases and other health threats, changing policies and systems to build healthy communities and environments, and partnering with hospitals, clinics and others to improve access to quality, affordable, and integrated health care. Granted, it’s a huge undertaking, the work will not be easy, and we may not succeed on every level, but I am confident that we are better off deciding what our public health future will be as opposed to letting the circumstances of the day decide for us.

We have seen a regional approach succeed with Emergency Medical Services and Trauma Care, we have seen it succeed with public health emergency preparedness efforts, and it is time to consider it in rural public health.

**In Summary**

All of us who work on rural health issues have gotten pretty good at figuring out creative ways to make most health services available to people in those communities. However, rural communities have to recognize times are changing. We have to be willing to sit down at the table, evaluate our strengths and weaknesses, build on those strengths, and let someone else do work we are not as good at or can no longer afford. Those decisions are very hard to make, but we must make them.

Mary Selecky has been Secretary of the Washington State Department of Health since March 1999, serving under Governors Chris Gregoire and Gary Locke. Her first position in public health was as the administrator for the Northeast Tri-County Health District in Colville, Washington, a position she held from 1979 to 1999. As secretary, Mary has made tobacco prevention and control, patient safety, and emergency preparedness her top priorities. She is known for bringing people and organizations together to improve the public health system and the health of people in Washington State.

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Innovative Approaches to Maternal and Child Health Services in a Rural Health District

Teri L. Thalhofer

North Central Public Health District is a small health department located along the beautiful Columbia River in North Central Oregon. Serving one rural (Wasco) and two frontier (Sherman and Gilliam) counties provides an interesting set of challenges. Its population of 27,505 is spread over an area of 4,449 square miles in small towns and communities. Traditionally agricultural, many families live on isolated farms and ranches. Delivering maternal and child health services requires flexibility and collaboration.

Shared Service Delivery

Our staff consists of three public health nurses well-versed in all areas of public health. One of our nurses with over 35 years of experience visits pregnant women, infants at risk of developmental delay, and children with special health needs requiring nursing case management. She also is the school nurse for several small districts, immunization coordinator for the district, and a family planning counselor. Another nurse provides home visiting and Healthy Start services. Our third nurse sees clients in the largest population center in the district, The Dalles. She also supports the Community Connections Network, a multidisciplinary team providing coordination for children and youth with special health care needs and works closely with the local Oregon State Department of Human Services office to coordinate services for children at risk for abuse or neglect.

We provide WIC (Special Supplemental Nutrition for Women, Infants, and Children) services not only in our main office in The Dalles but throughout the district. Our staff speaks Spanish fluently—an asset in the outlying clinics. Previously we found that families who spoke only Spanish were not accessing services due to perceived language barriers. As word spread that we spoke Spanish, more families began accessing services. Along with providing nutrition education and vouchers, staff are able to assist families find other services, including immunizations and family planning.
We also provide immunization services at our main office in The Dalles on a walk-in basis, five days a week. This allows families in town to shop or for appointments to more conveniently access services. Immunization services are also provided by rural health clinics, Federally Qualified Health Centers, and private providers.

One of the great rewards of serving rural communities is seeing the outcomes of our work. Watching a child for whom we provided home visiting services as an infant become a successful high school student is powerful reinforcement for our efforts. Often, because communities are small and no one is anonymous, people form long-term relationships. We frequently visit siblings, cousins, nieces, nephews, and even children of our early clients.

Collaborative Partnerships

None of our work would be as effective or efficient without collaborations and partnerships. With only two prenatal provider offices and one hospital in the district, communities need to be creative with time, money, and resources. Prenatal providers routinely screen women, with their written consent, using the Healthy Start questionnaire. Providers of health and social services meet regularly to review programs to ensure that families receive appropriate referrals and to avoid duplication of services. Participants in the meetings include home visiting nurses, the Healthy Start program provider, Head Start and Early Head Start staff, Early Intervention staff, and health promotion staff from the local Federally Qualified Health Center. Advantages to this regular review include:

- Health and social services providers are more knowledgeable about other programs
- Medical providers can obtain services for their clients as each of the participating programs passes along referrals, with client consent
- Families are not offered multiple programs
- Families do not need to remember the names of specific programs, just that programs are provided through home visiting services

Early in our meetings, participants came to a consensus on how to direct referrals to different programs. A mother or child with any medical condition is referred to a public health nursing program. Because Oregon Healthy Start serves first births only, women delivering their first child and desiring home visits are referred to a local Healthy Start program. All subsequent births are referred to a local Early Head Start program. To help guide the process, we considered the mission of each of the programs and the pieces—starting with health, then a safe environment, then educational readiness—that need to be in place for a child to be ready to learn.

Maternal and child health professionals assisted us with our community health assessment and have become champions and ambassadors for additional public health services in the community. During the H1N1 outbreak, we were able to quickly access schools as points of distribution because the community was already familiar with our services as a result of our partnerships.

In Summary

Cooperation and flexibility allow us to effectively serve our communities. Resources are limited: collaborations and partnerships allow more families to access appropriate services.

Teri Thalhofer, RN, BSN, is director of the North Central Public Health District, which serves Wasco, Sherman and Gilliam Counties in north-central Oregon. After receiving a BS degree in nursing from the University of Portland, she practiced at Oregon Health and Science University, Portland, in high risk labor and delivery. She relocated to The Dalles and began her public health nursing career in 2000 as a maternal and child health home visiting nurse. She currently serves on the Wasco County Commission on Children and Families and as co-chair the commission’s Early Childhood Committee. In September 2011 she was named by Governor Kitzhaber to the Early Learning Council.

