



COMMUNITY HEALTH WORKERS AND CHILDREN WITH SPECIAL HEALTH CARE NEEDS

a report from the

National Center on Ease of Use
of Community Based Services
for CSHCN

in collaboration with

The HSC Foundation

prepared by

Judith S. Palfrey, Nerlie Ogilus,
and Myra Rosen-Reynoso

2014



COMMUNITY HEALTH WORKERS AND CHILDREN WITH SPECIAL HEALTH CARE NEEDS

a report from the

National Center on Ease of Use
of Community Based Services
for CSHCN

in collaboration with

The HSC Foundation

prepared by

Judith S. Palfrey, Nerlie Ogilus,
and Myra Rosen-Reynoso

2014



© Autism Society of North Carolina

ACKNOWLEDGEMENTS

The report was produced with support from Grant No. U42MC18283 from the Maternal and Child Health Bureau, Department of Health and Human Services, Division of Services for Children With Special Needs and support from The HSC Foundation. The report includes information from the “High Expectations” meeting co-sponsored by and held at The HSC Foundation in Washington, DC on November 12-13, 2013. We gratefully acknowledge the support of our colleagues at the American Academy of Pediatrics (AAP), the Association of Maternal and Child Health Programs (AMCHP), the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), and members of the Action Learning Collaborative on the Ease of Use of Community Based Services. The contents of the report are solely the responsibility of the authors and do not necessarily represent the official views of the Maternal and Child Health Bureau, Health Resources and Services Administration, or HHS.

Photographs are from New York-Presbyterian/Columbia University Ambulatory Care Network, Autism Society of North Carolina, Health Services for Children with Special Needs, Inc., as well as stock photography from 123RF.com.

THE REPORT

BACKGROUND

The National Center for Community Based Services for Children With Special Health Care Needs and The HSC Foundation have been collaborating to find ways of improving health and related services for children with special health care needs from traditionally underserved communities. The engagement of community health workers (CHWs) has emerged as a very promising strategy for addressing the persistent disparities in the delivery of health care and related services to CSHCN.

As part of our work, we have performed this environmental scan to identify programs across the United States that are combining the strengths of the community health workers with programming for CSHCN. We have focused primarily on programs that address Latino families.

WHAT THE LITERATURE TELLS US

Disparities in the Access to and Quality of Health Services for CSHCN of Latino Backgrounds

Children from traditionally underserved and marginalized communities have more health problems and less accessible, effective health care delivery than children generally.^{1, 2, 3} When children from underserved communities also have special health care needs, the problems they face are further compounded.^{4, 5, 6, 7}

Children with special health care needs (CSHCN) are those children and youth “who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”⁸ Approximately 15% of the United States population of children fit this definition.⁹

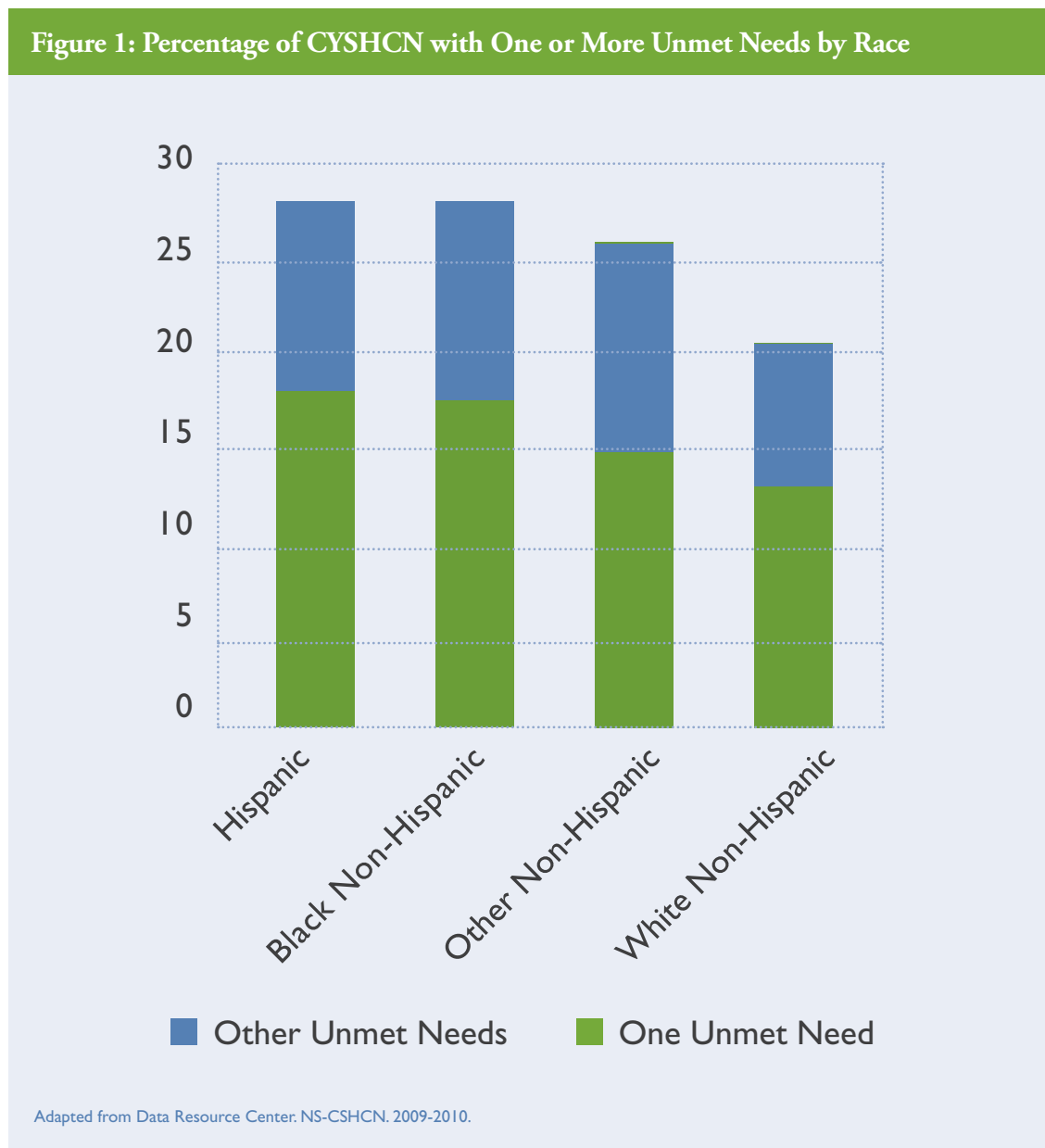
The United States Bureau of Maternal and Child Health (MCHB) has developed 6 core goals to assure that the system of care for all CSHCN is optimized.¹⁰ See Box 1 below:

