

MATERNAL & CHILD HEALTH SERVICES
Focus Group Study
March 2015

EXECUTIVE SUMMARY

Introduction

The Division of Public Health (DPH) contracted with Goeins-Williams Associates to conduct a statewide focus group study for Delaware's Maternal and Child Health (MCH) program to gain insight into needs, issues and priorities associated with women's and children's health in the state. The study is part of an overall comprehensive five year needs assessment effort to support the Maternal and Child Health Title V block grant application. The period for this contact was January 2 to March 31, 2015.

Goeins-Williams Associates, Inc., (GWA) managed the focus group process and study which included: planning meeting logistics; coordinating with community partners (to schedule facilities and recruitment referrals); editing focus group discussion guides and handouts; screening, recruiting and registering participants; moderating and staffing focus groups; recording and transcribing the discussions; providing translating services, analyzing findings and preparing written reports.

Eight focus groups were conducted statewide and, of those, two were conducted in Spanish. Five to ten respondents participated in each focus group for a total of sixty-two respondents. Focus group subject, locations, dates and topics are summarized in the table below:

Focus Group Subject	Discussion Topics	Dates and Location	No. of Participants
<i>MCHGeneral Health Needs (MCHGHN)</i>	- Health Needs, Services & Barriers to Access	- 2/24/15 – New Castle County, Parent Information Center, Wilmington	6
	- Women's Preventive Health	- 2/25/15 – Kent County, Hampton Inn, Dover	9
	- Perinatal /Maternal Health	- 3/4/15 – Sussex County, Easter Seals Tunnel Center, Georgetown	8
	- Children/Adolescent Health – Medical Home	- 3/10/15 – Spanish Speaking, Sussex County, Nanticoke Memorial Hospital, Seaford	10
	- Other Relevant Public Health Issues		
<i>Children and Youth with Special Health Care Needs (CYSHCN)</i>	- Health Needs & Issues	- 2/18/15 – New Castle County, Parent Information Center, Wilmington	7
	- Health Care Services – Medical Home	- 2/26/15 – Kent County, Hampton Inn, Dover	10
	- Family Partnership & Support System	- 3/9/15 – Sussex County, Easter Seals Tunnel Center, Georgetown	5
	- Transition Support for Children & Youth	- 3/12/15 – Spanish Speaking, LaRed Health Center, Georgetown	7
- Other Relevant Public Health Issues			

Two discussion guides were created for each set of the focus groups (Maternal and Child Health General Health Needs and Children and Youth with Special Health Care Needs) and were translated into Spanish for the two Spanish speaking groups. Respondents received handouts for which they were asked to review and identify priorities for women, infants, children, and adolescent health and children and youth with special health care needs. The complete discussion guides are contained in the Appendices.

Focus groups were scheduled for two hours each at community partner locations and meeting facilities. A light dinner and a \$50 gift card were provided to all respondents. The CYSHCN Focus Group Guide was lengthy with about 25 questions. Even though several questions were “yes/no” questions, it was challenging to discuss all questions, especially with the larger groups in the two hour time frame. Some questions were skipped when respondents answered in a previous question or the question did not apply to the group.

Dr. Devona Williams moderated all English speaking focus groups and Mary Perkins, GWA Associate, was recorder and observer. Catalina Natalini, GWA Associate, moderated the two Spanish speaking groups, translated the edited focus group guides into Spanish, transcribed and prepared the summary report in Spanish, and then translated the report back into English. Dr. Williams was the observer and recorder for the Spanish speaking groups. All focus groups were audio-recorded to assist with transcription of the discussions.

Pat Ward screened and recruited all participants. Some of respondents were referred by community partners, Family Shade and the Parent Information Center. GWA made every effort to recruit participants that represented a diversity of backgrounds and special health needs. The winter weather was a major challenge for this study and caused the cancellation and rescheduling of three of the focus groups. Cold weather, snow and rescheduled times affected expected attendance at some of the focus groups. Dr. Williams is the preparer of this report which is organized as follows:

- Executive Summary which includes Major Findings
- Summaries of Focus Groups with detailed findings for each question
- Appendices with Focus Group Guides and Handouts

FOCUS GROUP CHARACTERISTICS*

CYSHCN Focus Groups	Description
<p>1. New Castle County Parent Information Center, Wilmington 2/18/15</p>	<p>The group consisted of 7 women who were mothers of children with a number of health issues including: Autism/Asperger's Syndrome, Rheumatoid Arthritis, Attention Deficit Hyperactivity Disorder (ADHD), learning disabilities, speech problems and blindness. The group was diverse geographically from New Castle County and racially with three African Americans, three Caucasians, and one Hispanic. Incomes ranged from less than \$20K to over \$75K per year and parent ages ranged from 27 to 45. Parental educational backgrounds ranged from high school diploma to college graduates.</p> <p>All but one parent had sons with major health care issues. One mother had a blind daughter who was an older teen. It was a challenge to get through all of the questions. Four participants had been in a focus group previously; none were health care related. They found value in the group and when the discussion ended, the parents exchanged email addresses so they could continue to support each other.</p>
<p>2. Kent County Hampton Inn, Dover 2/26/15</p>	<p>The focus group of 10 people was made up of 8 women and 2 men. One of the women was from Middletown in New Castle County. Participants for Kent County were from: Frederica, Dover, Harrington, Smyrna, Hartly and Felton. Parents had from 1 to 7 children ranging in age from 2 to 40 years of age. Children's special health care needs wide ranging including: dyslexia, dyspraxia, ADHD/ADD, autism, Pervasive Development Disorder - Not Otherwise Specified (PDD-NOS), Down 's syndrome, dyspraxia, club feet, type I diabetes, a partial arm, type II diabetes with renal failure, bipolar disorder, oppositional defiance, and psychosis (hears voices). Several parents had more than one child with special health care needs. Two parents had adult children with Down's syndrome. Participants wanted to ask each other questions throughout the discussion. The group discussion ran over the allotted time by 20 minutes.</p>
<p>3. Sussex County Easter Seals Tunnel Center, Georgetown 3/9/15</p>	<p>Five women participated in the focus group. . Participants included 2 African Americans and 3 Caucasians Participants had children with special health care needs ranging in age from 3 to 16. One woman with two children was expecting her third child. Two women had children with multiple disabilities. Participants included 2 African Americans and 3 Caucasians from Bridgeville, Lincoln, Georgetown and Harbeson. Children's special health care needs included: bipolar disorder, learning delays, ADHD, failure to thrive, autism, seizure disorder, and scoliosis. Two participants were foster care mothers who were very familiar with the social services system. The group consisted of empowered women who seemed knowledgeable of services. This group was rescheduled due to snow – 5 people did not show. Despite the small group, the discussion was rich and lasted 2 hours. Two participants had been in focus groups previously.</p>

4. Spanish Speaking- Sussex County La Red Health Center, Georgetown 3/12/15	<p>The group consisted of 7 Latino women from throughout Sussex County, age 26 to 44, who were mothers of children with special health care needs. The women all spoke Spanish as their primary language and the group was moderated in Spanish. The women came from Millsboro, Lincoln, Bridgeville and Seaford. Two of the women recruited for the group did not attend. Health needs of the children included: high blood pressure, dental problems, asthma, allergies, eczema, speech problems, feet problems, autism, diabetes type I, chromosome # 9, one more chromosome, attention deficit disorder, mental delays. Three of the mothers had children with asthma. The mothers had 2 to 7 children each, ranging in age from age 1 to 31 and their children with special health care needs ranged in age from 1 ½ year to 15 years of age. The income range was less than \$20K to \$40K per year. The group was very talkative and shared details about their experiences. The group ran over 20 minutes and participants were not ready for it to end.</p>
MCH Genera Health Needs Focus Groups	Description
5. New Castle County Parent Information Center, Wilmington 2/24/15	<p>Six females from a variety of locations in New Castle County participated in the focus group; five were Caucasians and one was Hispanic. Four people who were recruited but did not attend were all African American. The women were mothers of one to four children ranging in age from 7 months to age 20 and two were expecting their first children. The women ranged from age 30 to age 43. All participants had some college education and two were college graduates. Incomes ranged from less than \$20K to over \$75K a year. The group was animated and most had participated in focus groups previously.</p>
6. Kent County Hampton Inn, Dover 2/25/15	<p>A group of nine women, 5 African Americans and 4 Caucasians, participated in the focus group discussion on general health needs for women and children. Participants live in Dover, Smyrna, Clayton and Camden/Wyoming. The women ranged in age from 22 to 44. All but one participant had children with ages ranging from 9 months to 24 years old. One woman was a grandmother. The income range for this group was less than \$20K to over \$75. The group discussion was lively and participants were knowledgeable of their own health and programs and services. Most of the group had previous experience in focus groups.</p>
7. Sussex County Easter Seals Tunnel Center, Georgetown 3/4/15	<p>Eight women who were all mothers participated in the focus group. The women had 1 to 3 children ranging in age from age 4 months to 25 years. One participant was 6 months pregnant and another participant was a grandmother. The group was made up of 3 Caucasians, 4 African American and 1 Hispanic/African American. The income range for this group was \$20K to over \$75K per year. The group came from communities in Sussex County that included: Bethany, Lewis, Georgetown, Milford, Lincoln, Seaford, and Bridgeville. Five of the women had participated in focus groups previously.</p>

<p>8. Spanish Speaking Focus Group- Sussex County Nanticoke Memorial Hospital, Seaford 3/10/2015</p>	<p>The group was made up of 10 Latino women age 23 to 42 from Greenwood, Lincoln, Georgetown, Seaford, Milton and Bridgeville. The women had one to 5 children ranging in age from 8 months to over twenty years of age. This group was conducted in Spanish and all of the group's primary language was Spanish and many were proficient in English. The income range was less than \$20K to \$40K per year. The group was extremely open with their responses and appeared to enjoy the discussion and chance to share experiences.</p>
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**For discussion purposes for this Executive Summary, the focus groups are grouped by subject for ease of analysis and are referenced by group number and name in the following section.*

MAJOR FINDINGS - CHILDREN & YOUTH WITH SPECIAL HEALTH CARE NEEDS FOCUS GROUPS

Health Needs & Issues

Group 1: New Castle County CYSHCN 2/18/15

- Most pressing health needs. Awareness of disabilities, the lack of adequate health insurance, lack of services in Delaware and assistive technology and support in the schools were the most pressing issues related to their children's health. Insurance coverage is an issue, especially without diagnosis. Insurance limitations for supports and tools that their children need are the biggest issues. Physical conditions are easier to diagnose than behavioral conditions.
- Awareness of services. Most of the parents knew something was not right with their child long before getting a diagnosis. Parents all stated they "have to keep fighting, pushing" to be an advocate for their child. Before a child is diagnosed the pediatrician visits are so short that the doctor doesn't spend enough time with the child to see the issues. Parents spoke of doing their own research and getting assistance from nonprofit and state agencies that were helpful in this process.
- Support services. Respondents were referred by hospitals and pediatricians to other medical specialists, Child Watch, and case workers. Some parents sought services on their own. Their experience with these different service providers was mixed.
- Successes. Several parents stated that some nonprofits they were referred to, namely Parent Information Center (PIC), Nurses and Kids, and Autism Delaware, work well along with: counseling, support groups and assistance from other parents who have children with similar health challenges.
- Recommendations. Support groups with volunteer moms to serve as mentors would improve the experience for families. They also recommended that doctors and special education teachers receive more training on disabilities. It was further suggested that doctors need to listen to moms.