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Who are the “safety net” providers of primary care services for vulnerable maternal and child health populations in your rural community? The answer may be: Community Health Centers (CHC), Federally Qualified Health Centers (FQHC), Tribal Clinics, Indian Health Service (IHS) Clinics, Rural Health Clinics (RHC), Critical Access Hospitals (CAH), Accountable Care Organizations (ACO), a combination of these, or “none of the above.”

State and local health departments along with maternal and child health programs are essential components of this safety net, focusing more on infrastructure-building, and population-based and enabling services. Maternal and child health professionals are well-positioned to collaborate with primary care safety net programs with the common goal of improving the health of individuals and populations with lower costs. This article describes the most common federal grant and incentive programs for primary care in rural areas.

Health Resources and Services Administration Health Center Program

Perhaps one of the most widely known types of federally funded safety net programs is the Health Resources and Services Administration (HRSA) Health Center Program. A health center grantee must be a public or private non-profit entity and must serve populations with limited access to health care, regardless of ability to pay.

Target populations include the low-income, the un- or under-insured, those with limited proficiency in speaking English, and those living in areas with populations insufficient to attract any private practice. Most health centers serve the entire community. Some health centers focus on meeting the needs of a) migrant and seasonal farmworkers, b) those who
are homeless, and c) those living in public housing.

All HRSA-funded health center sites are eligible for designation as a FQHC for the purposes of enhanced reimbursement for Medicaid and Medicare services (see side bar). For more information about the HRSA Health Center Program, see http://bphc.hrsa.gov/.

**Indian Health Service Funded Clinics**

Also common in rural areas are clinics funded by the Indian Health Service (IHS) directly (IHS clinics) or through contracts to tribes (tribal clinics). The IHS provides resources for comprehensive health service delivery systems for American Indians and Alaska Natives who belong to federally recognized tribes. Some tribal clinics have agreements with IHS that allow them to serve those who are not American Indian and Alaska Native when there are no or limited other providers in the area. In Region 10, a number of tribal outpatient clinics also qualify for and receive HRSA Health Center Program funds.

**Rural Health Clinics**

The Rural Health Clinic (RHC) Program was established in 1977 to address an inadequate supply of physicians serving Medicare and Medicaid beneficiaries in rural areas. The program provides qualifying clinics with payments from Medicare and Medicaid on a cost-related basis. These clinics are required to provide out-patient primary care services and basic laboratory services, and be staffed at least 50% of the time with at least one mid-level practitioner, such as a nurse practitioner, physician assistant, or certified nurse midwife. Clinics can be public, private, or non-profit. For more information on requirements for the RHC Program, see www.cms.gov/mlnproducts/downloads/rhcfactsheet.pdf.

**Critical Access Hospital**

The Flex Program, created by Congress in 1997, allows a small rural hospital to be designated as Critical Access Hospital (CAH) and offers “Flex” grants to states to implement initiatives to strengthen the infrastructure of rural health care. These hospitals receive cost-related reimbursement from Medicare and, in some states, from Medicaid. A CAH must be located in a rural area that is a specified distance from

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**Health Center Terminology**

It is not uncommon for a Health Resources and Services Administration (HRSA) Health Center Program grantee to be called a Community Health Center (CHC) or Federally-Qualified Health Center (FQHC). However, these terms are not interchangeable. Each has a specific meaning in relation to financial benefits and oversight.

**Community Health Center**

The term “CHC” is not defined in the HRSA Health Center Program statute, and there is no universal agreement on its meaning. It is commonly used to refer to grantees who target underserved communities or populations.

**Federally-Qualified Health Center**

A “FQHC,” as defined by the Centers for Medicare and Medicaid Services (CMS) statute, is an organization or entity approved for enhanced reimbursement. Three types of entities are eligible to apply to CMS for reimbursement as a FQHC:

- Individual clinic sites of HRSA Health Center Program grantees. A single grantee with multiple clinic sites may consist of multiple FQHCs.
- Individual sites of FQHC “look-alikes.” These organizations meet all requirements to receive grant funds under the HRSA Health Center Program but do not receive grant funds.
- Outpatient health clinics associated with tribal or Urban Indian Health Organizations. The Indian Health Service administers and oversees operations of these organizations.

Eligible sites are required to complete an extensive enrollment process with Medicare and its state Medicaid agency to be approved as an FQHC. Additional information can be found at: www.cms.gov/center/fqhc.asp.

Continued on Page 9
another hospital. They may operate primary care clinics, are required to provide 24-hour emergency care, have a small number of acute and nursing care beds, and must maintain a low average-length-of-stay for acute care patients. For more details on CAHs, see www.cms.gov/MLNProducts/downloads/CritAccess-Hospctsh.pdf.

Grants are also provided to states with critical access hospitals to provide technical assistance with quality improvement, financial and operational improvement, and health system development, including emergency medical services targeted specifically to the needs of CAHs. States participating in the Flex Program are required to have a rural health plan. For information on a particular state’s program, contact your State Office of Rural Health (see the directory at www.hrsa.gov/ruralhealth/about/directory/index.html.)

**Emerging Payment and Care Models in Rural Areas**

The Center for Medicare and Medicaid Innovation at CMS has the resources and flexibility to rapidly test innovative care and payment models, and encourage widespread adoption of practices that deliver better health care at lower costs. Most initiatives are focused on primary care; several can benefit rural providers.

Section 3022 of the Patient Protection and Affordable Care Act created the Medicare Accountable Care Organization (ACO) Shared Savings Program. In this program, Accountable Care Organizations (ACOs) are described as groups of doctors, hospitals, and other health care providers who provide coordinated, high quality care to their Medicare patients, avoid duplication of services, and prevent medical errors. One model, specifically designed for rural providers, offers an advance payment of projected savings to organizations whose ability to achieve success would be improved with access to capital. For more information, see http://innovations.cms.gov/initiatives/aco/.