Box 1: Core Outcomes to be Achieved for Children with Special Health Care Needs

1. All children with special health care needs will receive coordinated ongoing comprehensive care within a medical home.
2. All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need.
3. All children will be screened early and continuously for special health care needs.
4. Services for children with special health care needs and their families will be organized in ways that families can use them easily.
5. Families of children with special health care needs will partner in decision making at all levels, and will be satisfied with the services they receive.
6. All youth with special health care needs will receive the services necessary to make appropriate transitions to adult health care, work, and independence.

Source: www.mchb.hrsa.gov/programs/specialneeds/achieving success.html

Progress toward achieving the 6 core goals is measured every 3 to 4 years through the National Survey of Children With Special Health Care Needs (NS-CSHCN).⁹ While there has been some improvement in several of the measures, there remain glaring gaps for children from traditionally underserved families. For instance, CSHCN from racial and linguistic minority backgrounds have more unmet needs than children from white backgrounds as is seen in Figure 1.



It is of particular concern that only 43% of CSHCN benefit from a medical home (as measured by the NS-CSHCN). Among African-American CSHCN, only 33% of their families report meeting the medical home criteria. The figure is 35% for English-speaking Latino families and as low as 25% for Spanish-speaking Latino families. These poor rates are striking in face of federal recommendations and of evidence suggesting the effectiveness of the medical home for CSHCN.¹¹

WHAT STUDIES TELL US ABOUT INTERVENTIONS TO DECREASE RACIAL AND ETHNIC DISPARITIES

Over the past decade, health care providers and policymakers have begun to explore interventions directed at decreasing the persistent disparities in health care access and health outcomes associated with race and ethnicity. Strategies have included health education programming for patients, communications skills enhancement for professionals and the engagement of community health workers.¹² While the literature is just emerging, there are strong suggestions that the integration of community members onto health care teams can decrease health disparities. These community health workers (CHWs) serve as “liaisons,” “health ambassadors,” “peer navigators” or “cultural brokers” who can bridge cultural, linguistic and other gaps between patients and health care providers.^{13, 14}

COMMUNITY HEALTH WORKER DEPLOYMENT

In 1978, the World Health Organization published the Alma Atta Declaration that defined the essentials of primary care and recommended the engagement of community health workers as team members in disease prevention and health promotion efforts.¹⁵ Ever since that time, programs around the world have been developed to integrate community health workers into health care teams.

The Section on Community Health Workers of the American Public Health Association defines a Community Health Worker as:

- “...a frontline public health worker who is a trusted member of and/or has an unusually close understanding of the community served. The trusting relationship enables the CHW to serve as a liaison/link/intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery.’
- “A CHW also builds individual and community capacity by increasing health knowledge and self-sufficiency through a range of activities such as outreach, community education, informal counseling, social support and advocacy.”¹⁶

Over the years since Alma Atta, the principles that lead to highly successful CHW programming have become increasingly clear. In 2008, the World Health Organization articulated 5 principles for CHW deployment.¹⁷

1. Strong management
2. Appropriate selection
3. Suitable training
4. Adequate retention strategies
5. Good relationships with other health care workers

In 2011, Campbell and Scott argued for the critical importance of a 6th principle, namely, “community embeddedness.”¹⁸ By this, they meant that CHWs need to be deeply rooted in the culture of the community and that they need to share the experiences and expectations of the people they work with. They urge the participation of the community in the selection and on-going support and management of the CHWs’ work in partnership with health care providers or organizations.

While these principles make strong theoretical sense, community health care worker deployment is constrained by many real world factors — the most difficult being financial limitations. An extensive review of the CHW workforce in the late 2000s revealed that approximately 1/3 of CHWs were volunteers and that, of the paid workers, the majority received less than the minimum wage.¹⁹

WHAT COMMUNITY HEALTH WORKERS CAN ACCOMPLISH

Despite low wages and other challenges, CHWs as team members have advanced the care of people with a wide variety of conditions. This is particularly true for adults with conditions such as diabetes, hypertension, heart disease, HIV, TB and malaria.^{20, 21} CHWs are particularly helpful in the implementation of screening programs (e.g. mammograms, colorectal screening) and for disseminating educational information about prevention (e.g. smoking cessation).^{22, 23}

While formal engagement of CHWs around child health has been less robust than that for adults, the integration of CHWs into child health practice has the potential to make big impacts. A recent Cochrane meta-analysis by Lewin reports that the deployment of CHWs probably improves immunization rates and breastfeeding, may help decrease the number of children with fever and diarrhea, as well as under 5 mortality, and may increase the number of children whose parents seek care for them when they are sick.²⁴

Recent experimentation using CHW interventions in asthma have shown exciting results.^{25, 26, 27} Home visiting and liaison activities by CHWs can lead to:

- Improved health status for children with asthma,
- Better use of preventive medicines,
- Decreased emergency room visits, and
- Decreased or shortened hospital admissions.



© Health Services for Children with Special Health Care Needs

WIN for Asthma is a particularly impressive program that takes place in the Washington Heights Inwood neighborhood of New York City. Among all program graduates to date, hospitalizations decreased by 70%, emergency department visits decreased by 55%, and nearly 100% of caregivers reported feeling able to manage their child's asthma (see http://nyp.org/services/acn_outreach_win.html).

Based on the promise of CHW involvement as a powerful tool for reducing health disparities, our group was interested in determining whether and where CHWs were engaged in activities specifically targeted to the needs of CSHCN.