Group 2: Kent County CYSCHN, 2/26/15

- Most pressing health issues. Health care insurance coverage and coordination of benefits is the most pressing health issue related to their child's health. Several participants had an issue with providers who would not accept United Health Care medical insurance. There is a lack of psychiatric services in the area as well as doctors who understand their children's health issues.
- Awareness of services. The majority of participants were connected with programs and services by their hospital, doctor, school, or day care.
- Support services. Everyone was assigned a social worker or case worker through a hospital, school or insurance company.
 - Some respondents conducted their own research, found services through word of mouth, took advantage of state services or obtained services such as Medicaid once their child was diagnosed. The group stated that Medicaid appears to discriminate against some families and there is confusion or a lack of information about what benefits are available.
 - Some respondents have not been able to find or receive services because they are either not available in Kent County, they were denied services because of income, or there have been inconsistencies in how disabilities are determined by service providers.
- Challenges. The biggest challenge for parents is the reality of their growing older and ensuring their children will continue to receive proper care. Siblings assume they will have to care for special health needs children. One parent spoke of the lack of psychiatric services in Kent County.
- Successes. Respondents reported success with transition from high school to Kent Sussex Industries (KSI), the Charlton School, Individual Education Plans (IEPs) and 504 programs at Smyrna and Lake Forest School Districts.
- Recommendations. The group recommends that information about programs and services be made more readily available through a websites and require training for pediatricians. They also suggest more resources in Kent County and explicitly psychiatric services.

Group 3: Sussex County CYSHCN, 3/9/15

- Most pressing health needs. The most pressing health issues for this group were finding health care providers (physician, psychiatrist, dentist, special education support) who can accommodate their children's special health needs.
- Awareness of services. All of the participants became aware of programs and services through family, caseworker, social worker, employer, and doctor. Once they obtain initial services, they received referrals to multiple professional health providers, programs and services.
- Support services. Participants reported receiving services from the Arc of Delaware, Easter Seals, the 2-1-1 Hotline, Nemours Pediatrics, AI DuPont Hospitals, Parent Child Interaction Therapy, Family Partners, Delaware Guidance Services, The Seaford House, and Children and Families First. Participants are generally pleased with the way their various providers coordinate services and obtain resources for them.
- Challenges. Respondents voiced concerns about the lack of specialists with the exception of AI DuPont Hospital. Several people encountered problems when the State Medicaid insurance switched

the insurance carrier to Highmark Blue Cross/Blue Shield. Another concern expressed was the failure of drug stores to recognize prescriptions for diapers for an older child.

- Successes. Communication, support and follow-through from health care providers and support groups work well.
- Recommendations. All participants agreed that they have to be advocates for their own children, be persistent, do the follow up work and have a lot of patience. One participant shared her story of how her son now has a meaningful life even though a nurse told her when he was born to give up her son because of his severe disability.

Group 4: Spanish CYSHCN, 3/12/15

- Most pressing health needs. The issues that respondents found more pressing were early and continuous screening, transportation, coordinated services, and organized and easy to use community based services. Respondents felt that early screening in children was necessary to allow for early diagnosis and to provide better treatment for the illness. Respondents mentioned that there was lack of coordination in services between the school and the family.
 - Other issues included the need for education. Parents should be educated regarding their child's condition. Respondents thought that it was not enough to give a diagnosis, it was also necessary to explain to parents' consequences and implications of the illness. Education was also mentioned regarding information for parents to know where to get help.
- Awareness of services. Respondents expressed that in many cases it was a nurse who helped them obtain Medicaid. They mentioned that most of the help they found was in the school services, Easter Seals, and Child Watch. They found that education on their child's illness and meeting with specialists had been the most useful services as well as the recommendation for transport.
- Support services. Overall, respondents felt they did not have much information about programs and services available. They were not satisfied with the services received especially health care and transportation. They also felt that they needed help to access services. It was agreed that Spanish-speaking personnel was needed to answer calls from Spanish-speaking people. Language barrier was seen as a hindrance to the provision of services. Most respondents agreed that they were engaged in the decision making about health care services, and for most of them coverage was adequate. However, they stated that out of pocket expenses were high, and that there was no state help, and that insurance coverage was expensive.
- Challenges. Participants wished that doctors listened to them earlier about the problems they noticed with their children. Visits with doctors are rapid and they did not listen to them – they would say something was wrong with their child and the doctors would dismiss them. They changed their pediatricians and eventually got diagnoses.
 - Schools are challenging for participants. They said that schools ask for lots of information about them but they don't give information. Communication between parents of CYSHCN and schools is poor. Children have had major health issues at schools.
- Recommendations. The respondents agreed that the best thing to do was to ask for information. They also agreed on changing doctors if the services were unsatisfactory.

Health Care Services – Medical Home

Group 1: New Castle County CYSHCN, 2/24/15

Medical home. Medical home is not a term they are familiar with. But once their children are diagnosed, all but one stated that their care providers work collaboratively and function as a “Medical Home”. The exception was the one parent who could not get services needed for their nonverbal autistic child in Delaware citing that that team does not communicate effectively with each other.

- who could not find services for her child in Delaware.
- Relationships with doctors. Parents feel good about the relationships they have with their primary care doctors once their children are diagnosed. Respondents feel informed and involved in the decisions affecting the health care of their children.
- Cultural sensitivity. Some of the group agreed that their providers are sensitive to their cultural preferences and wishes. As a group they did not agree that the need to be culturally sensitive applies to the care they receive.
- Improvements needed. The biggest issue for the group was that the medical diagnosis is not the educational diagnosis. Participants voiced concerns with school officials and insurance taking on the role of “diagnosis”. Insurance coverage and the school/health diagnosis are areas for improvement.

Group 2: Kent County CYSCHN, 2/26/15

- Medical Home. Only a few people had heard of the term and after the concept was explained only two parents stated their child’s doctor’s office was their “Medical Home.”
- Relationship with doctors. Most participants have a good relationship with their primary care provider or pediatrician. Several people described problems that cause delays with getting medication for their children. The majority of the group feel informed about their children’s health issues and they are all actively involved in their health care needs.
- Cultural sensitivity. The majority of the group feels their provider is sensitive to their preferences and wishes but none feel they are sensitive to their cultural needs and backgrounds.
- Improvements needed. Half of the group agreed that every physician in Delaware should have to accept State of Delaware Medicaid insurance.

Group 3: Sussex County CYSHCN, 3/9/15

- Medical Home. No one was aware of the term “Medical Home” but two respondents said their pediatricians provided Medical Home and one respondent has multiple specialists that function as a “Medical Home.”
- Relationship with doctors. A large majority of the group reported having supportive and caring relationships with their pediatricians. Their pediatricians know their children, check on their progress and make appropriate referrals when needed. Everyone in the group feels informed about their children’s health issues and is actively involved in their health care needs.
- Cultural sensitivity. The majority of the group feels that their providers are sensitive to their preferences and wishes and their cultural needs and backgrounds.

- Improvements needed. Participants would like to see reasonable waiting periods to see providers and receive services, to be able to receive supplies and not having to negotiate with insurance and other providers to receive services and supplies recommended by the physician.

Group 4: Spanish CYSHCN, 3/12/15

- Medical Home. No one had heard of the terms “Medical Home” or “Dental Home.” Once explained, several respondents agreed that their child’s doctor was a “Medical Home” and said their doctors do their best to provide care and they felt there was effective communication between them and their providers. Their doctors have an interest in knowing how the children are doing. Those respondents who did not agree their child’s doctor was a “Medical Home” said they noticed lack of interest by their providers, lack of follow-up and no coordination between the providers and the parents.
- Relationship with doctors. Overall respondents felt that their relationship with their pediatrician was good. However many mentioned the fact that they had to change providers because they were not happy with the services, and finally had found a provider that was a good fit for them. It was also mentioned how hard it was to get a new pediatrician. All respondents agreed that they felt informed of their child’s health issues and needs. Regarding their participation in decisions regarding their child’s health care needs, two of them felt they were “more or less” able to participate in making decisions while the others felt they were able to participate about ninety percent of the time.
- Cultural sensitivity. A large majority of the group agreed that their health providers are sensitive to their preferences and wishes. However, the question on cultural sensitivity was not asked here but is addressed with other responses.
- Improvements needed. Respondents felt that children with special needs should have priority in terms of treatment and reduced waiting time for appointments.

Family Partnership & Support System

Group 1: New Castle County CYSHCN, 2/24/15

- Meaning of Family Partnership. “Team” was the top response when participants heard the words “family professional partnership” and these words reflected their experiences.
- Experiences. Participants recounted their experiences of having to fight for their children and do their own research to get doctors to diagnose their children’s conditions. They described their initial experience as a struggle to get their child diagnosed, having to be “a momma bear.” One mother stated, “Diagnosis earlier supports more progress faster.”
- What they value about partnerships. The group responded that they value when they are listened to and they have learned how to be advocates for their children.
- Supports. Respondents report that they have found the services they need and the services are available in their community. However, they said that parent groups and teaching children about other children who have disabilities would give them the support they need. Parents have had positive experiences with nonprofit organizations especially Child Watch, and Autism Delaware, Arthritis Foundation.

Group 2: Kent County CYSCHN, 2/26/15

- Meaning of Family Partnership. The group was silent for a while after the question was posed and offered somewhat negative comments about its meaning. Several people did not understand the term or felt that it does not exist.
- Experiences. Some respondents had positive experiences with their providers working in partnership with one another for the best interests of their children. Insurance co-pays and costs have an adverse impact on building partnerships. One respondent had a positive experience using the State’s 2-1-1 Help Me Grow hotline.
- What they value about partnerships. A few participants agreed that partnerships help them get to know and understand their child better
- Recommendations. Participants recommended changes in insurance company benefits for special health care needs children and increasing the level of services and compensation for health specialists in Delaware compared those who are out of state.
- Supports. Half of the group suggested safe respite care for parents of children with special health care needs. Parents also need help with group homes and navigating insurance eligibility. They recommended having purchase of care program for parents of special health care needs children and a way for parents to find support groups of other parents whose children have the same disabilities. A large majority of the parents have not been able to find the support they need and they are finding that the services are not available locally. The group would like to see services and support for group homes, occupational and speech therapy, psychiatric services and support groups.

Group 3: Sussex County CYSHCN, 3/9/15

- Meaning of Family Partnership. Specific professionals such as social workers and family members are the words that the group considers “family-professional partnership.” Participants do not have enough support. The group also reported positive experiences with the CASA workers who have provided additional support.
- Experiences: Participants have mixed experience about viewing health providers as partners. Two participants reported great relationships with caring providers.
- What they value about partnerships. The group values respect, time, honesty, continuity, trust, confidentiality, and valuing their opinion.
- Recommendations. The group recommended continuous education and training for those involved with children with disabilities including daycare providers, police, paramedics, teachers, DFS workers, parents and foster parents. They suggested “a connector” to help them connect or navigate with others, more support groups, and understanding and respect.
- Supports. Everyone said that they were able to find supports they need. However, they said that services missing in Sussex County are: pediatricians, OB/GYNs, and specialists.