Oregon State’s proposed Coordinated Care Organizations (CCO) Program for Medicaid enrollees is an example of a state model similar to the Medicare ACO model. Beginning in 2012, CCOs will coordinate physical, mental, and dental health care for people with Medicaid in an entire community.

The Affordable Care Act provides states with a new Medicaid option to provide “health home” services for enrollees with chronic conditions. In November 2010, CMS issued guidance and a template to states to streamline the approval process for establishing health homes in their Medicaid programs. See www.cms.gov/smdl/downloads/SMD10024.pdf for more details.

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**RESOURCES**

**HRSA Health Center Program**  
Health Resources and Services Administration  
www.hrsa.gov

Directory of State and Regional Primary Care Associations (PCA)  
www.nachc.com/nachc-pca-listing.cfm

Directory of State Primary Care Offices (PCOs)  
http://bhpr.hrsa.gov/shortage/hpsas/primarycare-offices.html

**FQHC Program**  
CMS - Federally Qualified Health Centers Center  
www.cms.gov/center/fqhc.asp

**IHS Funded Clinics**  
Indian Health Service website  
www.ihs.gov/
Rural Health Clinics (RHC)
CMS fact sheet, “Rural Health Clinic”
CMS - Rural Health Clinics Center
www.cms.gov/center/rural.asp

Critical Access Hospitals (CAH)
CMS - Critical Access Hospital Fact Sheet

State Rural Health Programs
Directory of State Offices of Rural Health (SORH) and State Rural Health Associations (SRHA)
www.hrsa.gov/ruralhealth/about/directory/index.html
HRSA Rural Health home
www.hrsa.gov/ruralhealth/index.html

Emerging Payment and Care Models in Rural Areas
CMS – Medicare ACO Shared Savings Program
CMS fact sheet on ACOs and how they will work in rural areas
Oregon’s Coordinated Care Organizations: Frequently Asked Questions
www.oregon.gov/OHA/OHPB/health-reform/docs/cco-faq.pdf?ga=t

HR 3590 - Patient Protection and Affordable Care Act

Developing and Influencing Policy for the Public’s Health
Michael R. Fraser, PhD, CAE

Monday, May 7th, 2012
4:00 - 5:30 PM
Hogness Auditorium, Health Sciences Building, University of Washington, Seattle

Dr. Fraser is the CEO of the Association of Maternal and Child Health Programs in Washington, DC. He is former deputy director of the National Association of County and City Health Officials and was regional program manager with the Centers for Disease Control and Prevention. In 2002, he received a distinguished service award from US Department of Health and Human Services for his emergency response work after the 9/11 terrorist attacks.

For more information, contact Carmen Velasquez at carmv@u.washington.edu

Sponsored by the Maternal and Child Public Health Leadership Training Program, Northwest Center for Public Health Practice, Department of Health Services, Department of Epidemiology, and the School of Public Health, University of Washington, Seattle
The Challenges of Discharging an Infant from a Neonatal Intensive Care Unit When Home is Far from Specialized Care

Michael D. Neufeld, MD

Discharging infants with complicated problems from the neonatal intensive care unit (NICU) is always a challenge, but it is even more difficult when the family lives in a rural area where health care resources are limited. Rural areas have shortages of pediatricians and other primary care providers and almost no specialty care providers, such as speech and physical therapists and home health nurses. Families often must travel long distances to obtain specialty care at considerable personal and financial costs. The cost of travel and time away from work is especially burdensome because children in rural areas are more likely to live in poverty. Though parents from rural areas learn how to take care of their infants at the NICU before discharge, this is just the beginning of a difficult adjustment for these families.

Preparation For Discharge Begins at Admission

Social workers are key to planning and preparing for discharge, beginning with an assessment of the family’s resources and needs when their infant is admitted. Social workers also assist in obtaining financial support as well as providing emotional and mental health support, when needed.

Education is essential to ensure that parents are capable and confident in caring for their infant at home. Everyone helps prepare parents for discharge: nurses, social workers, physicians, nurse practitioners, respiratory therapists, pharmacists, physical and occupational therapists, nutritionists, and lactation consultants.

As discharge nears, parents often room with their infant and provide most of the care in order to anticipate what the process at home will be. Usually both parents learn how to care for their infant though this may be difficult or impossible for parents with limited resources who live long distances from the NICU and have other children to care for.

A Complicated Home-Coming

Prior to discharge from the hospital, home health care agencies need to be contacted
and arrangements made for medical equipment to be delivered to the home and for the family to be taught its use. Discharge, travel time, and equipment delivery must be carefully coordinated. Home health nurses can be very helpful in the transition from hospital to home life, but pediatric home health services in rural areas are limited.

The most important aspect of post-NICU care is establishing a patient- and family-centered medical home. This involves identifying a primary care provider who is comfortable taking care of an infant who may have complex medical needs and requires coordination of care with multiple specialists. Because pediatricians have extensive training in anticipating problems and caring for these infants, we generally suggest that parents find a pediatrician. However, in many rural areas, there are no pediatricians.

Fortunately, most family physicians are great at coordinating care and accessing resources, but parents need to partner with their family physician and also be proactive in getting care. If parents participate in an early intervention program, their service coordinator will be able to help them. (For more information about early intervention, Individuals with Disabilities Education Act Part C, see articles on pages 13-15.)