THE ENVIRONMENTAL SCAN

Methodology and Criteria for the Scans

We carried out a literature review using search terms including “community health worker,” “promotora,” and “community liaison” to identify reports about the engagement of CHWs in working with families of CSHCN. To augment the literature review, we searched the web using Google to identify Latino serving organizations that publicized information about the engagement of CHWs. Often this led us to Facebook pages for details about organizations. We also probed our informal networks for nominations of programs that were involving CHWs in their outreach to and services for CSHCN.

We identified nearly 60 groups in this way. The identified groups were providing an impressive array of services for Latino families including health services (e.g. programs for elderly, for adults with disability and adults with diabetes, as well as programs for children with asthma and obesity). To identify those programs that were engaging community health workers and/or community outreach strategies to enhance services for CSHCN from Latino families, we applied the criteria in the Box 2.

Box 2: Criteria for Inclusion in CHW Environmental Scan

1. Program(s) has ability to provide services to Latino families
 - a. Latino serving organization (specifically), or
 - b. Serves many populations including Latino, or
 - c. General population but is making a special effort to reach out to Latino families
2. Program(s) has decided to provide services (or link families to services) for CSHCN
 - a. Is providing services (define type), or
 - b. Is linking to another organization, or
 - c. Is developing systems to make linkage
3. Program uses community health workers (promotoras) or other specific community based mechanism *to reach families where they are*
4. Size of program. Minimum number of families involved. At least 20.
5. Length program has been in existence: At least 1 year.
6. Funded and unfunded.
7. Replicable: Has components that could be copied in other settings.

Fifteen groups met (or came close to meeting) the criteria and another four met some of the criteria. To obtain more details, we conducted additional information gathering including phone calls, further review of written documents and some site visits. Here we present six exemplary programs.

EXEMPLARY PROGRAMS

NEW YORK-PRESBYTERIAN/COLUMBIA UNIVERSITY MEDICAL CENTER PROJECTS IN UPPER MANHATTAN

The New York-Presbyterian hospital system supports an extensive Ambulatory Care Network of 15 primary care practices, 70 subspecialty clinics, and 9 school-based health centers. In the Washington Heights and Inwood neighborhoods of upper Manhattan, the New York-Presbyterian system engages CHWs to assist Latino families with childhood asthma and adult diabetes (Type 2). These bilingual CHWs are the central point of contact for individuals and their caregivers who require comprehensive information, support, and referrals for community services, such as those related to housing, immigration, and employment. They are based in partnering Community Based Organizations (CBOs). These CHWs are trained through health system resources and represent both the hospital and the community to serve as a bridge for families.

© New York-Presbyterian/Columbia University
Ambulatory Care Network



Recently, the practices of the Ambulatory Care Network have earned the designation of Level 3 Patient Centered Medical Home (PCMH) from the NCQA. The team has stratified all children with asthma into a registry for PCMH and those with the greatest needs are assigned to CHWs for participation in a one-year care coordination program.

The team is also currently stratifying all children with special healthcare needs into a registry by level of complexity for their PCMH. Eventually, the vision is to expand the CHW program to outreach to these children and their caregivers. The registry will link to utilization data to facilitate the identification of heavy utilizers and provide a mechanism for tracking both the clinical and the financial impact of engaging CHWs in the care of CHSCN.

Community Outreach Around Autism in North Carolina

In North Carolina, the Public Health Department's Title V program has created innovative partnerships to reach out to the Latino community of families of CHSCN. They work with the Cabarrus Health Alliance (<http://www.cabarrushealth.org>) that has trained 15 parent leaders to serve "a support group" for Latino parents with CYSHCN with diverse diagnosed health needs. The team uses Spanish modules from the University of Vermont to train parent leaders for CSHCN (<http://www.uvm.edu/~pcl/modules.php>). There are plans to expand this work to an additional seven counties.

A particularly effective program runs through the Autism Society of North Carolina. Mariela Maldonado is the community liaison to the Autism Society. She is the mother of a young adult with a disability. She runs parent support groups for families to introduce them to topics related to autism. The groups have attracted increasing numbers of families. The educational materials that Mariela shares with the groups are designed to answer questions, dispel myths and get families who have children with developmental concerns and autism on the way to receiving appropriate health and related services. The Autism Society of North Carolina's Spanish-language Webpage presents authoritative information in an accessible form for parents (see <http://autismsociety-nc.org/index.php/get-help/en-espanol>).

Community Outreach through Schools in Rhode Island

The Rhode Island Parent Information Network (RIPIN) (see www.ripin.org) employs a number of creative community outreach strategies in partnership with schools in order to assist families of CHSCN. They engage Spanish-speaking peer navigators to enhance RIPIN's ability to direct Latino families to helpful resources and to assist them access health insurance coverage. These peer navigators often are parents of children with special health care needs who are able to share their stories, experiences and empathy with other families of CHSCN.

Working with the schools, the RIPIN peer navigators who are trained to welcome new families into the community, and build awareness of community-based resources. They help connect families to professionals who can screen for special health care needs and direct them to health services, including community-based therapies and counseling as well as to educational services such as early intervention and special education.

The peer navigators also collaborate with the schools in helping to staff Family Resource Rooms where trained parent volunteers assist by checking in with families whose children have been ill and/or experienced school absences for a variety of reasons. They identify questions that parents may have about their children's school experiences and they assist the school administration develop and promote family-oriented programs and activities.

RIPIN's peer navigator program built a strong collaborative relationship with the RIREACH (the R.I. Insurance Resource, Education, and Assistance Consumer Helpline) program. RIREACH helps consumers get what they need from their health insurance coverage by assisting consumers in accessing health coverage, health care benefits, or community resources to address social determinants of health. RIREACH is an innovative consumer assistance outreach program that meets families where they are to bring information about health insurance access. In preparation for the launch of the Rhode Island Health Insurance Marketplace, RIREACH conducted a session about health insurance at a back-to-school fair. They fielded questions from over 600 individuals and followed up with 185 families from this event who requested additional support. RIREACH connected with families to ensure their questions were adequately answered and whatever issues or barriers to care they were encountering were resolved. In addition to this, over 100 Spanish-speaking Latino families from this event received guidance and coaching on how to access healthcare benefits through the Rhode Island Health Benefits Exchange.



