

Chat and Chew Focus Groups (English-Speaking)

A Review of Key Findings and Recommendations

Introduction

In 2019, the Delaware Department of Health and Social Services, Division of Public Health sought to gain insight from community members regarding the research question ***How can health care be more patient centered for Delaware's women, children and families?*** Twelve focus groups were convened: 2 groups of preconception women, 4 groups pregnant women and women with children (“mothers”), 2 groups of fathers, and 4 groups of parents of children and youth with special health care needs (“mothers with CYSHN”). Three focus groups were conducted in Spanish (one of the mothers’ groups and two of the parents with CYSHN).

A consulting firm (Goeins-Williams Associates) prepared a comprehensive report including, for each of the 4 types of groups, a qualitative thematic analysis of discussions, quantitative analysis of surveys completed by participants, synthesis of conclusions and recommendations. The Division then contracted with John Snow, Inc. to have transcripts made of the 9 English audio recordings, review the transcripts, and the comprehensive report, and provide corroboration and/or refinement of the results.

Analysis Method

We used NVivo qualitative coding software to assist our thematic analysis of the 4 groups of nine transcripts. We did not establish codes on a priori based on the original consultant’s report (the deductive approach), but rather derived codes based on the data (the inductive approach). We then compared our results to the report and determined similarities or differences.

We also used NVivo’s internal text processing algorithm to create a dendrogram visualization for each of the 4 groups of themes. The algorithm involves looking for similar words across themes (using the Pearson correlation coefficient). The dendrogram portrays which themes cluster together conceptually and which ones are more different; reviewing the dendrograms helped us refine coding when clusters did not make clear sense.

Summary of Findings and Recommendations

After our review of the preconception women, mothers, fathers, and CYSHN focus group data, ***we found the original thematic analysis to be clear and coherent, and we largely agree with the findings. Our re-analysis found some additional nuances in the data that we believe are informative and so suggest some refinements to, or prioritization of, the recommendations.*** However, the original report also incorporates the Spanish language results, and our report does not; that is an important limitation.

In order to organize our thinking about the meaning of the analysis results, we relied upon two frameworks. They are: quality of health care, as defined by the Institute of Medicine; and whole person care, which incapsulates social determinants of health and mental-physical health connection.

Ultimately, the answer to Delaware’s overarching research question lives within the larger context of a complex system and its underpinning of ensuring quality of care. As such, revisiting the characteristics of

quality health care system provides a framework and a mechanism for Delaware to be strategic as it engages in public health planning and policy to curate the state’s system of care for the next decade.

The Institute of Medicine (IOM) identifies quality health care as having the following attributes: safety, effectiveness, client-centered approach, timeliness, efficiency, accessibility, equity and value. Key themes that arose from the focus groups across the populations of preconception women, maternal health, fathers, and children and youth with special health care needs touch upon several of the eight attributes. However, one consistent theme that arose which is not adequately captured in IOM’s six domains of quality health care is the social and emotional supports necessary for overall health and well-being. Increasingly, public health is trying to conceptualize and implement interventions to address these elements (whole person care) by increasing awareness of social determinants and integrating behavioral health into primary care practice through team-based care as well as provision of care coordination services. These strategies along with IOM’s six domains have the potential to address the emotional supports that focus group participants describe and are looking to the healthcare system to help address either directly, through care and treatment, or indirectly through a referral to community resources.

Based on analysis of focus group data and the literature, what is evident is: 1.) delivery of care has become increasingly demanding (IOM, 2013)¹; and, 2.) delivery of care “has become increasingly fragmented, leading to coordination and communication challenges for patients and clinicians.”¹ Thus, in the brief bullet list below, JSI “rolls up” our recommendations taking into account the domains of quality healthcare and the landscape of Delaware’s system of care, resting in key areas and not necessarily discrete interventions. While many of the focus group findings point to opportunities for provider improvements learned from IOM’s work on the learning health system that “traditional systems for transmitting new knowledge—the ways clinicians are educated, deployed, rewarded, and updated—can no longer keep pace with scientific advances.” In its promotion of a learning health system, IOM goes on to note that given “real-world impediments” initiatives need to go beyond incremental improvements to address (and change) the environment, context, and systems in which professionals practice which in turn should support genuine patient engagement. Our recommendations are directed to the environment, context and systems and emphasize continuous quality improvement strategies.