**Pediatric Specialists**

Most pediatric specialists practice in urban areas though they may establish outreach clinics in moderate-sized communities in rural areas. Unfortunately, specialists are usually available only once or twice a month so clinic appointments may be difficult to obtain. Pediatric pulmonologists are the most common specialists seen by NICU graduates, helping manage chronic lung disease in infants needing oxygen or ventilators.

Most infants discharged from the NICU, especially the most premature infants, should have ongoing formalized neurodevelopmental follow-up in addition to developmental screening by the primary care provider. Very premature babies should be examined by an ophthalmologist at least every five years throughout life. Infants also may need to see a pediatric surgeon for follow-up if they have had bowel surgery or if they need hernia repair.

**In Summary**

Having a premature infant or infant that requires care in a NICU is very difficult for families. If their home is far from that NICU, the challenges of separation and travel begin at birth. Most NICU graduates do very well, but they are at higher risk for ongoing medical problems and learning difficulties when they reach school age. It takes a team of health care workers along with federal, state, and local public health programs to support these families.

Michael D. Neufeld, MD, MPH, is a clinical associate professor of pediatrics in the Division of Neonatology at the University of Washington School of Medicine; and an affiliate faculty member in the Maternal and Child Public Health Leadership Training Program at the University of Washington School of Public Health. He is an attending physician at the University of Washington Medical Center neonatal intensive care unit and is medical director of the neonatal intensive care unit at Providence Regional Medical Center, Everett, Wash. His interest is in long-term neurodevelopmental outcomes of premature babies.

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**RESOURCES**

The Center for Children with Special Needs  
Seattle Children’s Hospital  
http://cshcn.org/

Early Support for Infants and Toddlers  
Washington State Department of Early Learning  
www.del.wa.gov/development/esit/Default.aspx

National Center for Medical Home Implementation  
www.medicalhomeinfo.org/

National Rural Health Association  
www.ruralhealthweb.org/

Washington State Medical Home  
http://medicalhome.org/

Continued on page 13
Three new videos, funded through the American Recovery and Reinvestment Act, can help answer this question and others about early intervention. They can also be accessed through Washington State’s Early Support for Infants and Toddlers Program at www.del.wa.gov/esit

**Babies Can’t Wait.** This 2:41 minute video gives a short overview about how to connect with Early Support for Infants and Toddlers the early intervention program in Washington State. The video describes the steps parents can take if they are concerned about their child’s development. It emphasizes that no doctor referral is needed and screenings and eligibility evaluations are at no cost to families. www.youtube.com/watch?v=JoaFNGmSU5U

**Early Support for Infants and Toddlers (ESIT) Guiding Concepts.** This 3:11 minute video reviews the guiding concepts for early intervention in Washington State. The state developed and adapted these materials from national principles with extensive community involvement. This work was a part of a Statewide System Improvement Project funded by the American Recovery and Reinvestment Act. The video highlights the important role of relationships and families. www.youtube.com/watch?v=yGqAOZrvQQU&feature=related

**Child Outcomes Step by Step.** Early intervention falls under the Individuals with Disabilities Education Act. As a result, the Office of Special Education Programs requires that all state early intervention (Part C) and preschool special education (Part B/619) programs report on these outcomes as part of their annual performance report. The University of North Carolina, Chapel Hill, has developed an 8:42 minute video that explains and provides examples of these outcomes. These explanations also help you understand “the point” of early intervention. www.fpg.unc.edu/~eco/pages/videos.cfm

Sheri L. Hill, PhD, is an early childhood policy specialist and served as the system improvement project coordinator for Washington State’s early intervention (Part C) program, Early Support for Infants and Toddlers. She is a member of the editorial board of the Northwest Bulletin.

**Web site:** www.earlychildhoodpolicy.com
Early Intervention Services: Building a System of Equitable Services Across Washington State

Mary Perkins

Since 1985, Washington State has been a part of the Federal Part C (then Part H) of the Individuals with Disabilities Education Act, which mandates services for children with developmental delays or disabilities through the age of two years, and their families. The purpose of the law is to ensure that parents, who are concerned about their child’s development or have a child with a disability, can access the services they need for evaluation, support, and treatment. The law provides funding for infrastructure to access a variety of federal, state, local, and private services. While multiple services, including state and privately funded neurodevelopment centers, exist in the urban areas of the state, such a wealth of services is lacking in most of our rural counties. What are the challenges and opportunities for increasing services in rural areas?

Challenges

**Capacity.** Physicians who can diagnose disabilities, along with therapists, teachers, and social workers trained to work with children who have developmental delays or disabilities and with their families, are in short supply in rural areas and often have to serve a large geographic area. Because of this shortage, families often must travel to services rather than having a service provider come to their home.

**Training.** Those willing to provide services for children and their families often are trained to work one-on-one with older children or adults; however, working with young children usually requires working with families. The physician, therapist, or teacher acts as a coach or consultant to adults in the family. While some children do require direct, regular, hands-on therapy, many who are eligible for services do not. Service providers in rural areas may have limited experience with either very young children or with a more coaching oriented approach.

**Transportation.** Families with children who need more intensive services often must travel to urban areas. For example, a family who lives in Grays Harbor County with a child who has a hearing impairment may have to travel to Tacoma or Seattle for specialized audiology services.

Opportunities

**A family-focused coaching approach.** Limitations on service providers’ time requires families to step into the gap. One evidence-based approach includes an interdisciplinary team to consult with a single “primary service provider” who works directly with the family. (See page 15 for information about the primary service provider model.) We are seeing better outcomes for children with this approach. Implementing the approach, however, still requires trained personnel who are often unavailable in rural areas.