© http://www.123rf.com/profile_jarenwicklund

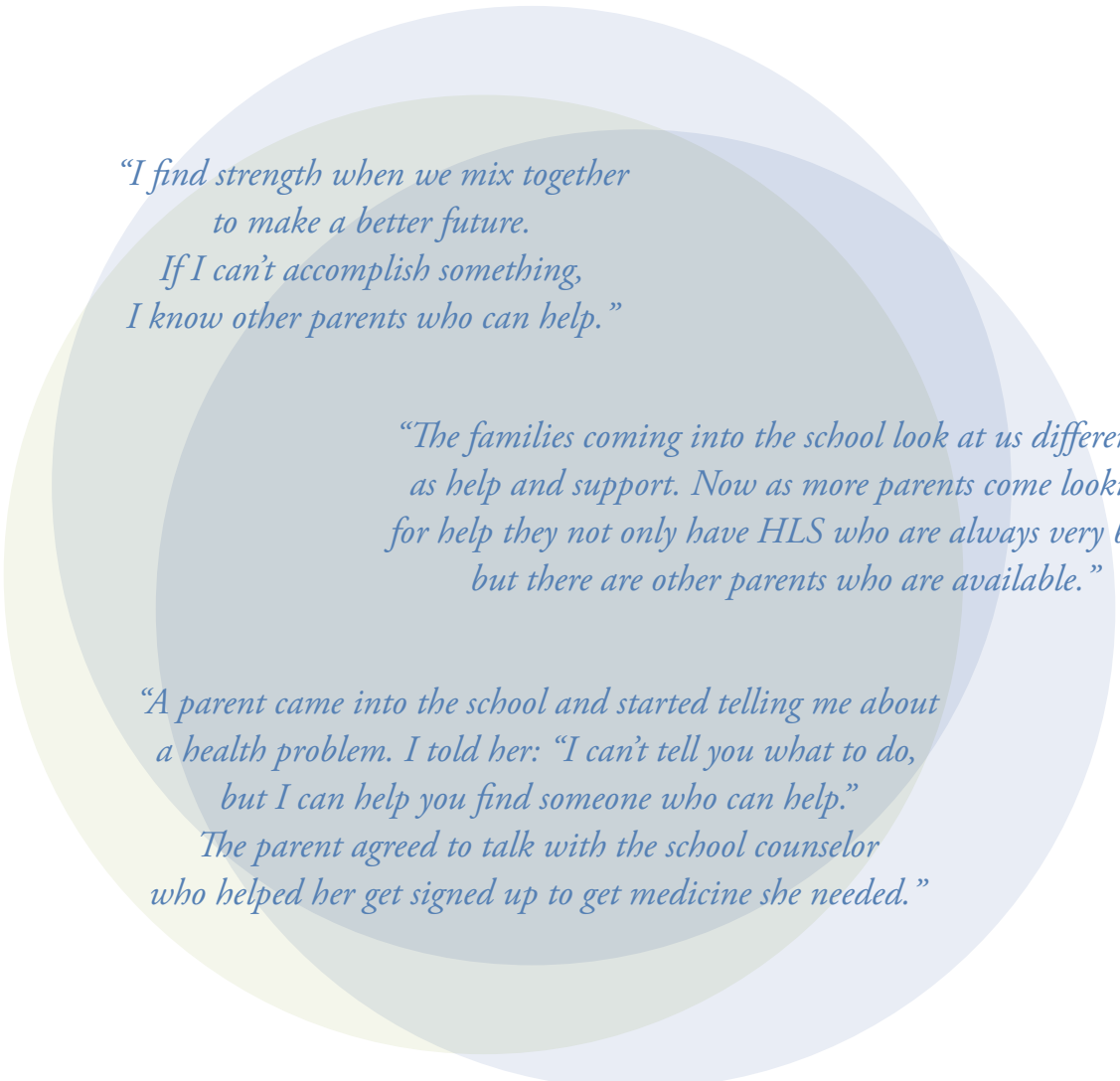
As part of this project, parent leaders are able to serve as cultural brokers between a Latino school community and English speaking school professions and community partners helping to clarify issues so that services can be delivered more efficiently.

Example of the type of issues the parent leaders have addressed:

- Treatment and control of asthma
- Support for students with special educational services
- Fitness programs for children with special needs
- Tobacco, drug, and suicide prevention
- School uniforms and anti-bullying initiatives
- School-wide fitness celebrations
- Learning English, continuing education, and attaining employment

The Parent Navigator project found that family leadership development requires prolonged commitment to flourish and that positive outcomes occur when parents take ownership of and develop work that connects their personal interests to a larger common goal.

The following quotes reflect the sentiment captured during final listening sessions.



*“I find strength when we mix together
to make a better future.*

*If I can’t accomplish something,
I know other parents who can help.”*

*“The families coming into the school look at us differently,
as help and support. Now as more parents come looking
for help they not only have HLS who are always very busy,
but there are other parents who are available.”*

*“A parent came into the school and started telling me about
a health problem. I told her: “I can’t tell you what to do,
but I can help you find someone who can help.”
The parent agreed to talk with the school counselor
who helped her get signed up to get medicine she needed.”*

.....

HSCSN (Health Services for Children with Special Needs, Inc.)

The HSC Foundation (www.hscfoundation.org) is dedicated to improving access to services for individuals who face social and health care barriers due to disability, chronic illness or other circumstances that present unique needs. Health Services for Children with Special Needs, Inc. (HSCSN) is a subsidiary organization of the Foundation, and a dedicated health plan for Supplemental Security Income-eligible youth and young adults in the District of Columbia (www.hscsn-net.org).

HSCSN provides a comprehensive set of benefits for Medicaid recipients up to 26 years of age and offers health, long-term care and social support services for members that include individualized care coordination, behavioral health services, outreach programs and respite care. Utilizing a network of more than 2,000 providers, HSCSN coordinates traditional Medicaid benefits plus expanded wraparound services that include intense management of social factors that affect health status.