Group 4: Spanish CYSHCN, 3/12/15

- Meaning of Family Partnership. Respondents gave the following words to describe Family Partnership: communication, coordinated efforts, and to speak frankly and be understanding of the parent and patient.
- Experiences: Respondents commented about how they needed to change providers because their relationship was not good.
- What they value about partnerships. Respondents commented that because they do not know if these supports are available, they could not comment on them.
- Recommendations. They recommended that medical interpreters should be provided instead of bilingual people. It was mentioned that interpreting services were not satisfactory, specially telephone interpreting. They suggested improving the quality of these services and the provision of “real” medical interpreters. Respondents also wished their doctors listened more and explained more, and be motivated to learn a second language to communicate better with their non-English speaking patients.
- Supports. Everyone agreed that families need more psychological support and more information because illnesses affect the whole family. They also agreed that these supports are not available in their area and that financial support is greatly needed, especially where some parents had to stop working to take care of children.

Transition Support for Children & Youth

Group 1: New Castle County CYSHCN, 2/24/15

- Concerns. No one in the group felt that their children would be ready to transition into adult services. The biggest fear they have is how their child transitions at every major milestone – from preschool to kindergarten, middle school, high school, and adult hood. Their experiences with major transitions

have mostly been negative. They fear that their children will be taken advantage of once they transition into adulthood.

- Supports. Parents would like additional resources for transitional services and workshops for their children that focus on careers, life skills and financial management.
- Recommendations. The group recommends training for pediatricians on diagnosing a variety of disabilities including non-stereotypical symptoms, and listening skills for interacting with parents. They also recommend training for educators on disabilities and more awareness of disabilities for school aged children.

Group 2: Kent County CYSCHN, 2/26/15

- Concerns. Less than a third of the group agreed that their child would be prepared to transition to adult services. They are concerned with their children's mental and physical health and their needs being met. They have fears and worries related to school transitions. They lack information and support to make the transitions.
- Supports. Members of the group said counseling for children and social workers/case workers who could help them "from diagnosis through adult transition" would be helpful.
- Recommendations. Participants said they could benefit from a roadmap or requiring state agencies to hire people with disabilities.

Group 3: Sussex County CYSHCN, 3/9/15

- Concerns. The two parents of adult children agreed that their children will be prepared sufficiently to transition to adult services. Participants are concerned about their children being able to live independently and about the ongoing support they will need and if they will get it. Participants were pleased with their children's transition experiences at younger ages.
- Supports. Adult transitional services identified by the group included: more supports for high school students, grief counseling, health insurance, and a booklet that describes services.

Group 4: Spanish CYSHCN, 3/12/15

- Concerns. Overall, there was no information about transition services. When two respondents asked for help they were told that there were none. The parents were concerned about how their children were going to take care of themselves as some are still very dependent. They felt school transitions were difficult especially, when addressing changing teachers and therapists with whom the children had already bonded. It was mentioned that some therapists are better with children than others.
- Supports. Respondents agreed that children in school should be allowed a period of adaptation in general for important changes.

Top 3 Health Priorities

Focus Group	Top 3 Health Priorities
Group 1: New Castle County CYSHCN, 2/24/15	<ol style="list-style-type: none"> 1. Adequate Insurance Coverage 2. Developmental Screening 3. Medical Home
Group 2: Kent County CYSCHN, 2/26/15	<ol style="list-style-type: none"> 1. Adequate Insurance Coverage 2. Transition 3. Bullying
Group 3: Sussex County CYSHCN, 3/9/15	<ol style="list-style-type: none"> 1. Developmental Screening 2. Bullying 3. Adolescent Well-Visits/Adequate Insurance Coverage (tie).
Group 4: Spanish CYSHCN, 3/12/15	<ol style="list-style-type: none"> 1. Developmental Screening 2. Adequate insurance Coverage 3. Physical Activity/Adolescent Well-Visits. (tie)

Additional Recommendations

Group 1: New Castle County CYSHCN, 2/24/15

- Screening and case management from the time a child is diagnosed would improve health care for children and youth with special health care needs. The majority of the group also suggested that Child Watch should not end at age three.

Group 2: KC 2/26

- None.

Group 3: Sussex County CYSHCN, 3/9/15

- It was the general feeling of the group that the needs are for more services for children with special needs and “no excuses”. Additionally, behavioral services, training for other children and support groups are needed.

Group 4: Spanish CYSHCN, 3/12/15

- The biggest recommendations are for transportation, more specialists in the area, better communication and more information about programs and services. Respondents stressed the need for hospitals with specialists and support groups in their local area. It was mentioned that more medical support at home so that parent may rest would be helpful.

MAJOR FINDINGS MCH GENERAL HEALTH NEEDS FOCUS GROUPS

Health Needs, Services & Barriers to Access

Group 5: New Castle County General Needs, 2/24/15

- Most pressing health issues. Available, affordable, personalized, competent care and getting doctors to listen were the most pressing health issues for women. Prenatal care that is available, affordable and personalized was important for this group. Education on developmental milestones, immunizations, being good parents, breastfeeding, decision making, and proper health care were most important for newborns and infants. Looking at broad health care needs for children physically, socially, and emotionally including dental and vision care and regular checkups were important for this group. Education for parents and doctors, individualized care and attention, understanding milestones and the availability of specialists were also important. Sex and drug education and meeting overall health needs of the adolescents.
- Programs and services. Participants were not very knowledgeable about specific services. A few people in the group named Planned Parenthood and the Delaware Money School programs that help women meet their general health needs. The rest of the group could not identify specific programs. Participants were familiar with a number of agencies that offered programs such as birthing classes for pregnant women including: Birth Right, Door of Hope, Christiana Care Health System, St. Francis Hospital and Children & Families First. Everyone in the group was familiar with WIC and the breastfeeding assistance it provides. The group was also familiar with other programs including Child Watch, Children & Families First and Mommy and Me. Participants named Head Start, West End Neighborhood House and Medicaid as specific agencies that help children. For adolescents, they named Planned Parenthood, Brandywine Counseling, ARC, and school mentoring programs.
- Barriers and access. More information about what is available for all population groups is needed and the lack of education is a barrier to health. Transportation, the lack of education and awareness, availability and affordability of services were barriers to access that were identified by participants. The group had noticed Department of Health & Social Services (DHSS) sponsored billboards on the 2-1-1 hotline, gambling, and breastfeeding and see this as an effective way to increase awareness about programs and services. They also recommend increasing awareness through social media.

Group 6: Kent County General Needs, 2/25/15

- Most pressing health issues. Getting health screening tests like mammograms, balancing family and career, and a finding a doctor that listens were the most pressing issues identified by the group for women. Good prenatal care, education related to pregnancy and related issues, managing stress and costs are key concerns for pregnant women. Education on immunizations for parents was the top issue along with education for new mothers. The most pressing issue for children was insurance coverage especially for braces, eyes, accidents, and nutrition/healthy eating. Education for teens in a number of areas including: pregnancy prevention, stress management, sex education, suicide awareness, and bullying. Issues related to depression and mental health was important for adolescents.

- Programs and services. The group was familiar with lots of programs and services for all population domains although they were not able to name specific programs for all. Mentioned were WIC, Christiana Care Health System, Children & Families First, Catholic Charities, Parks & Recreation, Purchase of Care, Head Start, DARE, Boys & Girls Clubs, and the YMCA.
- Barriers and access. Cost, transportation and availability, and awareness were the barriers to access to programs and services identified by the group. Several people agreed that children's summer camp costs are high. Most of the group responses related to the lack of adequate financial resources. There is a barrier to receiving social services based on income and appointments are hard to get. However, once you get services then one has more access. The group recommended a public relations campaign and audit of State Social Services programs so people will know how to obtain programs and services.

Group 7: Sussex County General Needs, 3/4/15

- Most pressing health issues. Preventive care through health screening and annual checkups was the most pressing issues for women in the group. The group identified good prenatal care, regular checkups and a variety of factors that contribute to a healthy pregnancy such as nutrition, rest, managing stress, time management and financial stability, as the most pressing needs for pregnant women. Immunizations that are up to date, good eating habits and regular care by a good doctor were the top issues identified by the group for newborns and infants. Overall health of children including mental, physical and nutritional were the most pressing health issues for children. For teens, peer pressure, bullying, drug prevention and education are major issues.
- Programs and services. The group was only aware of Children and Families First, social services and Screening for Life, that provide programs and services in the community for women. The group was only aware of two programs for pregnant women, DAPI and WIC. The group mentioned the "Y", Boys and Girls Clubs, summer camps and Children and Families First for programs and services for children. Programs named for adolescents included: Talent Search, Upward Bound, and Delaware Mentor. As a group, it appears that they were not well aware of the programs and services in the areas or overall efforts to promote programs that do exist. They shared information about free screening programs in some of the schools such as dental, eye and physical exams.
- Barriers and access. Affordability is an issue for programs and summer camps. The group stated that there is a gap in programs and services for teens. A third of the group identified cost as a barrier to access programs and services. Other barriers identified by participants included awareness, distance and transportation (gas, time and cost) and availability of services. The group recommended social media (Facebook, Instagram and Twitter), the use of "infomercials" to get the word out about programs and services such as the 2-1-1 hotline, and sending information home with school children.

Group 8: Sussex County General Needs, 3/12/15

- Most pressing health issues. Respondents mentioned: language barriers, transportation, insurance, lack of cultural competence and poor quality care due to doctors being overloaded. Respondents felt that it is necessary to have doctors that speak their language. They talked about language barriers and the need for the translation of information for the Hispanic community. Another issue that was mentioned was the need for transportation services and the lack of transportation being a cause for

missing appointments. Doctors do not question the living conditions or environment of their children.

- Some respondents mentioned the fact that pediatricians are overloaded which translates in long waiting time and poor attention. It was also mentioned that it is hard to find doctors and services for teenagers. Regarding attention, respondents expressed they felt treated differently because of being a foreigner, not speaking English or not having insurance. These factors influence the quality of care and attention they receive.
- Programs and services. Service providers mentioned were: West Side Health in Dover, Nanticoke Immediate Care in Georgetown, Medicaid and the walk in clinic at Nanticoke Hospital in Seaford.
- Barriers and access. Respondents picked the following barriers from the prompts: knowledge about available programs and services, need of help to access the services, need of insurance to access certain services, lack of transportation, interpreters are needed and information and/or services in Spanish. Respondents felt that nothing or very little is being done for women and families to have access to programs and services. It was also mentioned that doctors are overloaded and waiting time to get an appointment is long.
 - Respondents were unfamiliar with the term *community health worker* which was explained by the moderator. They all agreed that community health workers would bridge communication between them and the health system and be a liaison between the community and providers. They need someone with whom they can feel comfortable that can bridge the lack of cultural knowledge and cultural sensitivity.
- Information. They said that some information is provided but not enough to have a clear picture. Some information is passed through friends, acquaintances and neighbors. It is also the case for those in the Hispanic community who have this information and would not share it.