**Involvement of multiple agencies.** In rural areas, service providers who work in different agencies and practices are likely to know one another. They often serve on the same committees, attend the same churches, and shop in the same grocery stores. Many eyes may be on a child and, as a consequence, families are less likely to slip through the cracks.

**School districts in the mix.** In September of 2009, the Washington State Legislature mandated that, as a part of the early intervention service system, school districts serving children who have developmental delays or disabilities, aged 3 through 21 years, also participate in serving children through age two. Districts may provide services directly or through a contract. This mandate has increased the amount of...
funding as well as the number of therapists and teachers available to work with families.

Issues of access to quality early intervention services will continue to exist in rural and frontier areas of our state. Urban areas will always be “resource rich” but a plethora of services does not always guarantee quality. In rural areas, collaborations among health professionals offer unique opportunities to positively influence the amount and quality of services. While building capacity through training in evidence-based practice may continue to be an issue, the use of technology for professional development should help solve that problem as we build a system of equitable services across our state.

Mary Perkins is retired but continues to work as a contractor for the Educational Service District 112, Vancouver, Washington. She also serves on the serves on the Washington State Early Learning Advisory Council. She began her career as a Head Start teacher and coordinator for professional development for Region X at Portland State University, Oregon, and then became an early childhood special education director for Yakima Public Schools, Washington. Before retiring, she was the early learning director for Educational Service District 113, Tumwater, Washington, where she managed professional development for public school staff in five counties and directed the Infant Toddler Early Intervention Program, Grays Harbor, Washington.

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RESOURCES
National Early Childhood Technical Assistance Center
www.nectac.org/partc/partc.asp

Mary Perkins

The evidence-based primary service provider model for service delivery in early intervention shows significant promise in Washington State. The model uses a team approach to working with the child and family but instead of multiple service providers inundating a family, as often happens when the child has multiple developmental needs, one service provider takes the lead in interacting with the family. This provider typically has the skills to best meet the needs of the child and is usually the person on the team who has established the best relationship with the family.

The primary service provider gives information and support to the family and helps the child gain skills to participate in family life through coaching and modeling behaviors. The approach incorporates learning into the daily routines and activities of the family so that there are multiple times for the child and parents to practice new skills. The other members of the team act as consultants and may respond to questions from the provider and the family or visit the family to provide direct support. They may also become the primary service provider as needs change.

As the needs of children identified for early intervention are often developmental rather than therapeutic, this service delivery model enables specialists, including physical, occupational, and speech and language therapists, to work directly with children and families most in need while, at the same time, consulting with children and families not requiring regular, specialized services.

REFERENCES
I have wanted to be a mother for as long as I can remember. My dreams of motherhood, however, met the reality of three of our four children receiving a diagnosis of autism. Our excitement for our future when my husband and I married has met the reality of caring for our children with special health care needs. And while living in a rural area has its advantages, the lack of access to pediatricians trained to screen children for developmental disabilities and to services and support creates challenges not encountered in urban living.

A Missed Window of Opportunity

From the moment our second child was born, we knew something wasn’t quite right. He would shriek at a high pitch for hours and would not be comforted. He lacked the ability to suck which made feeding difficult. He had to be treated for jaundice for over a week, and an early illness resulted in thrush, which we continuously treated for the next 18 months. He received diagnoses of torticollis and eye motor problems, and had hernia surgery, all before he reached the tender age of five months. He had nine months of uninterrupted ear infections, until tubes were placed in his ears at 18 months of age. As he got older, he was slow to talk and wanted to spend time alone, playing with trains for hours.

I brought these and many other concerns to my pediatrician and was reassured that he was fine. It was pointed out that he had good eye contact, which seemed to make all of my other concerns nonexistent as far as that practitioner was concerned. By the time he was over four years of age, when other community members began commenting about his behaviors, I called early intervention.

When the autism consultant visited our home, there was very little doubt that my child had a developmental disability that should have been diagnosed long before.
Later, I found a child psychologist in a distant town who confirmed the diagnosis of autism and referred us to a geneticist who diagnosed this genetic disorder. We had missed a window of opportunity for early intervention. Had our pediatrician been trained in screening for developmental disorders our son would most likely have gotten help earlier.

Finding Services During My “Spare Hours”

It has been challenging to care for and raise three children with special health care needs. As we learned that our children had autism, I desperately needed an entity or an agency that could help me navigate services but was told that no such entity existed in our area. Therefore, navigating services fell upon me before my children woke up in the morning or after they went to bed at night. Eventually, we were fortunate to find respite care through Lifespan Respite. It wasn’t until my third child received a diagnosis of autism that I became aware of Oregon State’s Developmental Disabilities Services and found a qualified service provider through that agency. She has been a Godsend and has probably saved our marriage.

Throughout this process, I was told by agencies that schools should be providing certain services and, by the schools, that agencies should be providing services. At other times, I was told that a certain services were provided in urban areas but not in rural areas or that services were funded state-wide but not found within our community.

Finding Support Through the Internet

I was desperate for support from others who were facing the same struggles. I tried organizing a support group in our community but found the logistics daunting. Many parents could not attend because they couldn’t find child care. Eventually, I found an online support group based in a town in another state. Although we are not able to attend most functions in person because of the distance, being able to communicate any time of the day with other parents who have children with special needs is priceless.

A Reevaluation of Our Goals and Expectations

Rural life has advantages for my children. A developmental therapist works directly with them at home as opposed to their going to a clinic for therapy. This has been instrumental in discovering antecedents to their behaviors. Last summer, we had an outing a family orchard, where they learned about orchard work and animals, and, in the process, worked toward their therapeutic goals.