The plan focus is to provide increased access to health and social services in a cost efficient and highly efficacious manner. HSCSN's Department of Family and Community Development (FCD), which is responsible for member education, engagement and targeted compliance, has a team that includes 10 "outreach representatives" who make community and home visits to enroll families in the HSCSN program. During these visits, outreach representatives educate eligible families about the health and related benefits that children and young adults are entitled to through the DC Medicaid program.

HSCSN also operates four ongoing programs to address the physical, mental, emotional, developmental and social needs of the HSCSN member community:

- Parent Advocate Leader's Support Group
- Male Caregiver's Advocacy Support Group
- Youth Athletic Program, and the
- Healthy Living Program

Through these programs, HSCSN staff engages with HSCSN members and their families to help empower them and to promote independence in dealing with physical, mental, emotional, developmental and social needs. HSCSN staff reaches out in a wide variety of ways and settings, meeting families where they are and addressing needs as they arise. The FCD can help with obtaining food, housing and assuring that other basic needs such as utilities are met, collaborating with over 110 local agencies and partners. In the past, outreach representatives have also coordinated their efforts with the Community Health Worker Network of DC.

The FCD team also supports care management in the preventive care compliance of HSCSN members. Members are able to receive approved incentives for attending annual health and dental visits and for keeping up to date with appropriate screenings (e.g., lead). The FCD staff continues active communication with members, reminding them of their appointments and authorizing incentives to families to encourage the importance of compliance with preventive health care practices. By maintaining this high-contact outreach program that closely collaborates with community partners, HSCSN works to help members and their families improve their health, social and environmental needs.



© Health Services for Children with Special Health Care Needs



Westside Family Healthcare

Westside Family Healthcare (<http://www.westsidehealth.org>) is a network of six community health centers providing care to over 26,000 patients throughout the State of Delaware. Certified as a primary care medical home (PCMH) by the Joint Commission, Westside Family Healthcare provides services to families that have multiple medical and social needs. Sixty percent of patients who seek services at Westside Family Healthcare identify themselves as Hispanic. Twenty-five percent of patients are children.

Delaware is home to large fruit and vegetable farms. Much of the farm work is done by migrant Hispanic farm workers, mostly from Mexico and Guatemala. While some of the workers are in Delaware only seasonally, others are permanent residents.

To assist their patients to meet the many challenges that face them, Westside Family Healthcare engages CHWs (promotoras) to help with coordination of services.

The promotoras are able to obtain important health information for the families through the Regional Migrant Assistance Program that tracks health information (such as immunization records) as families move from site to site and state to state. The program also has many community partnerships which include Reach Out and Read, school partnerships, State of Delaware, Food Bank of Delaware, Bayhealth Medical Center, and La Esperanza. Westside also collaborates with the Telamon Corporation (<http://www.telamon.org/default.aspx>), a state program for migrant farm workers that helps provide housing, medical care and educational services (particularly Head Start).

Westside Family Healthcare collaborates with the Delaware Health Information Network (DHIN) to access and share patient laboratory results with other providers, which helps to control healthcare costs. Westside also has an online Patient Portal where patients can access their laboratory results, request an appointment, and request a medication refill. Westside Family Healthcare has a strong relationship with the Nemours Hospital in Wilmington, Delaware. The community health workers, promotoras and the family medicine practitioners in the six community health centers can access subspecialty care for CSHCN through Nemours extensive network.

With an over 25 year history of providing affordable, quality health services in the Wilmington area, Westside Family Healthcare has developed a sustainable model with financing from the FQHC funding stream.

Yakama Valley Farm Worker's Clinic and Children's Village

Yakama Valley in Washington State is home to a diverse community largely involved in agricultural pursuits. Children's Village (<http://www.yakimachildredivillage.org>) is a multi-agency service site that partners with the Yakama Valley Farm Workers' Clinic (YVFWC) to assure comprehensive and coordinated health services for CSHCN. The Children's Village mission is *"Crossing the bridge... together. Partnering to connect children with special needs and their families to supportive services."*

Annually, Children's Village provides comprehensive services to over 4000 children and youth (birth to 19). Approximately 40% of these patients are Latino. Children's Village offers:

- Medical specialty clinics in conjunction with Seattle Children's Hospital
- Pediatric Dental services
- Physical, Occupational and Speech Therapy
- Genetic Counseling
- Infant and Toddler Early Intervention
- Behavioral Assessment and Treatment
- Autism Diagnostic and Treatment Programs
- Fetal Alcohol Spectrum Disorder (FASD) Diagnostic Clinics
- Nurse Family Partnership
- Family Care Coordination
- Parent to Parent



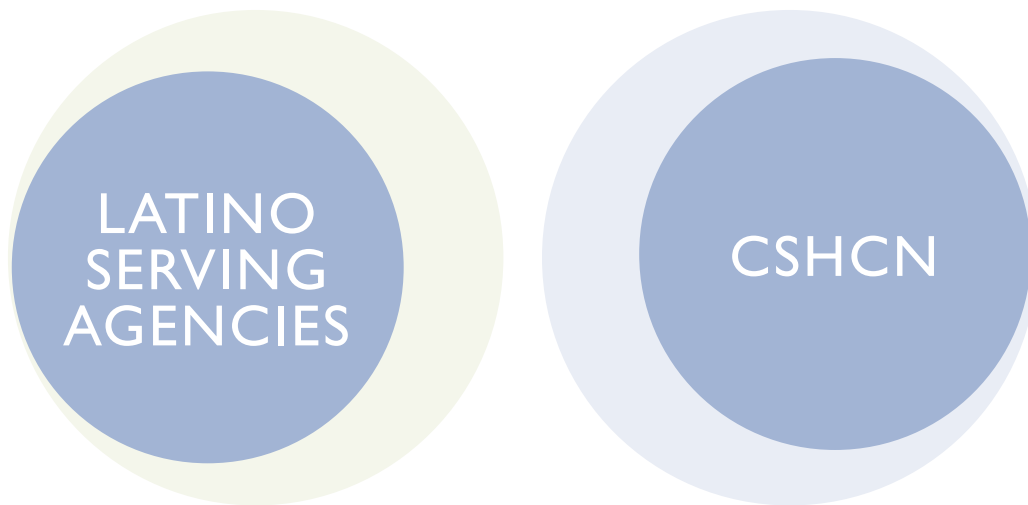
Much of the success of the Children's Village comes from its fundamental structure. Four trustee partners — Central Washington Comprehensive Mental Health, Memorial Foundation, Yakima Valley Farm Workers Clinic, and Yakima Valley Memorial Hospital — collaborate to assure comprehensive and coordinated services. Children's Village also has multiple partners within the Yakima community and the state of Washington, all with a commitment to provide comprehensive services for CSHCN and their families. A pediatric advisory committee meets 3 times a year to review operations and clinical offerings.