Women's Preventive Health

Group 5: New Castle County General Needs, 2/24/15

- Preventive care. The group gets information about preventive health care primarily from their doctors and their own research through Web MD and Google. The majority of the group did not receive any additional help during their regular checkups with a few exceptions. Three participants said they were offered dental health screening as part of the prenatal checkup. Respondents were asked individually by their physician about nutrition, physical activity, needing a post-partum appointment and help to stop smoking.
- Routine visits. The majority of the groups schedule annual checkups with the OB/GYN who schedule the annual visit at the conclusion of their appointment or send reminder cards for appointments. The group has to go to their primary care doctor first for any problem and then get a referral. The general perception of the group is they would rather go directly to a specialist. Insurance is the problem and they don't like the present system. The group was evenly divided about their level of comfort asking their doctor health care questions. The majority of the group has a clear understanding of their own preventive health care needs.

Group 6: Kent County General Needs, 2/25/15

- Preventive care. The majority of the group is relying on internet searches on Web MD, doctors, their insurance company, and employer health programs for their information on health care. Several people agreed that they do not trust their primary doctor to provide information. Nearly half of the group did not receive additional information during their regular checkups. Several people reported having the next appointments or mammograms scheduled during their regular check ups. The group as a whole does not have enough time during their appointments with their primary care doctors. Doctors are too quick to provide medications and tests. Respondents go to the OB/GYN, primary care doctor, specialist or mid wife for preventive care. Only half of the group felt that have a clear understanding of their preventative health care needs.
- Routine visits. The majority of respondents discussed the changes in the frequency of pap smears which they perceive is the insurance company taking on the role of doctor. A third of the group identified insurance as the greatest barrier for accessing care.

Group 7: Sussex County General Needs, 3/4/15

- Preventive care. All but one person in the group said they receive the preventive health care they need through their GYN. The group said they have a clear understanding of their own preventative care needs. Two people said that time, money and the distance to travel prevent them from accessing preventative health care. The majority of the group gets their information about preventive health through word of mouth from friends, family and their doctors' office. Also mentioned were: employers, television, and the Sussex Guide.
- Routine visits. The group gets preventive care information and thorough exams during their gynecological visits and as a group they are pleased with the level and quality of care they receive from their doctors. However, their experience with primary care physicians was a sharp contrast. Half of the group said their primary care physicians do not provide additional information. The group said they go to their primary care physician for their routine visit and complained that they are not accessible, appointments are rushed, or they are not available for emergencies.

Group 8: Sussex County General Needs, 3/12/15

- Preventive care. Most respondents obtain information in Health Fairs organized by churches annually. It was mentioned that insurance companies send reminders for vaccination and well-visits. Respondents received information about contraceptive methods when they asked for the information. They reported that they were asked questions about safety at home and mental health, nutrition, physical activity, alcohol and tobacco use during their regular check-ups. Overall, respondents agreed that information was scarce and brief. Respondents were aware of what their preventive care entailed. Respondents agreed that the main barrier was insurance.
- Routine visits. Most of the respondents expressed that they preferred a female doctor with whom they felt more comfortable.

Perinatal /Maternal Health

Group 5: New Castle County General Needs, 2/24/15

- Doctors care. The majority of the group agreed with the statement that prenatal care is good in their community, citing gestational diabetes classes and prenatal counseling. Everyone in the group said they received oral health care information during their prenatal checkup. Two respondents received nutritional and domestic violence information.
- Information. All agreed that there is not enough information about prenatal care in their community. Respondents get their information from their doctor, word of mouth or church.
- Needs for new mothers. Respondents said that pressing needs for new mothers was: to be able to stay home with their babies, have education and house calls from a nurse, and affordable and available child care.
- Support services. The group said that moms are going to WIC, parent classes, hospital birthing centers, mom's club, and social media for support services they need.
- Father involvement. The majority of the group said that teaching fathers "not to be afraid" would be an effective way to engage them. Other ideas included finding ways to incorporate them and being more "hands-on."

Group 6: Kent County General Needs, 2/25/15

- Doctors care. Respondents' experiences were mixed about the prenatal care experience and ranged from not getting the support or information they needed to having good nursing care. A few participants mentioned they received information relating to storing their placenta cord blood and milestones to expect during pregnancy.
- Information. Only a third of the group agreed that there is enough information about prenatal care in the community. Respondents get their information on health care from talking with others, online, books and social media. Respondents said that moms will go first to their friends and family, church, social media and lastly to doctors. Men will go to their peers.
- Needs for new mothers. Respondents said that the most pressing needs for new mothers are to get their rest, support and education.
- Support services. Visiting Nurses, church support groups and hotline for post-partum issues were support services identified by the group. Participants were only able to identify a few services for fathers: birthing and car seat classes and infant CPR.
- Father involvement. The group recognized the different parenting style and level of involvement of parents with their children. One participant suggested they be acknowledged while another suggested that too much emphasis is placed on the role of fathers.

Group 7: Sussex County General Needs, 3/4/15

- Doctors care. Half of the respondents reported negative experiences they had with their doctors during their pregnancies that included: miscalculating due dates; the traumatic loss of a child and insensitive treatment; and having to change a GYN because of their hospital affiliation. More than half (5/9) received prenatal care from a midwife. The group concluded that prenatal care is available in the community and people can "get it when it is needed."

- Information. Participants who responded to the question said they were given a list of baby doctors, information about WIC and Medicaid. Members of the group said they get their prenatal care information from the clinic, social services, friends and family and the Internet.
- Needs for new mothers. Childcare, a good support system, and secure housing were the most pressing needs for women who are pregnant or have just given birth. Half of the group agreed that “childcare is too expensive.”
- Support services. Participants identified several community resources for pregnant women in the community which included: WIC, the Stork’s Nest in Milford, social services programs and a clinic in Georgetown.
- Father involvement. Participants suggested engaging fathers more by: involving them, offering mentoring and natal classes, and infant CPR.

Group 8: Sussex County General Needs, 3/12/15

- Doctors care. Respondents answered that when you pay from your own money to a private doctor the care is excellent. They said that there is a long wait in public health in comparison to a private office. All of the respondent receive prenatal care with a gynecologist.
- Information. Respondents receive information on nutrition, oral health care, depression and mental health, labor and delivery, cesarean, and information on smoking. They found all the information useful and they feel nothing was missing. Respondents feel that there is enough information about prenatal care including information on genetic testing.
- Needs for new mothers. When prompted, respondents agreed that information and support to promote safe sleep was important as well as post-partum depression, planning between pregnancies, well-baby visits, immunization, baby checkups and vaccinations, also child care/resuming work schedule while nursing.
- Support services. Respondents had knowledge of programs for first time parents in Nanticoke hospital and in Georgetown public health, programs for risk pregnancies, and programs for older parents.
- Father involvement. Respondents expressed that some fathers are very interested but would be more likely to participate after work hours.

Children/Adolescent Health – Medical Home

Group 5: New Castle County General Needs, 2/24/15

- Medical Home. No one in the group had heard of the term, “Medical Home” or “Dental Home.” The group had a primary care doctor/practice and half of the group has a dentist where they regularly take their children. After hearing the explanation of a “Medical Home”, the majority of participants said that they did not think of their child’s doctor’s office as their medical home. Half of the group agreed they are informed about their child’s health issues and needs, and stated that their doctors involve them in decisions by giving options, information, answering questions, and asking about their family.
- Cultural sensitivity. The group agreed their provider is sensitive to their cultural background.
- Developmental Screening. Everyone was familiar with developmental screening and their doctors provided adequate information about the purpose. All but one respondent agreed that their doctor

explained the results of the screening. Participants stated it would be helpful to have more information about the screening process and what milestones to expect.

- Transition. Two respondents reported that their children's doctors spoke to them about transitioning them to adult services. The group would like to see more information available about programs and services and open programs and services to people of all income levels.

Group 6: Kent County General Needs, 2/25/15

- Medical Home. No one was familiar with the terms "Medical Home" or "Dental Home." When pressed, the few members of the group felt that their pediatricians provided a medical home for their children. More than half the group reported that they have a regular primary care or other doctor for their children and all feel informed of their child's health issues and needs.
- Cultural sensitivity. More than half of the group felt their provider is sensitive to their preferences and wishes, and appreciate that their providers show compassion, care and concern, are available, or can get appointments when sick. More than half of the group agreed that their provider is sensitive to their cultural background and shows it by asking questions and through mannerisms.
- Developmental Screening. All participants were familiar with the process of developmental screening and all but one agreed that their child's doctor provides adequate information. They said their doctors took too long to get results or failed to follow up adequately after the screening.
- Transition. One respondent was asked to transition her 18 year old to adult doctor services. Another respondent raised the question with her doctor about her pre-teen daughters and worked with the doctor to transition them to adult care. Participants mentioned compassion and communication as the primary ways the health care system can better meet the needs of children, adolescents and their families.

Group 7: Sussex County General Needs, 3/4/15

- Medical Home. No one in the group had heard of the term, "Medical Home" or "Dental Home". After hearing the explanation of a "Medical Home", the group said that they think of their child's doctor's office as their medical home. All of the women with children in the group had a primary care doctor/practice where they regularly take their children. Three quarters of the group has a dentist for their children. Respondents feel informed about their child's health issues and needs and stated that their doctors involve them in decisions by reviewing the growth development chart, eating habits, reading, flu shots, and giving referrals. Participants listed a number of positive characteristics of their providers that they appreciated including: going above and beyond what is needed, following up; calling the pharmacy to refill medication, kind, concerned staff with good attitude, and general concern shown by the doctor.
- Cultural sensitivity. Everyone on the group agreed that their provider is sensitive to their preferences and wishes. Nearly the entire group agreed their provider is sensitive to their cultural background. Sensitivity is demonstrated through asking about religious preferences; and showing charts with different races and explaining differences.
- Developmental Screening. Three quarters of the group was familiar with developmental screening and their doctors provided adequate information about the purpose. Half of the respondents agreed that their doctor explained the results of the screening.

- Transition. Two respondents reported that their children’s doctors spoke to them about transitioning them to adult services. The ages of their children were 19 and 18. In both cases, the doctor raised the question. The group would like to see more information available about specific programs and services related to: mental health screening, parenting, health classes in schools, managed care and follow up on miscarriage.

Group 8: Sussex County General Needs, 3/12/15

- Medical Home. No one had heard of the terms “Medical Home” or “Dental Home.” After hearing the explanation of a “Medical Home”, nine of ten members of the group said that they think of their child’s doctor’s office as their medical home. All of the women with children in the group had a primary care doctor/practice where they regularly take their children. The entire group feel informed about their child’s health issues and needs. Participants listed a number of positive characteristics of their providers that they appreciated including: listening, showing respect, explaining, returning calls and scheduling appointments quickly.
- Cultural sensitivity. Almost everyone in the group agreed that their provided is sensitive to their preferences and wishes. The majority of the group agreed their provider is sensitive to their cultural background.
- Developmental Screening. Everyone in the group was familiar with developmental screening and their doctors provided adequate information about the purpose. Respondents agreed their doctors provided adequate information about the purpose of the screening and they explained the results of the screening. All participants said that doctors need to provide follow-up for screening.
- Transition. No one had a doctor who spoke with them about adult transitioning services for their children.