Over the years, I have had to reevaluate my goals and expectations for my children. I would like to see them as happy, functional adults, with the skills to maintain a job and social life. I do not want them to go through life living on government disability. This is challenging, as most of the needed therapy services are just not available in our community. Also, we have had to make agonizing decisions about what therapies our children can receive based upon what we can afford.

Nonetheless, we are committed to helping our children and other families with children with special needs in our community. We are determined to do everything within our means to raise our children to become happy, well-adjusted adults who will be assets to their communities.

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Rural Health in the Northwest Region

While the Northwest region has a few highly populated urban areas, it mostly consists of sparsely populated, geographically isolated rural and frontier areas. This isolation creates significant challenges to ensuring that all women and children have access to routine preventive care as well as acute medical and specialty care.

Geography also represents a barrier to obtaining care for children and youth with special health care needs. Families often have to travel to urban areas to obtain specialty care for their children’s needs. Dental and mental health services are the most difficult to access: providers in geographically isolated areas are often not trained to provide care for these children. This lack of specialty services requires creative solutions on the part of the states. For example, Idaho’s Children’s Special Health Program provides partial funding to bring specialty physicians from Oregon to clinics in the northern and eastern parts of the state.

Health Professional Training

Most of the Northwest region is designated as a Health Professionals Shortage Area. The region’s two teaching hospitals are located at the Oregon Health and Science University, in Portland, Oregon; and at the University of Washington, in Seattle, Washington.

Fortunately, many collaborations exist between these teaching hospitals and the states to train health professionals. For example, the WWAMI regional medical education program, a partnership between the University of Washington School of Medicine and the states of Washington, Wyoming, Alaska, Montana and Idaho, provides publicly supported medical education for those states.

The Alaska Dental Health Aide Therapist Initiative, a collaboration between the University of Washington School of Medicine and the Alaska Native Tribal Health Consortium, trains Alaska Native dental health technicians for community-level dental disease prevention in underserved Alaska Native populations. The Oregon Health and Science University is Alaska’s partner in the Newborn Metabolic Screening Program, as well as in a research study of carnitine palmitoyltransferase 1 deficiency funded by the National Institute of Health.

Alaska

In Alaska, approximately 75% of communities, including the state’s capital of Juneau, are not connected to the road system. Health care delivery consists of three separate systems: state and local governments; the Alaska Native Tribal Health Consortium, funded by the US Indian Health Service; and federally funded military hospitals and the Veteran’s Administration.

Local governments consist of the Municipality of Anchorage and the North Slope Borough, which operate local health departments with limited services. The US Department of Health and Social Services offers a wide range of health assessment and disease prevention services through 20 public health centers and itinerant nursing services. The Alaska Native Tribal Health Consortium provides primary care at village clinics, primary and mid-level primary care at regional hospitals, and tertiary care at the Alaska Native Medical Center in Anchorage.

A number of innovative systems have been created to overcome high transportation costs and lack of skilled health care professionals in rural and frontier communities, including the Community Health Aide Program, the Alaska Dental Health Aide Therapist Initiative, and the Behavioral Health Aide Project.

Idaho

The state has an average population density of 19 persons per square mile. However, half of the state’s 44 counties are considered frontier, with an average of less than seven persons per square mile. Eighty percent of the land is either range or forest, and 70% is publicly owned. Approximately 66% of the population reside within one of the seven population centers, with the rest residing in towns, farms, and ranches radiating out from these centers.

The state’s seven public health districts are organized around these population centers. The Idaho Department of Health and Welfare, Division of Public Health, administers public health statutes and programs. The health delivery system is composed of the seven public health districts, 12 Community Health Centers, one Federally Qualified Health Center, and five Tribal and Indian Health Service Clinics.
Oregon

The state is largely a rural and frontier state geographically. Although the percent of the population living in rural areas of the state declined from 70% to 20% in the 20th century, the total number of rural residents has increased slightly since early in the century. The overall population density of Oregon is 37 people per square mile, ranging from 1,518 persons per square mile in Multnomah County to seven persons per square mile in frontier areas. National Forest Service lands and Bureau of Land Management lands cover approximately 46% of the state. Oregon’s public health statutes and programs are administered by the Public Health Division (Oregon Health Authority): each of the state’s 36 counties is a designated health authority. The health delivery system is composed of 33 county health departments, one health district serving three small rural counties, 93 Federally Qualified Health Centers, 57 Rural Health Clinics, 15 Migrant Health Centers, 11 Tribal and Indian Health Service Clinics, and 54 School-Based Health Centers.

Washington

The state has an average population density of 101 persons per square mile. Approximately 75% of the population is concentrated west of the Cascade Mountains, with the three most populous counties being King, Pierce, and Snohomish. Population density ranges from 913 persons per square mile in King County to less than four persons per square mile in Garfield and Ferry counties. Washington has 39 counties forming 35 independent local health jurisdictions funded with varying amounts of federal, state, and local dollars. Washington’s public health statutes and programs are administered by the Department of Health.

On-Line Training Opportunity...

Life Course Nutrition: MCH Strategies in Public Health

There is growing evidence that nutrition and growth in early life—during pregnancy, infancy and childhood—has an impact on chronic disease in adulthood. When state and local public health departments take steps to ensure the nutritional health of mothers and children they invest in the future health of the communities they serve.

This module, based on a life course framework, is designed to help public health leaders describe the role of maternal and child nutrition in population health and identify actions they can take to create equitable access to healthy foods and food environments. After completing this module, participants should be able to:

- Describe the role of maternal and child health (MCH) nutrition in the health of populations
- Access resources for assessment, assurance, and policy development for MCH nutrition

- Identify ways to integrate MCH nutrition within state and local public health agencies
- Apply the principles of the life course framework for population-based public health actions and initiatives

This course is offered through the Northwest Center for Public Health Practice at www.nwcpphp.org/training/courses/nutrition.