Community outreach is an integral component of the Children's Village. A team of 6 nurses provide home visits through the Nurse Family Partnership (NFP) program. The nurses have case loads of 25 children. Three of the nurses are bilingual. In this program the nurses work with low-income, first time mothers from their pregnancy through the second birthday of the child.

Funding for the Children's Village comes from the Village Trustee partners: Memorial Hospital, Memorial Foundation, Yakama Farm Worker's Clinic and Central Washington Comprehensive Mental Health. Annual community based fund raising is a strong component of the financial sustainability of the Children's Village. Funding and sustainability continue to challenge us. The four Trustee Partners contribute to the shared operational costs of Children's Village and shared services such as on-site child care. Each partner operates and bills for their individual programs, as well as grant and other funding. The Memorial Foundation provides the leadership for community fundraising efforts.

A LONG WAY TO GO

Our review of the literature, search of websites, Facebook and informal Delphi procedure has led us to the conclusion that at this point in time, there are only a limited number of programs that are engaging CHWs (promotoras or other community based health care managers) in the work of improving the medical home status and the ease of community based service use for CSHCN. Our review is, of course preliminary, but our impression at this time is that while there are many Latino Serving Agencies and while there are CSHCN serving groups, there is less than optimal overlap of these two — with substantial opportunity for improvement.



The schematic above shows very little overlap in the two groups. The schematic below shows the opportunities ahead.



PRINCIPLES AND OPPORTUNITIES

PRINCIPLES

In December, 2013, The HSC Foundation in conjunction with the National Center on Ease of Use of Community Based Services sponsored a working meeting called “High Expectations” to examine the questions of how CHWs could be most effectively engaged in work with CSHCN.

Through a workshop process, the group answered 3 basic questions about CHWs and CSHCN:

1. What are the core competencies that community workers need regarding children with special health care needs?

- Knowledge of Insurance — i.e. SSI, specifics to CYSHCN
- Glossary of terms relate to CYSHCN
- “Care book”/manual to share with families
- Competencies specialized services for CYSHCN
- General advocacy skills
- On-going professional development
- Focus on strengths of families
- Transitions to adulthood
- Organize events and celebrate accomplishments
- Develop leaders in families
- Understand family systems
- Develop benchmarks of success
- Reflective supervision — linked to Medical Home with formalized way to document visits
- Recruit, retain, increase job satisfaction
- Self-management, self-sufficiency
- Not volunteers — should be paid professionals
- Take advantage of pre-established CHW standards and policies already in place
- Know how to identify home alarm signals
- Developmental disability screening
- Definition/Glossary — who is a CHW?



© Autism Society of North Carolina

2. What do medical home providers need to know about community health workers?

- What their role is
- Training
- Addition to the Medical health team — what is the value added?
- Tiers of support
- Videotaped interviewing
- Clear expectations from both sides
- Training of realistic expectations
- Administration will be making decisions. Return on Investment
- Deemed as precious and valuable
- ACA — who can get paid for this type of work?
- Keep in the feedback loop

3. What do medical home providers need to know about Latino families of CSHCN?

- Deep understanding across cultures — respect the differences
- First generation vs. second generation
- Self-efficacy
- SES issues
- Issues around literacy
- Ability to form relationships
- Cultural competency — pillar around all of this and ecological, medical approach
- Don't assume they want to speak in Spanish
- Use qualified translators
- Connect with the family
- Provide privacy to hear diagnosis
- Offer tools to help prepare for visits
- Family centered care



© http://www.123rf.com/profile_pictrough

OPPORTUNITIES

While at the present time, there appears a relatively low level of experience with the integration of CHWs into systems of care for CHSCN, a number of factors make the likelihood that the coming years will see further movement. Prime among these is the 2010 passage of the Affordable Care Act²⁸ and the ensuing implementation of its regulations.

The Affordable Care Act opens up significant opportunities for the incorporation of Community Health Workers into systems of care for CHSCN.



© http://www.123rf.com/profile_yelo34

1. Requirement for hospitals to perform community health needs assessment (IRS).

Under ACA, hospitals are now required to conduct a community needs assessment every three years and adopt an implementation strategy based on their findings.²⁹ This will mean that each hospital must reach out to the local community to learn about health conditions and social factors that either worsen those conditions or make it difficult for families to access appropriate health care help. Recently The HSC Foundation published the report of their community assessment and their new strategies.³⁰ They noted: “In general, the interviews and surveys completed by the public health experts and community members support a continuation of the same unmet needs addressed in published data related to the special health care needs population for the past 10 years.” They found that most of the children did have health insurance coverage (generally with Medicaid), but reported that the coverage “falls short in covering needed services or attracting sufficient number of needed providers.” Based on the finding of continued lack of coordination and need for a wide range of health and social services, HSC used the occasion of the Community Needs Assessment to commit to 4 strategic initiatives including among them: “work with community partners as requested to help define a more effective “clinical care coordination” model.”

Since the ACA requires the community assessment and plan every 3 years and since there are significant tax related consequences for non-compliance with this recommendation, hospitals will need to be creative and forward thinking in their programming. This will highly likely involve the engagement of community health workers who can break down barriers and help with the coordination of care for families.