Other Relevant Public Health Issues

Group 5: New Castle County General Needs, 2/24/15

- 2-1-1. Only two respondents were aware of the 2-1-1 Help Me Grow toll free line. They used it to pay electric bills. Participants felt the way to improve it is for more people to know about it.
- Additional ideas. The group offered additional ideas that included increasing the amount of education and making it a priority to take care of women.

Group 6: Kent County General Needs, 2/25/15

- 2-1-1. Only one person was aware of 2-1-1 Help Me Grow toll-free line and had learned about it through social media.
- Additional ideas. Participants suggested more awareness of child neglect and abuse and education on illnesses that cannot be seen.

Group 7: Sussex County General Needs, 3/4/15

- 2-1-1. Several in the group had heard about 2-1-1 hotline but did not know what it has to offer.
- Additional ideas. The group offered additional ideas that included: a resource book for women, free classes on preventive health, bullying resources for children and health fairs sponsored by social services.

Group 8: Sussex County General Needs, 3/12/15

- 2-1-1. They recommend that more awareness and information be provided in the community and a health advocate be provided. Four participants had heard of 2-1-1 and one had called and received some assistance. They discussed the need for the service to be available in Spanish.
- Additional ideas. More communication and education is needed.

15 National Priorities

Focus Group	Top 3 Priorities
Group 5: New Castle County General Needs, 2/24/15	<ol style="list-style-type: none"> 1. Well Woman Care 2. Adequate Insurance Coverage 3. Breastfeeding.
Group 6: Kent County General Needs, 2/25/15	<ol style="list-style-type: none"> 1. Adequate Insurance Coverage 2. Developmental screening/Well Woman Care (tied), 3. Bullying
Group 7: Sussex County General Needs, 3/4/15	<ol style="list-style-type: none"> 1. Well Woman Care 2. Bullying 3. Affordable Insurance
Group 8: Sussex County General Needs, 3/12/15	<ol style="list-style-type: none"> 1. Adequate Insurance Coverage 2. Well Woman Care 3. Physical Activity

MAJOR CONCLUSIONS

Respondents in all focus groups appear to have poor relationships with their primary care doctors. As patients, they are not listened to and their appointments are rushed. Many experience long waiting times for appointments and information is not freely shared by doctors. Some respondents make appointments with their primary care doctors to get referrals and they do not feel that is necessary. Respondents have very good relationships with their children's pediatricians who show caring and concern toward their children and families, and with gynecologists who provide preventative care and are more attentive. Parents of special health needs children have a good relationship with their pediatricians once a diagnosis is made. For the Sussex County Spanish speaking group, for several respondents, it was not until parents changed pediatricians that their children were diagnosed; and some children were not diagnosed until they started school. Parents have to do their own research and advocate for their child to insure that diagnosis is finally made. Almost no one has heard of the term *Medical/Dental Home* but many respondents feel that their pediatricians or specialists take on that role. Respondents in Sussex County appeared to have the best relationships with their pediatricians because of the care and attention they provide.

Insurance is a primary concern for all respondents and it is a priority health issue for all focus groups. Insurance affordability and coverage are primary issues especially for special health care needs children. There appears to be a conflict between doctors' diagnoses and what insurance and other service providers will accept. This puts respondents in the position of negotiating the services or special tools they need for their children. There is a general lack of trust between respondents and insurance companies in women's health. For example, insurance companies are limiting the frequency of pap smears and respondents believe that is counter to their preventive care interests. Many feel the insurance companies and schools are making decisions on health care, often contrary to the doctors.

Overall general health care respondents are not very knowledgeable about programs and services in their community. Respondents are most knowledgeable about birthing programs, WIC and breastfeeding and a host of hospital and nonprofit programs. There appear to be gaps in services for adolescents especially in the area of mental health and bullying. Bullying was a top health priority for all respondents. Parents of special health care needs children are more knowledgeable because of the amount of research they have to do. More support groups are needed by parents of children with special health care needs. Parents have good experiences with nonprofits that provide services. Pediatricians appear to do a good job coordinating services for special health needs children. There is a lack of health care specialists in Kent and Sussex Counties, especially for psychiatric services. More education and awareness is needed to promote health programs and services. Billboard campaigns and social media appear to be effective ways to increase awareness of programs and services. Health navigators or community health workers would provide needed help, especially for Spanish speaking in Sussex County.

Insurance availability, coverage and affordability and acceptance of Medicaid are major barriers to access to health services. Delayed diagnosis by doctors of special health care needs children is also a barrier and influences the quality of the relationships that respondents have with their pediatricians. Developmental Screening is a top health priority for respondents. The lack of specialists especially in Kent and Sussex County is a major barrier to access health services for special health needs children. Transportation availability, distance, and cost are major barriers to access for parents of special needs health children especially for Kent and Sussex County residents who have to travel to New Castle County to receive hospital services or see specialists. Some respondents in New Castle and Kent County are traveling out of state to receive help from specialists. Waiting lists for services and lack of timely appointments with doctors are barriers to access.

All respondents need more information and support in transitions at every level. Only a few respondents had doctors who spoke with their children about transitioning into adult services. Transitions for younger children in school are problematic and parents feel they need more support.

Spanish speaking respondents have the greatest barriers to access to health care. In addition to those noted above, language barriers and the lack of cultural competence affect the quality and access to health care. Information is not available in Spanish and health and program service providers generally do not speak Spanish. The language barrier is also a factor in scheduling transportation which is provided by non-Spanish speaking drivers. They expressed some concern regarding discrimination for “being a foreigner”, not speaking English or not having insurance. Doctors are unable to communicate with them without an interpreter. They felt most doctors lacked an understanding of their cultural background and did not know how to interact positively with non-English speaking patients. They question the quality of interpreters that have been used who may be bilingual but not medically trained. Respondents felt that nothing or very little was being done for women and families to help them access services. They thought a *community health worker* could be a helpful bridge of communication between them and the health system.

Communications issues extend beyond the doctor to the schools for parents of special health care needs children which are a barrier in coordinating services and causes added stress for parents. As with all the groups more education and awareness was needed by Spanish speaking respondents for preventive health and

they have specific needs for more information on: safe sleep for infants, transition services, adolescent well-visit, oral health for children, and smoking (both pregnant women and people at home). While the CYSHCN Spanish group's top two issues were similar to the other groups, their additional priorities were physical activity and adolescent well-visit.

Major conclusions for the four Parents of Special Health Care Needs focus groups and four Maternal and Child Health Needs focus groups are discussed by topic in the section which follows.

Parents of Children with Special Health Care Needs

Health Needs & Issues

The most pressing health needs for parents of children with special health needs varied somewhat by county. For the New Castle and Kent County groups, key issues were the lack of adequate health insurance, limitation of coverage, and lack of services. In Sussex County the key health need was finding health care providers for their children. The Sussex County Spanish speaking group had compounded issues of the need for continuous screening, the lack of transportation, coordinated services, and an easy way to use community based services. Several parents encountered problems with providers that would not accept their public health insurance card after it was switched from United Healthcare to Blue Cross/Blue Shield.

It appears that when it comes to special health needs, parents are being connected with programs and services in the community after diagnosis of their children by their doctors, nurses, case workers, social workers, family, hospitals, employers, schools, and day cares. Although a theme throughout this study --that parents have to advocate for their special health needs children -- the New Castle County group was most vocal about this. Parents in all groups expressed the need to keep pushing for proper diagnoses of their children. Once the children are diagnosed, program and service referral appears to run smoothly. It was noted by parents that physical conditions are much easier to diagnose than behavioral conditions. The Sussex County Spanish speaking group found the most help with specialists, school services, Easter Seals and Child Watch. Parents are doing their own research and educating themselves on their children's special health needs.

The majority of parents and three out of the four focus groups were not satisfied with the support services. Parents are being referred by their hospitals, pediatricians, specialists, case workers or social workers to other specialists, and a host of nonprofit service providers. All parents of the Kent County group were assigned social workers or case workers through a hospital, school or insurance company. Parents in all groups are seeking services on their own. The Kent County group, (which has a higher range of income) stated that Medicaid appears to discriminate against some families and there is confusion or a lack of information about but benefits are available. The Kent County group was not able to find or receive services because they are not available in Kent County, services were denied because of income, or inconsistencies in how disabilities are determined by service providers. The Sussex County Spanish speaking group was the least satisfied with support services, especially with health care and transportation. They do not have much information about programs and services available and they need bi-lingual help to access services. They cannot afford the high cost of pocket expenses. The Sussex County group reported receiving services from a large number of community based organizations and they are pleased with the way their various providers coordinate services and obtain resources for them.

With regard to health services and access, the greatest successes parents expressed were their experiences with parent support and groups working with nonprofit organizations (New Castle County group) and communication, support and follow-through from health care providers (Sussex County group). The greatest challenges expressed by parents is the concerns they have about growing older and how their children will be cared for; the lack of specialists; limitations of insurance companies or failure of services to accept doctor's prescriptions; the inability of doctors to listen to them; and poor communication with the schools (Sussex County – Spanish group). Having more support groups, and information on programs and services and training for health providers and education, and more psychiatric specialists (Kent County) were recommendations by parents.

Health Care Services – Medical Home

Almost no one has heard of the term *Medical or Dental Home*. Once prompted with a review of the definition, only a few parents agreed that their child's doctor provided a Medical Home. A few parents said that the collaborative team of specialists functioned more as a Medical Home than their doctor

Overall parents have supportive and caring relationships with their primary care doctors or pediatricians once their children are diagnosed. The majority of the group feel informed about their children's health issues and they are all actively involved in their health care needs. The Sussex County Spanish speaking group said they had to change providers that were a good fit.

Parents have a problem with medical diagnosis being challenged by educators and insurance companies and other service providers who do not support it. Parents recommend that all medical providers in Delaware accept Medicaid and have reasonable waiting times for appointments.

Family Partnership & Support System

Most parents described their experiences with family provider partnerships based on positive relationships they have had with health professionals. Attributes of family-provider partnerships they identified were: team work, communication, coordinated efforts and patience. About half of the parents' experiences did not reflect this kind of partnership. Partnership values that parents listed were: listening, respect, communication, confidentiality and helping them to understand their children.

The groups were mixed with their ability to find the support services they need in their communities. The Kent County group suggested respite care, group homes and help navigating insurance eligibility and more occupational and speech therapy, psychiatric services. Both New Castle and Kent County groups suggested more parent support groups. Sussex County parents said that more pediatricians, OB/GYNs, and specialists are needed in their community. The Sussex County Spanish speaking group suggested more psychological support services for the whole family which are not available in their community.

Participants recommended changes in insurance company benefits for special health care needs children, ongoing education and training for health and community providers about children with disabilities, and a service "connector". The Sussex County Spanish speaking group recommended quality medical interpreters.