Presenters: Donna B. Johnson, Elizabeth Adams, Marion Taylor Baer, Leslie Cunningham-Sabo, Dena Herman.

Northwest Bulletin: Family and Child Health
Anemia caused by iron deficiency is the most common type of anemia. Among infants and children, iron deficiency can affect motor and mental development. Among women, maternal iron deficiency anemia might cause low birth weight and preterm delivery. High rates of iron deficiency and anemia among Alaska Native individuals living in rural areas, particularly in the southwest and north where a subsistence lifestyle is common, have been well documented for many years. Iron deficiency in Alaska Native children living in rural areas is ten times higher than national guidelines. Studies indicate that inadequate nutritional intake may not be the only cause of the deficiency.

For our study, we collaborated with Alaska WIC to analyze hemoglobin level data for 50,964 children, aged six months through five years, for years 1999-2006. Children aged 6 to 11 months had the highest prevalence of anemia (28%). Prevalence decreased with increasing age. In all age categories, children living in the rural southwest and north had the highest prevalence of anemia. Alaska Native children had a 40% higher risk for pediatric anemia.

Previous studies have found that one-half to two-thirds of cases of pediatric anemia in southwestern Alaska were associated with low ferritin levels, meaning iron deficiency was the most likely cause. The patterns of anemia found in this study support those findings. However, nutritional iron deficiency cannot be the only causal factor. Alaska Native populations living in the southwest and north have a high prevalence of anemia yet have iron-rich subsistence diets that exceed the US recommended dietary allowances. Iron deficiency and anemia may have evolved among some populations as a protective factor against infectious disease, thus having a genetic basis. Could it be that Alaska Native individuals have adapted to an iron-rich subsistence diet by lowering iron absorption and that a switch to non-traditional diets led to iron deficiency? If so, anemia and iron deficiency should be greater outside the regions with the greatest reliance on subsistence diets—the north and southwest. This is not the case: living in the north and southwest is a risk factor.

The etiology of iron deficiency and anemia among Alaska Native rural children remains unknown. Future research may focus on the prenatal period or early infancy.

Yvonne Goldsmith, MS, tracks health indicators and engages in research on maternal, child, and family health for the Alaska Department of Health and Social Services, Division of Public Health. She also serves on the editorial board of the Northwest Bulletin: Family and Child Health.

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REFERENCE

Lack of Medical Specialists Creates Barriers to Care

Dieuwke Dizney-Spencer

In Idaho State, children with special health care needs (CSHCN) fare better by many measures than these children do nationally. As a percentage of all children, the state has 2.5% less CSHCN than the national average of 13.9%.(1) Per student special education spending is more than 5% higher than the national average.(2) A greater percentage of CSHCN are enrolled in Medicaid than the national average, and 100% of the state’s pediatricians accept Medicaid coverage.(2) More of these children have a primary care provider and more of their families report that their care is “family centered” than the national average.(2)

However, access to medical services in geographically isolated areas of the state continues to be a challenge for families with children who have certain conditions. Idaho has only two pediatricians per hundred children, as compared to the national average of more than seven per hundred.(2) There are no practitioners of several medical specialties in the state. Those specialists who are in the state mostly practice in the southwestern region where the capital city of Boise is located. The Idaho Children’s Special Health Program, using Title V funds, brings in physicians with metabolic and genetic specialties from Oregon State to provide much needed specialty services for CSHCN. In the 2010 Idaho Maternal and Child Health Five-Year Needs Assessment Survey, the number one need identified by providers, parents, and organizations was “improve access to medical specialists for children with special health care needs.”

Survey Casts Stark Light on Problems

The Idaho Children’s Special Health Program surveyed a convenience sample of families with CSHCN as part of the five-year needs assessment. Results of the survey were released through the two parent organizations who work with these children: Idaho Parents Unlimited and Idaho Families of Adults with Disabilities. The survey examines geographic lack of access to medical specialties in the state; some of the results cast a stark light on the problem. A full 66% of the respondents answered “yes” to the question “Does traveling to visit your child’s medical specialist present your family with difficulty?” When asked “Has your child ever missed an appointment with his or her specialist for travel-related reasons?” 39% responded “yes.”

When families were asked how many miles they had to travel to visit their child’s medical specialist, one quarter had to travel over 100 miles, and more than half of those had to travel over 250 miles. Of the families who had to travel over 100 miles to reach their specialist, 12% had to visit their specialist more than twice per year.

Idaho has more than the national average of school absences for CSHCN.(1) While we have no correlative data, it is likely that a lack of medical specialists contributes to the number of days of school missed.

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REFERENCES

Oregon State has developed a variety of maternal and child health initiatives to increase access to health care services for families living in rural areas of the state. Three are highlighted below.

Early Hearing Detection and Intervention Program. In Oregon, only hospitals with more than 200 births per year are mandated to perform newborn hearing screenings. As a result, rural counties with low population densities or high out-of-hospital births have high rates of unscreened infants. Using birth certificate data, the Oregon Early Hearing Detection and Intervention Program developed a system to monitor the status of hearing screening, diagnostic evaluation, and early intervention enrollment for infants. The program can then identify counties with low rates of hearing screening and diagnostic evaluation and implement strategies to improve screening. These strategies include:

- provide equipment, training, and technical assistance to hospitals with no screening capacity so that they can begin screening and reporting
- partner with midwives to provide education to their clients about newborn screening
- partner with public health nurses to provide screening for their communities

The Children’s Health Equity Outreach Project, a federally funded grant shared by the Office of Family Health and Office of Healthy Kids, enrolls eligible children with undocumented immigrant parents into a health insurance plan (Healthy Kids/Oregon Health Plan). The program funds five safety net health entities representing 14 different sites in 11 counties. In two years, community health workers have reached over 12,000 families with information about health insurance coverage and enrolled more than 6,500 vulnerable children. Analysis of project data indicates that over 80% of children enrolled through the project live in rural areas of the state.