- Characteristics of a Continuously Learning Healthcare System
- Science and Informatics
- Real-time access to knowledge
- Digital capture of the care experience
- Patient-Clinician Partnerships
- Engaged, empowered patients
- Incentives
- Incentives aligned for value
- Full transparency
- Continuous Learning Culture
- Leadership-instilled culture of learning
- Supportive system competencies

Overall Recommendations

Accessibility, Equity and Value

¹ Institute of Medicine 2013. Best Care at Lower Cost: The Path to Continuously Learning Health Care in America. Washington, DC: The National Academies Press. <https://doi.org/10.17226/13444>.

- Increase availability of community health workers and patient navigators
 - Enhance patient-provider communication
 - Navigate system of care; and access community supports and services
 - Navigate financial assistance
 - Financial assistance to address the high emotional and financial burden on women and families
- Work with insurers:
 - Help practices develop payment plans for copayments, especially for low-income working people;
 - Improve the understandability of benefit information;
 - Reduce the red tape for approvals, especially for children with special health care needs.
- Educate young adults in their twenties, who may have been on their parents' insurance up to age 25, on how insurance works
- Practice staffing models are dictated in large part by how they are paid by insurers.
 - Examine the business case for billing for longer appointments with physicians (e.g. E&M codes for people with chronic conditions so there is time to discuss) and promote the annual preventive checkup. Also, ways to pay for non-provider staff time with patients.

Client/Patient-Centered Care (Whole Person Care)

- Promote team-based care to facilitate integration of primary care and behavioral health care services
- Continuous quality improvement for care coordination and listening to the parents for high-risk pregnancies, with an emphasis on down state labor and delivery settings
- Support initiatives that facilitate systems coordination and/or integration (improved referrals, enhance awareness of community services and supports, etc.)
- Consider the success of the Chat & Chew Model – facilitated small group discussions as ways to help people connect with their peers for advice and support --- and expertise from the facilitator (s).

The rest of this report provides more detailed analysis and synthesis for each of the 4 groups of community members. We corroborate the themes from the original report, highlight some aspects based on our two-part framework. For the reader's reference, the appendix contains the original consultant's recommendations for each of the four community groups represented in the focus groups.

Preconception Focus Groups (English-Speaking)

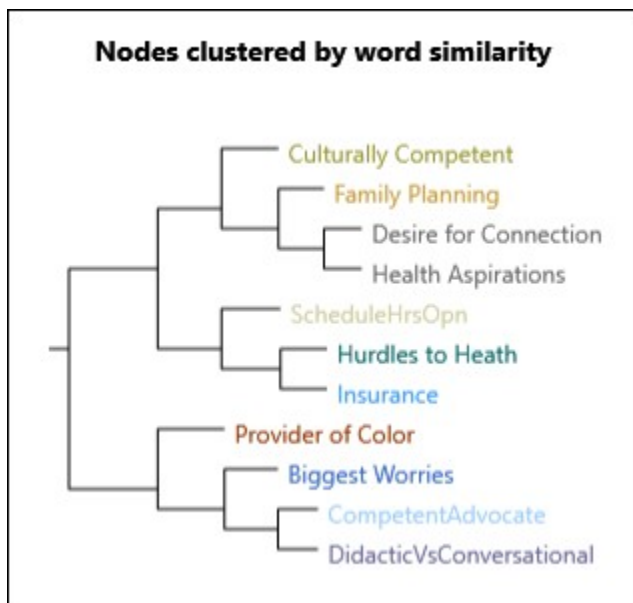
Tabulation of JSI Themes for the Preconception Groups