Transition Support for Children & Youth

Overall parents feel that they and their children are ill-prepared to make the transition into adult services. Only a handful of doctors talked to children and their parents about transition services. Parents fear their children will not be able to live independently and will be taken advantage of. They have fears and worries about all school transitions and the majority of the parents reported negative experiences, although there are some positive experiences as well. It appears that school districts have varying levels of success in working with parents of children with special health care needs. Parents need additional resources on transition services to include counselors, workshops and materials, and career and life skills training for adult children.

Parents recommend a roadmap on key developmental milestones, training for pediatricians on diagnosing a variety of disabilities including non-stereotypical symptoms, and listening skills for interacting with parents, training for educators on disabilities and more awareness of disabilities for school aged children.

The top three health priorities overall for all four CYSHCN focus groups were: 1) Adequate Insurance, 2) Developmental Screening and 3) Bullying.

MCH General Health Needs

Health Needs, Services & Barriers to Access

Finding competent, quality care, doctors who listen and annual checkups and health screenings were most important for women. Quality prenatal care, regular checkups, education, balancing work and life stress, cost of care, good nutrition were concerns for expectant mothers. New mothers, education on developmental milestones, immunizations, breastfeeding were key concerns. For children, top concerns were the overall health (physical, social and emotional), meeting developmental milestones, and regular checkups. Adolescents need education on mental health, drug prevention, sex, and bullying. The most pressing health issues for the Sussex County Spanish speaking group was language barriers, transportation, insurance, lack of cultural competence and poor quality care due to doctors being overload. It is hard to find doctors and services for teenagers. Respondents expressed that they felt treated differently because of being a foreigner, not speaking English or not having insurance which influence in the quality of attention they receive.

The majority of respondents in the group were not knowledgeable of specific programs or services for a number of the population domains. Women mentioned the importance of screening programs for women such as mammograms. To assist with financial needs, respondents named agencies such as the Delaware Money School and Catholic Charities. Respondents were able to identify more programs for pregnant women and named birthing programs at hospitals, health centers and nonprofit agencies. The majority of the group was familiar with WIC, breastfeeding services, Child Watch, and Children & Families First. Other agencies that were mentioned for children and adolescents were Head Start, Boys & Girls Clubs, the YMCA and several other nonprofit agencies.

The lack of education and awareness, availability and affordability, distance and transportation (gas, time and cost), and waiting lists for appointments with doctors, were barriers to access that were identified by participants. Affordability is an issue for programs and summer camps for children. The Kent County group felt there is a barrier to receiving social services based on income; however, once in the system people have greater access to services. The Sussex County group stated that there is a gap in programs and services for teens. In addition to these barriers, the Sussex County Spanish speaking group said they need help and insurance for services, interpreters, and information and/or services in Spanish. This group felt that nothing or very little is being done for women and families to have access to programs and services, and that there is a lack of cultural knowledge and cultural sensitivity.

Respondents recommend increasing awareness of programs and services through state sponsored billboards, “infomercials”, sending information home with school children, and use of social media. They also recommended a public relations campaign and audit of State Social Services programs so people will know how to obtain programs and services. The Sussex County Spanish speaking group recommended the use of community health workers to bridge communication between them and the health system, and to be a liaison between the community and providers.

Women’s Preventive Health

New Castle and Kent County groups get information about preventive health care primarily from their doctors, their own research through Web MD and Google, their insurance company, and employer health programs. All but one person in the Sussex County group said they receive the preventive health care they need through their GYN. The majority of respondents from the Sussex County Spanish speaking group obtained preventative information at church sponsored health fairs and receive reminders for vaccination and well-visits from insurance companies. Respondents go to GYNs, midwives, primary care doctors, or specialists for preventive care. Most of the women did not receive additional information during their regular visits with their primary care doctors, and if they asked, the information they received was brief. Several respondents said they do not trust their primary care doctors, appointments are too brief, and doctors are too quick to provide medications or recommend tests.

Almost all respondents receive routine preventative care through their annual checkups with their OB/GYN who provide information, screening and send out reminder cards for annual appointments. GYNs are doing a good job of providing additional information during visits in contrast to their primary care doctors who are rushed or not accessible. Insurance is also a barrier to preventive care for those without it or because insurance is determining the frequency of some preventative procedures (like pap smears) rather than doctors.

Perinatal /Maternal Health

Respondents experiences were mixed in regard to their prenatal care. About half had received additional information such as on oral health care, during their prenatal visits. Similarly about half of the respondents overall felt that prenatal care was good in their community. Some people had very negative experiences such as their doctors miscalculating their due date, being insensitive with treatment upon the traumatic loss of a child, and not getting support or information needed. A large number of respondents felt that there is not enough information in their community about prenatal care. The Sussex County Spanish speaking group said that people who pay for services receive better care.

The majority of respondents in New Castle and Kent County focus groups do not think there is enough information in the community about prenatal care. They get their information on health care from talking with friends, family, online, books, clinics, social services, WIC, Medicaid and social media. Sussex County group said they feel that there is enough information in their community about prenatal care and even about genetic testing. They receive information on nutrition, oral health care, depression and mental health, labor and delivery, cesarean, and information on smoking. They found all the information useful and they feel nothing was missing.

Respondents said that pressing needs for new mothers was: to be able to get their rest, stay home with their babies, affordable and available child care when returning to work, education, secure housing and support. Respondents were knowledgeable about some support services for new mothers.

Children/Adolescent Health – Medical Home

No one was familiar with the terms “Medical Home” or “Dental Home.” No one in the New Castle County group and only a few members of the Kent County group felt that their pediatricians provided a medical home for their children. The experience was quite different in Sussex County where all respondents considered their pediatricians medical homes for their children.

The majority of respondents agreed they are informed about their child’s health issues and needs and involved in their decisions with the Sussex County groups most satisfied. Respondents stated that their doctors involve them in decisions by giving options, information, answering questions, and asking about their family, reviewing the growth development chart, eating habits, reading, flu shots, and giving referrals.

Positive characteristics of their children’s doctors identified by the Sussex County groups included: going above and beyond what is needed, following up; listening, showing respect and concern, calling the pharmacy to refill medication; kind, concerned staff with a good attitude, and scheduling appointments quickly. The majority of respondents agreed that their children’s health providers are sensitive to their preferences and wishes and are sensitive to their cultural background.

All participants were familiar with the process of developmental screening and the majority agreed that their child’s doctor provides adequate information. Respondents said that doctors took too long to get results or failed to follow adequately after the screening and it would be helpful to have more information about the screening process and what milestones to expect and provide follow-up for screening. Sussex County Spanish speaking group agreed their doctors provided adequate information about the purpose of the screening and they explained the results of the screening. All participants said that doctors need to provide follow-up for screenings.

All groups with the exception of the Sussex County Spanish speaking group had doctors who asked their adult children about transitioning to adult services. Some respondents said that compassion and communication as the primary ways the health care system can better meet the needs of children, adolescents and their families. The group would like to see more information available about programs and services and open programs and services to people of all income levels.

Other Relevant Public Health Issues

Most respondents were not aware of the 2-1-1 Help Me Grow toll free line and those who were aware of it did not know what services were offered. They had learned about the service through social media. A few people had actually used the hotline and obtained services which met their needs. Overall respondents suggested more education and awareness of programs and services that are available and specific information on child neglect and abuse, bullying resources for children, social services sponsored health fairs, resource books for women, and free classes on preventive health.

15 National Priorities

The top priorities overall for general maternal and child health needs chosen by respondents were: 1) Well Woman Care; 2) Adequate Health Insurance; 3) Bullying; and 4) Developmental Screening.

CONSULTANT'S RECOMMENDATIONS

The following recommendations are suggested by the consultant as possible strategies to address the needs and issues identified in this focus group study.

1. Increase Insurance Availability, Coverage and Affordability.

- Communicate to all Medicaid recipients the change of the state's health insurer from United Healthcare to Highmark Blue Cross/Blue Shield. This will address the issue of some Medicaid recipients from being denied services at the time of appointments because they have not switched their coverage.
- Clarify eligibility requirements that cause confusion for parents of children and youth with special health care needs (CYSHCN). Perhaps a meeting could be convened with parents to determine areas of confusion and then address these issues by improving communication.
- Convene a meeting with third party payers to discuss: coverage limitations for CYSHCN, to determine if there are opportunities to expand coverage or decrease out of pocket expenses; investigate ways to have pharmacies honor prescriptions from doctors which should be covered by insurance; discuss and review insurance guidelines for preventive health screenings for consistency with medical standards.
- Collaborate with the Department of Education to discuss areas of conflict between medical diagnoses for children and youth with special health care needs (CYSHCN), delays in diagnoses and transition needs and issues for CYSHCN to ultimately examine school district policies.

2. Provide Training Opportunities to Decrease Barriers to Quality Health Services

- Work with the Department of Education to provide or encourage training for teachers to increase awareness and understanding of children and youth with special health care needs.
- Primary Care Doctors need training on listening skills, increased skill on non-physical developmental diagnoses, and cultural competency with the Latino population. The results of the focus group study could be shared with the Delaware Academy of Medicine (DAM) and Delaware Association of Pediatricians to encourage the development of training to address these needs.
- Consider customer service training for Public Assistance employees.
- Collaborate with the Health Equity Commission to develop cultural competency training for bus drivers and phone dispatchers who provide transportation services to Spanish-speaking CYSHCN in Sussex County.

3. Increase Access to More Health Care Providers and Latino Health and Services Providers

- More specialists are needed in psychology and other areas. Discuss with the Health Care Commission/Health Equity Commission ways to encourage more pediatricians and specialists to work in Kent and Sussex County.

- Collaborate with the Workforce Investment Board and the Governor's Hispanic Commission to review/discuss methods to encourage the health sector to recruit more health care providers and community service providers who are Latino and bilingual.

4. Develop Primary Care Doctors as Medical Homes

- It appears that this study has shed some light on practices that respondents describe as Medical Homes; they are demonstrated by pediatricians and specialists who work collaboratively with CYSHCN and also GYNs as a model for patient interaction and preventive health. Work could be done in collaboration with the DAM to discuss opportunities for specialists and GYNs to coach primary care physicians on improving the patient-doctor experience and approaches to improve the patient experience (i.e., increasing the length of appointments, helping people ask questions of their doctors; decreasing wait times; providing phone-in prescriptions for refills or referrals, etc.).

5. Improve Access to Quality Health Care and Services for Spanish Speaking Community Members

- Communication problems expressed in this focus group study by Spanish speaking respondents are related to compliance with Title VI and the provision of interpreting and translating services for non-English speaking parents. Further studies should be done to find out how schools, hospitals and health services agencies are complying with Title VI. It may also be necessary to implement language access plans for the provision and compliance of these services.
- Qualified medical interpreters should be recruited to work in the health care field especially in Sussex County to address language barriers of Spanish speaking population. Contact the International Medical Interpreters Association (IMIA) to get more information on medical interpreting education and certification. There are national certifications available and tools to screen candidates, both as interpreters and bilingual personnel, so that errors in interpreting or hindrance in communication will not occur.

6. Community Health Workers for Spanish Speaking Community Members

- Actions should be taken to train and to provide the services of bilingual community health workers. A community health worker can provide guidance to navigate the health system in the foreign language but it can also help soften the roughness in the relationships between non-English speaking patients and their providers.