Project LAUNCH is an initiative of the US Substance Abuse Mental Health Services Administration to promote healthy child development and well-being through an integrated system of family and child wellness campaigns, prevention efforts, and treatment services. Project LAUNCH is being pilot tested in Deschutes County, which includes both small urban and rural communities. The project includes evidence-based home visiting and parenting services, as well as integrated primary care and mental health services at three school-based health centers. These child and family support services may be the only services families who live in the more rural parts of the county receive. Workforce development is also an essential element of Project LAUNCH. Lessons learned from this pilot project will be shared throughout Oregon and with the other 24 national demonstration sites.

Beth Gebstadt, MPH, MS, is manager for Project LAUNCH and Heather Morrow-Almeida, MPH, is a system and policy specialist. Both are with the Maternal and Child Health Section, Office of Family Health, Oregon Public Health Division.

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The Washington State Department of Health’s Children with Special Health Care Needs Program won a competitive grant from the CDC to pilot a campaign to raise awareness of developmental milestones of children. Learn the Signs. Act Early targets Spanish-speaking, Hispanic families with children under the age of four years who live in rural, underserved, and designated Health Professional Shortage Areas—areas where migrant populations in particular have difficulty accessing primary care.(1) While the main audience is Hispanic parents, the campaign also targets health care and child care providers and others who work closely with this population. The goal is to raise awareness of milestones, thus prompting parents to seek assessment. This campaign is part of a larger effort to develop a system for universal screening in Washington.

Hispanic residents often face serious obstacles to accessing health care including lack of providers and insurance, long distances to providers, and language and cultural barriers. In Washington, Hispanic children, aged 17 years and younger, are significantly less likely to have a usual source of care, to receive family-centered care, or to have a medical home, compared with non-Hispanic White children.(2) National studies suggest that limited English skills are associated with difficulties accessing health care,(3) children not receiving needed medical care,(4) and medical misdiagnoses.(4)

In addition, Hispanic children are less likely to receive a diagnosis of a developmental delay and be referred to a provider.(5) Increasingly, there is evidence that autism spectrum disorders are often diagnosed several years after the onset of symptoms or are misdiagnosed even though experienced clinicians can accurately diagnose autism spectrum disorders in children as young as two years.(6) Early detection and treatment of developmental delays leads to a better quality of life later in life.

Using a multi-cultural educational outreach, the campaign encourages parents, clinicians, and caregivers to use development milestones to gauge a child’s development starting at three months of age and to seek medical attention if they have concerns. It also raises public awareness of developmental differences through Spanish radio talk shows, public service announcements, bus posters, and promotion within Head Start, WIC, and other programs. The CDC is evaluating these campaigns in four states. ◊

Carol L. Miller, MPH, is a consultant with the Children with Special Health Care Needs Health Program, and Teresa Vollan, MPH, is an epidemiologist, both with the Department of Health.

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REFERENCES
Resources...

Alaska Center for Rural Health
http://acrh-ahec.uaa.alaska.edu/

Alaska Office of Rural Health
State of Alaska Health and Social Services
www.hss.state.ak.us/dph/healthplanning/rural-health/default.htm

Idaho Rural Health Association
www.idahorha.org/


National Center for Frontier Communities
www.frontierus.org/index-current.htm

National Organization of State Offices of Rural Health
www.nosorh.org/

National Rural Health Association
www.ruralhealthweb.org/

National Rural Health Resource Center
www.ruralcenter.org/

National Rural Recruitment and Retention Network
www.3rnet.org/default.aspx

http://mchb.hrsa.gov/nsch/07rural/

Office of Rural Health Policy
Health Resources and Services Administration, US Department of Health and Human Services
www.hrsa.gov/ruralhealth/

Rural Assistance Center
www.raconline.org/

Office of Rural Health Policy, US Department of Health and Human Services

Rural Health Research Findings
Agency for Healthcare Research and Quality, US Department of Health and Human Services
www.ahrq.gov/browse/ruralra.htm

Rural Health Section
Washington State Department of Health
www.doh.wa.gov/hsqa/ocrh/

Office of Rural Health and Primary Care

Idaho Department of Health and Welfare
http://healthandwelfare.idaho.gov/default.aspx?TabId=104

Oregon Office of Rural Health
Oregon Health and Science University
www.ohsu.edu/xd/outreach/oregon-rural-health/index.cfm

What is Rural?
National Agriculture Library
US Department of Agriculture
www.nal.usda.gov/ric/ricpubs/what_is_rural.shtml

WWAMI Rural Health Research Center

MCH Navigator is a portal to training opportunities for maternal and child health professionals and students. On the web site, you will find archived webcasts and webinars, instructional modules and self-guided short courses, video and audio recordings of lectures and presentations from university courses and conferences.

Chart your professional growth pathway
MCH Navigator helps you determine where you are now, where you want to be, and the best route to get there. You can identify the skills and competencies needed to meet your goals and find the learning resources appropriate for those goals. Learning categories include: MCH 101, MCH conceptual models, management, communication, epidemiology, leadership, MCH planning cycle, and targeted MCH populations and topics.

MCH Navigator
http://navigator.mchtraining.net/