Name	Description
Desire for Connection	This theme describes participants' desire for a supportive person or people to help live healthily; it also describes a related theme of creating spaces for peer groups to gather and talk and support each other. Connection means being able to speak freely about deepest concerns, ask questions, offer ideas - be heard and participate in dialog. It could also be a place to learn and try new things, have fun. Ultimately, there is a deep desire among participants to feel they are not alone in what they are going through and somebody (especially peers) cares and will encourage them. The Chat and Chew sessions themselves were a special time and place of bonding for the participants. JSI also noted this phenomenon during the 2018 Chat & Chew sessions. This theme is related to the Health Aspirations theme as well as the Family Planning theme. These hang together because of the desire have trusted peers to talk about family planning (with a trusted facilitator) and live healthily.
Family Planning	This theme describes participants familiarity with the concept of a reproductive life plan (none were; however all were familiar with the term family planning and had access to contraception), their description of their interaction with their providers in terms of planning to have a baby, concerns over birth control, and relationships (extremely limited). It also covers deep sharing among the group members about concerns over pregnancy and desires for children and relationships.
Health Aspirations	This theme incorporates responses to questions about what participants were most proud of in terms of what they do for their health and related follow-up questions. The key areas were healthy living (diet, exercise), mental health and handling worry, and going to the doctor. The nuance, particularly for healthy living, was the aspirational way this was expressed – wanting to do better, having support to do so, and better understanding of HOW to do it. Role models were mentioned in one group – including famous people; a key nuance was that the specific people mentioned were not random, but highly associated with the aspirations mentioned and/or the region (<i>Jennifer Hudson</i> -former spokeswoman for Weight Watchers, successfully lost substantial weight, lost family to gun violence, <i>Queen Latifah</i> – from New Jersey & successfully lost substantial weight, <i>Zooki</i> (sp?)– Wilmington local celebrity.
Schedule, Hours of Operation (part of Provider – Practice Theme)	Not having access to prompt appointments was a concern; for some, it may be related to worry over the severity of their health condition. Another, related, obstacle is hours of operation; all of the participants were working or students and mentioned practices close early and have limited weekend hours. For downstate residents the additional drive travel time amplifies this concern. For Wilmington residents trying to negotiate appointments at locations on bus routes (or not on bus routes) amplifies this concern. Both groups suggested having multiple services at one location (downstate – multiple locations, upstate on a bus route), such as at a mall, would be a great help. Suggested

	services: primary care, gynaecological care, counselling, help with insurance, nutrition, eye care. This theme is related to Hurdles to Health in the sense both relate to inability to physically accomplish something important (visit doctor, exercise); it relates to Insurance as a barrier to care.
Hurdles to Health	Hurdles to health –to reaching aspirational goals. The sub-themes were: struggles with eating healthier or exercising within their context: working on their feet all day and coming home tired, having to accommodate their asthma when trying to exercise outside (pollen and heat being triggers), or lack of safe places to walk (no sidewalks, especially down state); healthier living on a tight budget (food costs); having family or friends who challenge their aspirations (questioning why they are taking a mental health medication or seeking counselling); not having peer (s) to help motivate them.
Insurance	Only one participant was aware that under the ACA they were eligible for a free annual preventive care exam. Not having this type of longer visit may limit provider-patient relationship building. Co-payments, particularly for specialists (GYN, MH) are a big issue, and for some, the inability to pay/indebtedness (which causes a great deal of worry and cuts off access to care). Rules (e.g. formularies, higher co-pay for the ED) are hard to understand. For those on parent’s insurance, they do not receive the benefits materials directly.
Provider of Color	Being able to speak to a woman, especially a woman of color, is especially important for deeply personal concerns about family planning, pregnancy, and relationships. It is also true for mental health. Participants assumed that women providers of color would relate to what they had to say and would listen to them. In a clinical setting, the provider (GYN, PCP) would have to be willing/able to enter into a conversational encounter rather than a didactic one for this aspiration to be met. This could also be coded as a sub-theme under Providers and Practices, but was pulled out as its own theme because being able to talk to woman of color – not just a medical clinician, but also a health expert (e.g., a nutritionist), counsellor (MH), mentor, group facilitator, or role model - also applies.
Biggest Worries	The last question asked during both focus group was “what are your top 3 concerns?”, or “what are the things that keep you up at night?” (health-related or not). Prominent sub-themes were financial burdens, including finding a better job and continuing education; caregiving and losing loved ones - especially elders; mental health and worry, living healthier, other health issues (overweight, asthma), relationships. This theme connects with provider communication because health (personal and of loved ones) is a big worry.
<i>Providers and Practices</i>	
Competent Advocate	The first requirement for trusting and using providers is that they know what to do, that they are clinically competent – able to identify and treat an urgent health concern. Most described appointments for problem-focused issues (which were likely brief visits), or annual GYN appointments where this requirement is amplified. Many do internet searches prior to visits, and getting feedback about whether that information is correct or applicable is important. Providers are advocates for patients when they make referrals, write prescriptions, and provide written materials. This is valued, but