7. Education and Awareness

- The lack of awareness is a barrier to accessing quality health care. More information is needed on women's health services, programs and services for adolescents and 2-1-1 Help Me Grow hotline. Develop and implement a statewide billboard and social media marketing campaign in English and Spanish.
- Work with community partners like Child Watch, Children & Families First and the "Y", to encourage more support groups for parents of CYSHCN to share ideas, information and coping strategies. Spanish-speaking support groups could be encouraged with community partners such as Nanticoke Hospital and LaRed Health Center.

8. Transition Improvements and Education

- Work with community partners to develop information and resources on transition of CYSHCN to adult services. These resources should include the development of workshops, support groups and milestone charts and other materials for parents and life skills workshops for adult children. All services should be provided in English and Spanish.
- Work with community partners, parents of CYSHCN, and the Department of Education to develop transition models for schools to help parents and children with key transition points and hurdles.

9. Increase Awareness, Affordability and Access to Adolescent Health Programs and Services

- Work with community partners to:
 - Develop a comprehensive list of affordable programs and services for adolescents and make this information, especially drug and sex education services, available in English and Spanish through marketing campaigns (billboards and social media) and services like 2-1-1 Help Me Grow hotline.
 - Assess programs for adolescents in mental health and bullying and promote what exists statewide.
 - Investigate ways to expand, provide and promote affordable summer camps for children and adolescents that also offer opportunities for physical activity.

10. Improve Transportation Options for Parents of CYSHCN

- Convene a meeting with Medicaid to discuss options for increasing transportation access for parents of CYSHCN who reside in Kent and Sussex Counties. Could a voucher program be implemented for parents who use their own vehicles or share rides from friends or family members?

COMMUNITY DINNER AT THE LATIN AMERICAN COMMUNITY CENTER

Focus Group Report November 2014

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FOCUS GROUP CHARACTERISTICS

A. Group 1

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B. Group 2

Twelve people, consisting of four men and eight women, participated in the second focus group. The estimated age range of the group was between 25 and 40 years. Everyone had children. The number of children per household ranged from one child to six per household (four men; two children each; three women, two children each; four women, three children each; one woman, four children; one woman, six children). Participants were very animated, open, and grateful for the opportunity to express their opinions.

MAJOR FINDINGS

Conclusions

Focus group participants were expressive and appreciated the opportunity to voice their opinions about health care. They appear to have a high level of dissatisfaction with the care they are receiving. Participants believe they are not receiving quality healthcare services because of discrimination which they experience because of language, income level, insurance and race.

Overall, the focus group participants were unfamiliar with specific health care services and programs. Only two people had heard of the State of Delaware's 2-1-1 Helpline. There was no mention of specific programs for mothers and children, and only hospitals were mentioned. These participants are not receiving insurance through Affordable Care Act and one person in each group mentioned that their immigrant status prevented it. It appears that health system terminology is not well understood because of the language barrier.

The majority of participants receive their health care at West Side Medical Health Center and St. Francis Hospital. Some participants also use CCHS. Participants have difficulty scheduling medical appointments at West Side Health and St. Francis Hospital. When medical appointments are provided by West Side Health and St. Francis Hospital, they are given for many weeks out, which is a source of much frustration. Parents use A.I. DuPont Hospital for Children for their children's health care.

Focus group participants would like doctors and medical providers to give more caring and attentive treatment. Participants want doctors to listen more and to diagnose and explain conditions. Language interpreters that are used do not always properly explain patient concerns. Other issues related to the discrimination and frustration they feel may cause some to avoid seeking health care. The following quote from a participant illustrates this point of view.

To be honest, and let's be realistic here, I keep it together as much as we can and then we 'auto medicate' ourselves because they don't want to see us or we have to wait a long time for an appointment. If it's an emergency then I go to the hospital. Westside makes us wait such a long time for an appointment.

Many participants have Community Healthcare Access Program (CHAP) health insurance for their children although they did not identify it as a health program for children. Overall, the group seemed to be satisfied with their children's health services. Participants mentioned that adults do not have access to the same health services as children, such as dental care.

Visits to the emergency room for non-emergency care were not high in frequency. Those who have used these services are visiting two to five times a year, including visits for their children. However, those that use emergency room services generally do so because they cannot get appointments for urgent care for themselves or their children. A few people have called 911 for ambulance services.

Participants travel to their appointments by private vehicle, bus, or taxi, or they walk. Some people do not drive. Participants mentioned that they do not feel safe walking in their community because of crime.

As a group, participants practice preventive care by getting flu shots and taking their children for annual physicals and vaccinations. Women are practicing some preventive care through mammograms and gynecological checkups. Not all women admitted to having a mammogram or annual gynecological exam.

Participants would like to receive education on preventive healthcare, but not just one-time classes. They would like to have regularly scheduled classes available to them on healthcare and nutrition to learn more about healthy lifestyles for adults and children, and how to prepare meals.

Obstacles to receiving quality health care were identified as: discrimination, cost of insurance, not being able to take off from work, transportation, and the language barrier. Language is also the greatest barrier to becoming more knowledgeable about available programs and services. As one participant stated,

*We need more healthcare centers for Hispanics and more respect,
and then the insurance would not be a problem.*

Focus group participants stated that there are not enough licensed interpreters who speak Spanish. They need more information and guidance about services and would prefer to receive

information and literature in Spanish. Spanish-speaking staff and interpreters would improve the quality of service delivery. As one participant stated,

Language interpreters are not well trained; phone interpreters are not accurately interpreting. One time this staff person was helping me but I understand some English so I knew that she was not saying everything. Then a lady came with the interpreter badge and she was great.

Other barriers also exist. Immigrant status is a barrier for some in receiving insurance. Unsafe neighborhoods limit the ability to walk for exercise or walk to appointments. Healthy lifestyles are also affected by the language barrier. For example, one person suggested having Spanish-speaking trainers in the gym:

I go to the Y and sometimes I don't even know what weight to pick up in the classes because the trainers don't speak Spanish. I just follow whatever else people are doing but it's really hard. It's really embarrassing when you don't understand what they're saying but you want to work out.

Language is a huge barrier.

Participants said focus groups and community meetings are a useful way to inform people about health services and programs. They would like to see 24-hour clinics and/or clinics for Hispanics and more information made available in Spanish. They said they could benefit from a health navigator or community health worker.

Consultant's Recommendations:

1. Work with partners to develop literature in Spanish on State health programs and services; and distribute materials through LACC, Westside Health, St. Francis, CCHS, area churches, and health ambassadors.
2. Encourage more cultural competency training for medical and health care providers at targeted locations.

3. Encourage hiring of more licensed interpreters in Spanish. Hire more Spanish-speaking staff in area hospitals and community centers.
4. Work with Westside Health and St. Francis to improve scheduling times for appointments. Consider establishing an area walk-in clinic for urgent care needs.

5. Develop a special outreach program for women's health to promote mammograms, sexual health, and breastfeeding.
6. Develop nutrition and healthy lifestyle workshops or video series in Spanish that can be offered at the LACC, in area churches, or by medical providers.

FINDINGS BY FOCUS GROUP

C. *Health Care Programs, Services*

and Policy Group 1

- The most important health problems mentioned by participants were family illness, long hospital waits, and the lack of transportation or insurance.

- The group was unfamiliar with health programs for women. For pregnant women, they mentioned the Westside Health Center. For emergency care for infants, they mentioned Christiana Care's Wilmington Hospital and St. Francis Hospital. One respondent identified A.I. DuPont Hospital for Children as a place for children's specialists. Respondents also mentioned: where to get flu shots and pregnancy prevention programs, and stated that there is discrimination in the hospitals.

- No one in the group had signed up for the Affordable Care Act Insurance. Participants gave these reasons: having to pay, not being able to qualify, and immigrant status.

D. *Group 2*

- While everyone did not respond to this question, the two who did expressed the need to have greater knowledge from their doctors about prevention, specifically how to prevent virus symptoms in their children.

- The group said the question was too broad and were not sure what to write. The majority of the group did not know of specific programs and their general answers primarily mentioned flu vaccines, mammograms, and cancer detection. They spoke of barriers to health care including: language, lack of transportation, unsafe neighborhoods, and discrimination.
-

- No one had signed up for the Affordable Care Act Insurance. One person tried but was not accepted because of immigration status.

Barriers and Access

Access to Services

E. Group 1

- Half of the group goes to Westside Medical Health Center. Participants were not familiar with the Henrietta Johnson Medical Center. For emergency care, respondents mentioned the Wilmington Hospital, St. Francis Hospital, CCHS, and their family doctors.
- Participants get to their appointments by car, bus, by taking a taxi paid by Medicaid; or by walking.

F. Group 2

- The majority of the group goes to Westside Health for their adult needs. For children, participants take their children to A.I. DuPont Hospital for Children, their pediatrician, the emergency room (ER), and walk-in clinics. A few people mentioned that they do not go for medical care and try to “self-medicate.” Several complained about the long waits to get an appointment at Westside Health and the cost.
- Participants take the bus, use their own car, try to find a ride, or walk to appointments. Several people have called 911 for an ambulance.

Emergency Room Visits

G. Group 1

- The group responded that they use the ER for emergencies and non-emergencies including: asthma, bad colds, toothaches, injuries, pains, and need of medicine.

- Participants said they go to the emergency room for early morning emergencies, the inability to get timely appointments, and suspect serious infections.

- Families who visited the ER during the past year reported they went two to four times.
- The group expressed a desire for help in finding caring medical providers outside of emergency rooms. They discussed the need for 24-hour clinics. They stated that they are treated poorly and cited these issues: racism, the lack of insurance, and lack of caring.

H. Group 2

- Participants take their children to the emergency room for fevers and allergies.

Another participant goes to the emergency room because of severe headaches or as a “last resort.”

- No participants said they only went to the emergency room for medical care.
- Families visited the ER one to five times over the past year.
- Resolving four issues would help the group find health care providers instead of using an emergency room: 1) appointments (longer, less waiting time, and more flexibility; 2) poor quality of or lack of interpreters; 3) racism and discrimination and; 4) lack of insurance.

Prevention Services

I. Group 1

- The majority of the group received preventive services over the past year.

Three- quarters of the group received medical examinations and half received flu shots. A majority of the women reported they had mammograms, yearly gynecological examinations, or contraception counseling. Two people had their teeth cleaned and one had a blood test for diabetes.

J. Group 2

- A few people stated that over the past year, they received flu shots and other general shots.

Barriers to Service

K. Group 1

- The group identified four major issues that keep them and their families from being healthy or receiving the care they need: 1) health insurance cost, residency requirements, employee benefit, and information; 2) nutrition education and healthy eating; and 3) lack of time and motivation to exercise.
- Cost was the biggest problem, followed by transportation (three people did not know how to drive) and not being able to take off from work. The group did not understand the description pertaining to the health care system. Group members also mentioned the lack of insurance and doctors.