2. Extension of the Patient Navigator Program (ACA Para 773, p. 430)

ACA extends the Patient Navigator Program until the end of 2015 to assist “in overcoming obstacles to the prompt diagnosis and treatment of health problems. Patient navigators guide individuals to find health insurance. They coordinate referrals and they help facilitate enrollment in clinical trials. The Patient Navigator Outreach and Chronic Disease Prevention Act of 2005 (PL 109-18) which is extended by ACA authorizes grants for patient navigator programs and emphasizes the role of navigators and of community organizations in the prevention and care of chronic diseases and in the attack on health disparities. ACA authorizes the appropriations for 2011 through 2015.

3. Grants to Promote the Community Health Workforce (Para 1559, p. 746)

Recognizing the promise of CHWs and the need for high quality training and supervision of the CHW workforce, the ACA includes provisions for the establishment of a new community health worker training program. The program focuses on the promotion of positive health behaviors among “medically underserved populations.” Appropriations are made for “such sums as may be necessary for fiscal years 2010 through 2014.”

There are also provisions for home visitation and education services grants related to maternal health and prenatal care.

The “Community health workers programs receiving grants will be encouraged to collaborate with both academic institutions and one-stop delivery systems and also to implement outcome based payment systems.”



© http://www.123rf.com/profile_lisafx

4. Medical Home and Credentialling

The medical home (also health home ACA para 555) is foundational for the care of children and youth with special health care needs. While most CSHCN can identify their primary care provider, traditionally underserved children and their families still report difficulty with family centeredness of care and with the coordination of health and social services.



© http://www.123rf.com/profile_rmarmion

The promotion of the Patient Centered Medical Home by internists and family practitioners has spurred increased discussion and innovation in health care delivery around the medical home. As a result, CMMI and other insurers have begun to emphasize care planning, coordination of care and, even, community outreach. The NCQA and other forms of credentialing offer an opportunity for practices to “stand out” in comparison with other clinicians as true medical home providers. NCQA places high value on coordination activities and the mechanism allows remuneration to practices either through bundled or per member per month payments.

These moneys are a potential source of payment for the services of community health workers.

5. Federally Qualified Health Centers and CHWs.

Federally Qualified Health Centers have long been a key component of the health system for families in poverty, those at social and economic risk as well as those new to the United States and those who do not speak English as their first languages. The ACA encourages experimentation and expansion of FQHCs particularly as health homes (para 555). FQHCs have the potential to engage CHWs as an adjunct to care and coordination of services. Increasingly there are opportunities for larger systems such as emerging Accountable Care Organizations (ACOs) to partner with FQHCs.

REFERENCES

1. Smedley, B., Stith, Y., Nelson, A., 2003. Unequal treatment: Confronting racial and ethnic disparities in health care; Executive summary. *Institute of Medicine*, Retrieved from: <http://books.nap.edu/catalog/10260.html>.
 2. Chamberlain, J., Joseph, J., Patel, K., Pollack, M., 2007. Differences in severity-adjusted pediatric hospitalization rates are associated with race/ethnicity. *Pediatrics*, 119, 1319-1324.
 3. Flores, G., Tomany-Korman, S., 2008. Racial and ethnic disparities in medical and dental health, access to care, and use of services in US children. *Pediatrics*, 121, e-296-e-298.
 4. Kerfeld, C., Hoffman, J., Ciol, M., Kartin, D., 2010. Delayed or forgone care and dissatisfaction with care for children with special health care needs: The role of perceived cultural competency of health care providers. *Matern Child Health Journal*, 15, 487-496.
 5. Ngui, E., Flores, G., 2006. Satisfaction with care and ease of using healthcare services among parents of children with special health care needs: The roles of race/ethnicity, insurance, language, and adequacy of family-centered care. *Pediatrics*, 117, 1184-1196.
 6. Ngui, E., Flores, G., 2007. Unmet needs for specialty, dental, mental, and allied health care among Children with special health care needs: Are there racial/ethnic disparities? *Journal of Health Care for the Poor & Underserved*, 18, 931-949.
 7. Stevens, G., Pickering, T., Seid, M., Tsai, K., 2009. Disparities in the national prevalence of a quality medical home for children with asthma. *Academic Pediatrics*, 9, 234-241.
 8. McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck PW, Perrin JM, Shonkoff JP, Strickland B. A new definition of children with special health care needs. *Pediatrics*. 1998 Jul;102(1 Pt 1):137-40.
 9. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. The National Survey of Children with Special Health Care Needs Chartbook 2009-2010. Rockville, Md. U.S. Department of Health and Human Services, 2013.
 10. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. Achieving and Measuring Success. www.mchb.hrsa.gov/programs/specialneeds/achievingandsuccess.html
 11. Homer CJ, Klata K, Romm D et al. A review of the evidence for the medical home for children with special health care needs. *Pediatrics* 2008; 122:e922-e937.
 12. Clarke A, Goddu A and Nocon RS, et al. Thirty years of disparities intervention research. What are we doing to close racial and ethnic gaps in health care? *Medical Care*. 2013; 51(11):1020-1026.
 13. Finding Answers Intervention Research (FAIR) Database. Finding answers disparities research for change at <http://www.solvingdisparities.org/fair> as accessed on May 20, 2014.
 14. Herman AA. Community health workers and integrated primary health care teams in the 21st century. *J Ambulatory Care Management*. 2011; 34:354-361.
 15. The World Health Organization. The Declaration of Alma Atta of 1978 as found at http://www.who.int/publications/almaata_declaration_en.pdf on May 20, 2014
-