	overwhelming, which is further unpacked in the Didactic Vs. Conversational Theme.
Didactic Versus Conversational	<p>Participants described a variety of clinical encounters (positive and negative) in which the clinician is directive – do this, do that, read this; the interaction is didactic in nature. On the one hand, this is acknowledged as indicative of competent advocacy, but in many instances, there are a whole host of issues that go unspoken because the interaction is not conversational in nature. These issues are slightly “off topic” but highly related to the topic: for example, referrals may prompt worry over the severity of illness; anti-depressant/anti-anxiety medications may prompt worry over a parent finding out about it. This phenomenon is very apparent for informational material, such as for nutrition and physical activity. Handouts are informative in a general way but prompts deeper questions about HOW to implement the guidance in their own lives, which are not discussed – patients are just sent home with the information. This issue may also be related to the Insurance Theme; patients come in for brief problem-focused issues, not an annual preventive care exam, during which there could be more time to talk. This issue may be amplified when providers are residents/medical students. Not being able to converse is very important for mental health, nutrition/exercise, and (exceptionally important) for family planning.</p>
Culturally Competent	<p>Responses to the directly asked questions of whether participants felt they could ask questions; felt they were respected personally and culturally. Participants were also asked for a show of hands about these issues. Nearly uniformly (especially upstate) the responses were positive. These strong responses seem to contradict the Didactic Versus Conversational theme. The nuance may be that providers do answer questions specific to the issue at hand and do offer comfort. But conversations about the implications of care are less likely to occur: what is not discussed is how this care (prescription, referral, nutrition handout) plays out when the patient walks out the door. This theme is also capturing non-provider aspects of clinical practices, in terms of it being respectful, welcoming, and inclusive of culture. Two sub-themes emerge: the physical layout is important – cleanliness, look good (chairs, fresh paint on walls), and simple amenities, such as access to a clean bathroom and a water bubbler/fountain. Not shabby or dreary. Of critical importance: having nice and competent front office staff (Note: these staff handle the extremely sensitive topics of insurance eligibility, co-payment, scheduling, and paperwork!). One practice downstate uses an automated check-in system – not at all appreciated. Upstate, practice staff accommodated appointments to align with bus schedules which was appreciated. This theme includes different aspects of an accepting health care environment that could improve the sense of being connected and ability to be healthier.</p>

Dendrogram of Preconception Group Themes



Synthesis and Analysis

Our synthesis and analysis of the focus groups of young pre-conception African-American women resulted in similar themes and findings as the original report. However, there were three themes that especially stood out:

1. First and foremost, we found a deep desire for connection, especially with peers: people who can help motivate and encourage each other to live healthier, share their experiences and knowledge, and find comfort and hope among those who share the same struggles and aspirations. Having facilitated groups with a trusted role model was highly regarded as a way to get people to open up, keep things on topic, and provide solid information. The skill of the Chat and Chew facilitators was apparent. Representative quotes:
 - *"I feel like just a communal aspect. Like, I don't really feel like we have that where I live. We don't really know our neighbors or, like, talk to people. So, like, if you had people you could get in a group -- like, there's not even, like, a group option unless you go to a church or some type of thing, you know, to meet people. You can't find other people to hang out with and do things with."*
 - *Like [name] just said, like a peer group. I was in group counseling one time, and that really helped, hearing other people's stories. R: Especially your age. R: Yeah. R: So, it's like I'm not the only one.*
2. Participants were knowledgeable about the importance of eating well and getting exercise. They aspire to improve but bump up against the hurdles of work schedules, being tired after a physically demanding shift, cost of food. For those with asthma, pollen and heat are real safety concerns. They also recognized the importance of good mental health as part of self-care, but bump up against very

significant worries – finances and career paths, relationships, health of loved ones and themselves, [trauma], and stigma among family members for getting MH treatment. The deep desire for connection among peers and with trusted leaders, role models is to help reach these health goals.