L. Group 2

- Unsafe neighborhoods and the inability to walk, lack of money, and the lack of Spanish-speaking staff “at the Y” were cited as reasons that discourage participants and their families from receiving needed healthcare.
- Cost and not knowing where to go were the biggest problems, followed by transportation and not being able to take off from work. The group did not understand the description pertaining to the health care system and believe that there are many doctors in the area. The lack of interpreters was also an issue.

Gaps in Service

M. Group 1

- Participants need information about specific programs so they can make informed decisions. The group believes that they are discriminated against because they are Hispanic, or because they lack insurance or private insurance. They would like to have health care centers for Hispanics and be treated with respect. Nutrition classes were also suggested.
- The group would like to have more information about services, focus groups, and informational sessions in the community, health insurance, and child care.

N. Group 2

- The group would like to see Spanish work-out groups, a series of healthy cooking classes, and education for children about how to be healthier.
- To increase healthcare access, both groups said families need more information about programs and services including CHAP, childcare, computer and English classes, and insurance. Community programs should be offered at flexible times to accommodate work schedules.

Access to Information

O. Group 1

- Families become aware of programs and services through LACC flyers; word of mouth through friends, family, and neighbors; phone calls; mailed invitation cards and announcements; television; Facebook; and church.
- No one was familiar with the Delaware 2-1-1 helpline.
- The group suggested sharing information, advertising in schools, daycares and Head Start; conducting community focus groups; and sending text messages with community updates.
- Participants identified four ways they like to receive information: by phone, through community meetings, flyers, and text messages.

P. Group 2

- Families find out about programs and services primarily by word of mouth through friends and family. They also find out about programs through the LACC and Westside Health Center. Two people suggested the LACC does not help all in the community.
- Two people are familiar with the Delaware 2-1-1 helpline.
- Participants would like to receive information in Spanish and have Spanish- speaking staff available to help them.

Suggestions

Q. Group 1

- The group offered additional ideas to improve health care for mothers and children: vitamins for mothers and children; doctors to take their time with patients and make proper referrals to specialists; phone call reminders for appointments and for emergencies; and receiving services without delay when there are no appointments.
- All participants agreed they would benefit by having a community health worker.

They also would like to see literature provided in Spanish in both hospitals and the medical centers; and Spanish-speaking staff at these facilities. One participant raised a concern that dental plans only cover children.

R. Group 2

- The group wants to see more caring and attentive treatment from doctors who listen and take time to diagnose their health problems. Language and discrimination is a major issue. Interpreters are inaccurate in translating or untrained staff is used to translate.¹ Participants are dissatisfied with the treatment and care they receive.
- The group liked the idea of a community health trainer or worker. They also suggested they could use computer training and phones with Internet service.

¹ These individuals are described as regular staff persons who are not trained as interpreters who are asked to translate because they are bi-lingual.

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*We need more healthcare centers for Hispanics and more respect,
and then the insurance would not be a problem.*

Focus group participants stated that there are not enough licensed interpreters who speak Spanish. They need more information and guidance about services and would prefer to receive

information and literature in Spanish. Spanish-speaking staff and interpreters would improve the quality of service delivery. As one participant stated,

Language interpreters are not well trained; phone interpreters are not accurately interpreting. One time this staff person was helping me but I understand some English so I knew that she was not saying everything. Then a lady came with the interpreter badge and she was great.

Other barriers also exist. Immigrant status is a barrier for some in receiving insurance. Unsafe neighborhoods limit the ability to walk for exercise or walk to appointments. Healthy lifestyles are also affected by the language barrier. For example, one person suggested having Spanish-speaking trainers in the gym:

*I go to the Y and sometimes I don't even know what weight to pick up in the classes because the trainers don't speak Spanish. I just follow whatever else people are doing but it's really hard. It's really embarrassing when you don't understand what they're saying but you want to work out.
Language is a huge barrier.*

Participants said focus groups and community meetings are a useful way to inform people about health services and programs. They would like to see 24-hour clinics and/or clinics for Hispanics and more information made available in Spanish. They said they could benefit from a health navigator or community health worker.

Consultant's Recommendations:

1. Work with partners to develop literature in Spanish on State health programs and services; and distribute materials through LACC, Westside Health, St. Francis, CCHS, area churches, and health ambassadors.
2. Encourage more cultural competency training for medical and health care providers at targeted locations.
3. Encourage hiring of more licensed interpreters in Spanish. Hire more Spanish-speaking staff in area hospitals and community centers.
4. Work with Westside Health and St. Francis to improve scheduling times for appointments. Consider establishing an area walk-in clinic for urgent care needs.

5. Develop a special outreach program for women's health to promote mammograms, sexual health, and breastfeeding.
6. Develop nutrition and healthy lifestyle workshops or video series in Spanish that can be offered at the LACC, in area churches, or by medical providers.

FINDINGS BY FOCUS GROUP

Health Care Programs, Services and Policy

Group 1

- The most important health problems mentioned by participants were family illness, long hospital waits, and the lack of transportation or insurance.
- The group was unfamiliar with health programs for women. For pregnant women, they mentioned the Westside Health Center. For emergency care for infants, they mentioned Christiana Care's Wilmington Hospital and St. Francis Hospital. One respondent identified A.I. DuPont Hospital for Children as a place for children's specialists. Respondents also mentioned: where to get flu shots and pregnancy prevention programs, and stated that there is discrimination in the hospitals.
- No one in the group had signed up for the Affordable Care Act Insurance. Participants gave these reasons: having to pay, not being able to qualify, and immigrant status.

Group 2

- While everyone did not respond to this question, the two who did expressed the need to have greater knowledge from their doctors about prevention, specifically how to prevent virus symptoms in their children.
- The group said the question was too broad and were not sure what to write. The majority of the group did not know of specific programs and their general answers primarily mentioned flu vaccines, mammograms, and cancer detection. They spoke of barriers to health care including: language, lack of transportation, unsafe neighborhoods, and discrimination.

- No one had signed up for the Affordable Care Act Insurance. One person tried but was not accepted because of immigration status.

Barriers and Access

Access to Services

Group 1

- Half of the group goes to Westside Medical Health Center. Participants were not familiar with the Henrietta Johnson Medical Center. For emergency care, respondents mentioned the Wilmington Hospital, St. Francis Hospital, CCHS, and their family doctors.
- Participants get to their appointments by car, bus, by taking a taxi paid by Medicaid; or by walking.

Group 2

- The majority of the group goes to Westside Health for their adult needs. For children, participants take their children to A.I. DuPont Hospital for Children, their pediatrician, the emergency room (ER), and walk-in clinics. A few people mentioned that they do not go for medical care and try to “self-medicate.” Several complained about the long waits to get an appointment at Westside Health and the cost.
- Participants take the bus, use their own car, try to find a ride, or walk to appointments. Several people have called 911 for an ambulance.

Emergency Room Visits

Group 1

- The group responded that they use the ER for emergencies and non-emergencies including: asthma, bad colds, toothaches, injuries, pains, and need of medicine.
- Participants said they go to the emergency room for early morning emergencies, the inability to get timely appointments, and suspect serious infections.

- Families who visited the ER during the past year reported they went two to four times.
- The group expressed a desire for help in finding caring medical providers outside of emergency rooms. They discussed the need for 24-hour clinics. They stated that they are treated poorly and cited these issues: racism, the lack of insurance, and lack of caring.

Group 2

- Participants take their children to the emergency room for fevers and allergies. Another participant goes to the emergency room because of severe headaches or as a “last resort.”
- No participants said they only went to the emergency room for medical care.
- Families visited the ER one to five times over the past year.
- Resolving four issues would help the group find health care providers instead of using an emergency room: 1) appointments (longer, less waiting time, and more flexibility; 2) poor quality of or lack of interpreters; 3) racism and discrimination and; 4) lack of insurance.

Prevention Services

Group 1

- The majority of the group received preventive services over the past year. Three-quarters of the group received medical examinations and half received flu shots. A majority of the women reported they had mammograms, yearly gynecological examinations, or contraception counseling. Two people had their teeth cleaned and one had a blood test for diabetes.

Group 2

- A few people stated that over the past year, they received flu shots and other general shots.

Barriers to Service

Group 1

- The group identified four major issues that keep them and their families from being healthy or receiving the care they need: 1) health insurance cost, residency requirements, employee benefit, and information; 2) nutrition education and healthy eating; and 3) lack of time and motivation to exercise.
- Cost was the biggest problem, followed by transportation (three people did not know how to drive) and not being able to take off from work. The group did not understand the description pertaining to the health care system. Group members also mentioned the lack of insurance and doctors.

Group 2

- Unsafe neighborhoods and the inability to walk, lack of money, and the lack of Spanish-speaking staff “at the Y” were cited as reasons that discourage participants and their families from receiving needed healthcare.
- Cost and not knowing where to go were the biggest problems, followed by transportation and not being able to take off from work. The group did not understand the description pertaining to the health care system and believe that there are many doctors in the area. The lack of interpreters was also an issue.

Gaps in Service

Group 1

- Participants need information about specific programs so they can make informed decisions. The group believes that they are discriminated against because they are Hispanic, or because they lack insurance or private insurance. They would like to have health care centers for Hispanics and be treated with respect. Nutrition classes were also suggested.
- The group would like to have more information about services, focus groups, and informational sessions in the community, health insurance, and child care.

Group 2

- The group would like to see Spanish work-out groups, a series of healthy cooking classes, and education for children about how to be healthier.
- To increase healthcare access, both groups said families need more information about programs and services including CHAP, childcare, computer and English classes, and insurance. Community programs should be offered at flexible times to accommodate work schedules.

Access to Information

Group 1

- Families become aware of programs and services through LACC flyers; word of mouth through friends, family, and neighbors; phone calls; mailed invitation cards and announcements; television; Facebook; and church.
- No one was familiar with the Delaware 2-1-1 helpline.
- The group suggested sharing information, advertising in schools, daycares and Head Start; conducting community focus groups; and sending text messages with community updates.
- Participants identified four ways they like to receive information: by phone, through community meetings, flyers, and text messages.

Group 2

- Families find out about programs and services primarily by word of mouth through friends and family. They also find out about programs through the LACC and Westside Health Center. Two people suggested the LACC does not help all in the community.
- Two people are familiar with the Delaware 2-1-1 helpline.
- Participants would like to receive information in Spanish and have Spanish-speaking staff available to help them.

Suggestions

Group 1

- The group offered additional ideas to improve health care for mothers and children: vitamins for mothers and children; doctors to take their time with patients and make proper referrals to specialists; phone call reminders for appointments and for emergencies; and receiving services without delay when there are no appointments.
- All participants agreed they would benefit by having a community health worker. They also would like to see literature provided in Spanish in both hospitals and the medical centers; and Spanish-speaking staff at these facilities. One participant raised a concern that dental plans only cover children.

Group 2

- The group wants to see more caring and attentive treatment from doctors who listen and take time to diagnose their health problems. Language and discrimination is a major issue. Interpreters are inaccurate in translating or untrained staff is used to translate.¹ Participants are dissatisfied with the treatment and care they receive.
- The group liked the idea of a community health trainer or worker. They also suggested they could use computer training and phones with Internet service.

¹ These individuals are described as regular staff persons who are not trained as interpreters who are asked to translate because they are bi-lingual.