16. Section on Community Health Workers. American Public Health Association. Definition of Community Health Workers. As found at <http://www.apha.org/membergroups/sections/aphasections/chw/> on June 7, 2014
17. World Health Organization. Task Shifting to Tackle Health Worker Shortages as found at http://www.who.int/healthsystems/task_shifting_booklet.pdf on May 20, 2014.
18. Campbell C and Scott K. Retreat from Alma Atta? The WHO's report on task shifting to community health workers for AIDs care in poor countries. *Glob Public Health* 2011; 6(2):125-38.
19. Health Resources and Services Administration. *Community Health Worker National Workforce Study*. March 2007. Accessed December 11, 2013 at <http://bhpr.hrsa.gov/healthworkforce/reports/chwstudy2007.pdf>
20. Brownstein JN, Mirambeau AM, Roland KB. News from the CDC: Using web-based training to translate evidence on the value of community health workers into public health action. *Transl Behav Med*. 2013 Sep;3(3):229-30. doi: 10.1007/s13142-013-0204-5.
21. Brownstein JN, Chowdhury FM, Norris SL et al. Effectiveness of community health workers in the care of people with hypertension. *Am J Prev Med*. 2007;32(5):435-47.
22. Lewin SA, Dick J, Pond P, et al. Lay health workers in primary and community health care. *The Cochrane Database of Systematic Rev*. 2003; 4(Art. No: CD004015).
23. Weber B, Reilly B. Enhancing mammography use in inner city: A randomized trial of intensive case management. *Arch Intern Med*. 1997;157(20):2345-9.
24. Lewin S, Munabi-Babigumira S, Glenton C, et al. Lay health workers in primary and community health care for maternal and child health and the management of infectious diseases (Review). The Cochrane Collaboration. 2010. Issue 3. John Wiley and Sons, Ltd. May 20, 2014.
25. Flores G. Community health workers, promotores and parent mentors: Innovative, community-based approaches to improving the health and health-care of children. In *First Focus, Big Ideas: Children in the Southwest*. First Focus, Washington DC, 2013.
26. Woods ER, Bhaumik U, Sommer SJ et al. Community Asthma Initiative: Evaluation of A Quality Improvement Program for Comprehensive Asthma Care. *Pediatrics*. 2012 Mar;129(3):465-72. doi: 10.1542/peds.2010-3472. Epub 2012 Feb 20
27. Centers for Disease Control. Developing a Healthy Homes Program. http://www.cdc.gov/nceh/lead/publications/10_217029A_Walker_HealthyHomesBooklet_101310_UPDATED_WithCovers.pdf
28. CCH. CCH's Law, Explanation and Analysis of the Patient Protection and Affordable Care Act. Vols. 1 and 2. Wolters Kluwer, Chicago. 2010
29. Internal Revenue Service. New Requirements for 501c.3 Hospitals under the Affordable Care Act. <http://www.irs.gov/Charities-&-Non-Profits/Charitable-Organizations/New-Requirements-for-501%28c%29%283%29-Hospitals-Under-the-Affordable-Care-Act> as accessed May 20, 2014.
30. HSC Health Care System. Community Health Needs Assessment 2012-2014 as found at <http://www.hscfoundation.org/pdf/HSC%20PC%20CHNA%202012-2014%20Full%20Report.pdf> as accessed June 25, 2014.

“HIGH EXPECTATIONS” MEETING PARTICIPANTS LIST

NOVEMBER 12–13, 2013

Jennifer Akers, Project Coordinator

Family Voices – Indiana

Treeby Brown, Associate Director

Children's and Adolescents Health, AMCHP

Tom Chapman, President and CEO

The HSC Foundation

Manny Echevarria, Program Manager

RI Parent Information Network

Veronica Helms, Program Manager

Child and Adolescent Health; Program Team,
AMCHP

Yourlanda Johnson, Administrative Assistant

Division of General Pediatrics and Division
of Developmental Medicine, Boston
Children's Hospital

Diane Liebe, Medical Director

Children's Village (An affiliate of: Yakima Valley
Farm Workers' Clinic)

**Jessie McKinnon, Vice President of
Programs and Partnerships**

and COO, National Youth Transitions Center
The HSC Foundation

Yvonne Maddox, Deputy Director

Eunice Kennedy Shriver National Institute
of Child Health and Human Development

Mariela Maldonado, Hispanic Affairs Liaison

Autism Society of North Carolina

Marie Mann, Medical Officer

HRSA/MCHB

**Norma Marti, Minority Outreach Public
Health Consultant**

Children and Youth Branch, North Carolina
DHHS

Luz Adriana Matiz-Zanoni, Medical Director

Pediatrics, WIN for Health Team, CUMC

**Geraldine McPhee, Parent Involvement
Coordinator**

RI Parent Information Network

Jackie McPhee, Executive Director

Children's Village (An Affiliate of: Yakima Valley
Farm Workers' Clinic)

**Dodi Meyer, Associate Professor of Pediatrics
and Director of Community Pediatrics**

Columbia University Medical Center

Andres (Andy) Nieto, Director

Community Health and Outreach Ambulatory
Care Network (CAN), Columbia University
Medical Center

Nerlie Ogilus, Research Study Coordinator

Institute for Community Inclusion/UMass Boston

Yan Orellana, Parent Navigator

Children's National Medical Center

Beatrice (BB) Otero, Deputy Mayor

District of Columbia HHS

Judy Palfrey, Director

Global Pediatrics Program, Boston Children's Hospital

Shirley Payne, Director

Children's Special Health Care Services Division, Indiana State Department of Health

Lourdes Pichardo, Peer Navigator

RI Department of Health Immunization Program

Nathalie Quion, Pediatrician

General and Community Pediatrics, Children's Health Center at Adams Morgan

Maria Ivonne Rivera, Moderator and President

The Rivera Group

Myra Rosen-Reynoso, Director

National Center for Ease of Use of Community-Based Services, Institute for Community Inclusion/UMass Boston

Lucy Soriano, Community Health Worker

Northern Manhattan Improvement Corporation

Bonnie Strickland, Director

Services for Children with Special Health Needs, HRSA

Fan Tait, Director

Department of Community and Specialty Pediatrics, American Academy of Pediatrics

Veronica Thomas, Research Associate

Institute for Community Inclusion/UMass Boston

INVITED GUESTS

Nathaniel Beers, Chief of Special Education

DC Public Schools

Donna Cohen Ross, Senior Advisory

Office of External Affairs, Centers for Medicare and Medicare Services, Health and Human Services

Robert Hall, Associate Director

Federal Affairs, American Academy of Pediatrics

Kim Horn, Regional President

Mid-Atlantic States, Kaiser Foundation Health Plan

Diane Lewis, Executive Vice-President

Alta Consulting Group, Inc

Elena Rios, President and CEO

National Hispanic Medical Association

For a PDF copy of this report, please go to
www.communitybasedservices.org