- *Yeah, if other people was around me healthy then I'm like, "Okay, they can do it, I can do it too." R: Or a friend. R: Yeah, basically like a friend that lifts you up (inaudible) come to the gym with me.*
- *You know, I've got to get back to, you know, focusing on eating right, being healthier. And like [name], I think, was saying, mental health is definitely important.*

3. Providers play a key role in women's lives. For many participants, they have had positive experiences when seeking care for an acute need or for gynecological check-up and state they feel respected, able to ask questions. Particularly in the Wilmington group, practice staff (for scheduling and creating a welcoming environment) were also well regarded. But at the same time, there were cross-currents of not being able to talk about things or negative experiences. Most described communications with providers as didactic and directive – "do this, do that, read this", which was appreciated as addressing the problem at hand. However, there was desire for conversation and encouragement—to discuss how to eat healthier, or deal with health conditions, in one's own context. For deeply personal issues - mental health and reproductive health - discussions were difficult, with a belief that female providers of color would be more open to conversation.

- *I'm trying to find a person of color, just to be on the same field. But same thing that [name] said, someone to just -- I mean, to listen to me, because, I mean, we can do the in-and-out thing, but taking an extra five minutes just to hear my side [answer?] of really what's going on, or what I think is going on, giving me small feedback. It makes a world of difference to me.*
- *I'm not opposed to a male doctor, but I do -- for some reason, it seems like women are more relatable for -- in my experience from what I've seen. I've also had my wisdom teeth taken out recently, and the dentist office -- it wasn't the actual dentist, but he had -- one of his clerks or something called to follow up, and I thought that was really cool. I appreciated that.*
- *Like, I would like to see more black women in practice, because I think there'd be more things that would be easier for me to talk about. Like I said, I'm an open book as it is to my doctors, but, like, I feel like there's some other things I would probably end up talking about.*
- *No, he just be like, "When you ready to get pregnant just tell me and we'll have a talk." Yeah, he just -- we didn't really have a talk, he just be like, "You know you got to stop birth control." I was like, "Yeah."*

Suggestions Regarding Original Recommendations

Recommendation 9, encouraging the development of peer support groups for African-American women, and **Recommendation 5**, the shopping center concept are wide-ranging. Consideration should be given to starting simply, having places for facilitated peer support groups, that are thoughtfully developed and promoted (invest in local coordinator) and grow programming from there— nutrition or insurance classes, cultural events, and the like (incorporating the ideas of community people). People of

color should be involved in leadership and operation of these new programs. While it would be extremely beneficial to have medical care under one roof, it could take a great deal of time and resources; in the meantime, building supportive networks could still move forward. **Recommendation 1** is another good way to help create a supportive community; however, creatively designing and programming to make it easy for young working women to participate is key.

Campaigns that address self-care and reduce the stigma around seeking care for mental health in the African-American community (**Recommendation 8**) would be incredibly helpful. Campaigns that specifically inform and encourage young African-American women to participate in the peer groups and fun activities (walking groups, etc.) would also be helpful.

A special note about the role of local celebrities (**Recommendation 2**): this was discussed in one focus group in the context of nutrition and weight loss. Three celebrities were named in this context because their stories lined up directly with that issue (Table 1, Health Aspirations row). Care is needed in aligning the celebrity with the message. Incorporating these celebrities could also take different forms – discussing their accomplishments in groups, playing their music at activities, etc.

Recommendations 3 and 4 (regarding telehealth and videos) while reasonable, require additional consideration. With regards to telehealth, directing someone to this service without conversing in order to allay concerns, answer questions, and discuss the pros and cons, may well not be well received. With regards to videos, our analysis indicates interpersonal discussion would be more valued (of course video or printed material could be involved). **Recommendation 6**, promoting the annual preventive care visit, could open up time for discussion, is a good option (both for participants and in general), as is **Recommendation 10**, promoting training on trauma-informed care. **Recommendation 7**, encouraging practices to develop payment plans for co-payments is well-founded. In addition to foundation funding, the state could provide leadership in working with practices, insurers, and/or employers to come up with creative ways to develop payment plans or waive co-payments (e.g., for participating in a support group, etc.).

With regards to provider-patient communications: continuing efforts (workflow design, staffing/team building, cost/benefit analysis) to incorporate non-medical staff into teams and/or billing for longer provider visits to help provide the “conversation time”; also encouraging (discussing with) patients to try peer support groups (either on site or in the community) as they come online.

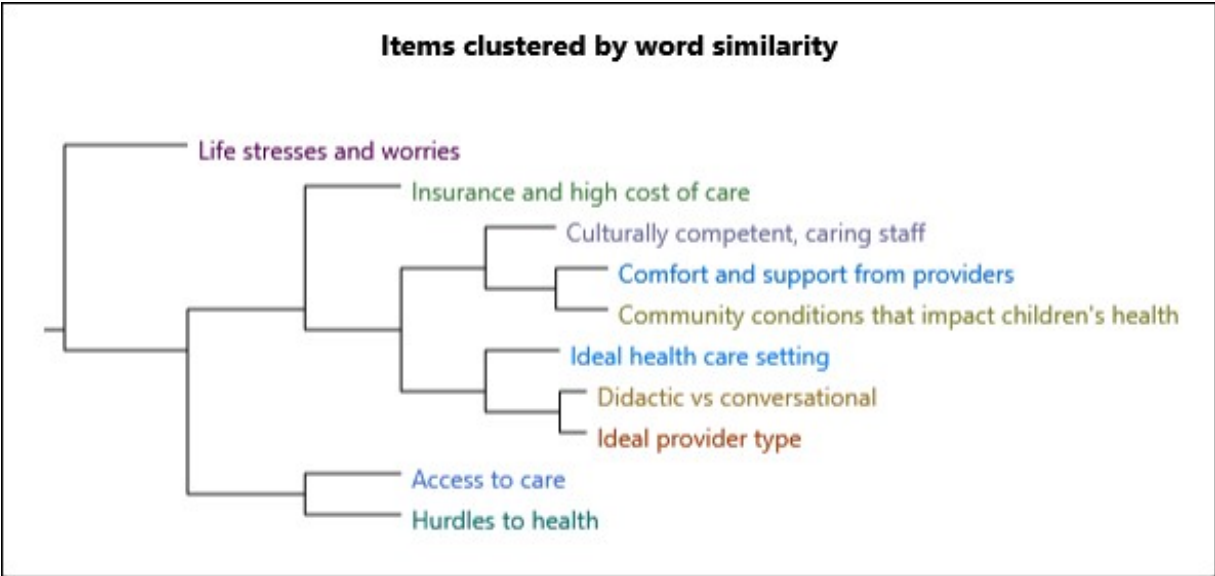
Mothers/Maternal Health Focus Groups (English-Speaking)

Tabulation of JSI Themes for the Mothers/Maternal Health Groups

Name	Description
Comfort and support from providers	This theme describes participants' level of comfort with discussing their medical issues and need for care with providers. Almost overwhelmingly, the participants indicated that they were comfortable at least bringing up or answering questions from their provider. This was true for discussing all health issues, including their reproductive or sexual health and mental health issues. It was generally agreed that honesty and speaking candidly to providers was the best way forward. However, participants also indicated certain characteristics that prevented them from speaking clearly. First, some felt some discomfort speaking to male providers. Second, some indicated that they would feel more comfortable speaking to their providers if they also had expertise treating children – they felt confined by only having their paediatrician to lean on for this support. Participants also spoke about using their community resources and internet for additional information if they did not receive it from their providers.
Community conditions that impact children's health	This theme outlines the concerns that many women expressed related to having and raising their children in their communities. Concerns that were brought up included community or gang violence, overcrowded and inadequate school facilities, bullying between peers, and unclean environments. Notably, some participants indicated that there is a feeling that several of the same children go to the same doctor, thereby making them reluctant to send their children to these providers for fear they may have too many patients to sufficiently provide them with attention.
Hurdles to health	This theme looks at the main barriers to care that women reported facing. Two main categories stood out 1) the high cost of care and navigating insurance and 2) difficulties accessing care due to social circumstances.
Insurance and high cost of care	This theme describes the financial burden and high costs of care and difficulties navigating insurance. Many women described the following issues with insurance and costs: 1) high and multiple co-pays 2) lack of health insurance 3) insurance not covering required medication or only generics 4) staff lacking sufficient knowledge of insurance and what care will cost patients
Access to care	This theme describes the difficulties that women faced while accessing care in addition to financial constraints. While women stated that they could access contraception and prenatal care, they often indicated that they would access urgent care or emergency rooms given restrictions related to their lives, such as inability to access transportation or get time off from work.

Ideal health care setting	This theme describes the characteristics that women looked for in their ideal health care setting. The participants specifically claimed the following as part of their ideal health care setting 1) a facility that provided more amenities and care for their babies and children 2) facilities that were comfortable and welcoming 3) staff who were friendly and caring (expanded on further in other themes) 4) a health care setting that was more easily accessible. Cost was also mentioned in relation to the ideal health care setting, though elaborated upon below. Participants complained mainly that the biggest drawbacks with providers now were lack of consistent staff, staff that spoke dismissively of their concerns, and long wait times and double-booked appointments.
Ideal provider type	This theme looks at the characteristics that women described that they desired in their ideal provider. Participants described that their ideal provider be part of a staff that is 1) culturally competent and caring 2) speaks to them with knowledge and authority yet is caring and knows who they are 3) pays attention to them and gives them the time they require to voice their concerns
Life stresses and worries	This theme describes the general life stresses that impact how these women view healthcare and their access to it. Some of the major stresses that women brought up included: 1) lack of financial stability and financial anxiety, also related to unstable or inadequate employment 2) low education standards and the desire for further advancement 3) the desire for more community and social support for their physical and mental health

Dendrogram of Mothers/Maternal Health Themes



Synthesis and Analysis

While our synthesis and analysis of the focus groups of the maternal health groups resulted in similar themes as the original report, two findings may change the emphasis of the recommendations suggested in the original report.

First and foremost, participants were deeply concerned with the hurdles to health and barriers to access to care. Time and again, the issues related to the high costs of care, multiple co-pays, and lack of adequate coverage or navigating insurance was brought up. This anxiety was often and clearly related to their life worries, namely financial and lack of stable employment and flexible schedules allowing them time to get the care they needed.

Participants also expressed frustration that providers were unaware of what insurance did or did not cover, and felt an acute lack of support in this regard. However, this frustration should also rightly be placed on the insurers as well – they decide what is covered and at what level, and how they explain that to their subscribers and members.

- *For me, personally, with me having asthma, I've ran into situations where my insurance will pay for my breathing machine, my nebulizer, but they won't pay for the solution that goes in it. How can you pay for the machine, but you won't pay for the solution? Those two run together. I need the solution to pour into the nebulizer. So, the doctors right now, and I get to the pharmacy, and I have to pay \$100 for the albuterol solution to go inside the nebulizer. They pay for the nebulizer, but not the solution.*
- *If you're going to write out a prescription, and you look at the chart, and you see what type of insurance that I have, these doctors should know what they are not going to pay for, you know what I'm saying? The doctors really need to know okay, well, she has Medicare...Okay, she has Medicaid. The doctor is not going to pay for -- what's the store medicine out there? Promethazine and codeine, because without taking codeine, I have asthma attacks. They won't pay for that either. That's \$87, \$100 for the solution. So, I just think that when the doctors open up the folder, and they look and see what type of insurance we have, you write us out a prescription for medication. When we get to the pharmacy, our insurance doesn't cover it.*
- *I couldn't even pay my credit card payments on time or do something on time to be able to build my credit. And to be able to afford a house, because you want a home for your child, you want somewhere for them to call home, you don't want to rent forever*
- *It's hard to take off work from your pay or you got to take some sick time or take leave without pay just to get to the doctor's office.*

Participants expressed that although they were comfortable speaking to their providers, their interactions often left much to be desired. The women mentioned that they desired a provider who had a good and caring relationship with them. They were less concerned if the provider spoke authoritatively, as long as their concerns were heard. The women however, mentioned numerous instances when their concerns were invalidated or they did not feel seen by their providers. There was recognition of the idea that finding a provider that fit their needs and that of their family was very important.

- *I'm 100 percent comfortable, because I want 100 percent feedback*
- *I don't want a doctor who has to look at my chart and remember who I am or when they last spoke to me, why I'm here.*
- *Some doctors are good for others and may not be for you*
- *Lots of things were just off. I was gaining lots of weight still. I felt like I was -- I started to gain facial hair. And then around that time I wasn't able -- still wasn't able to get pregnant. So, I was on Google, I was like, "My doctor won't listen." So, I was on WebMD and I was like, "Oh, I think I got this." So, I went to my doctor, I said, "I think I have PCOS." And he said, "Oh, no, just keep tracking yourself."*
- *I don't like going to doctor's office where it's like one day, you'll see this doctor, and the next time, you'll see another doctor.*

Suggestions Regarding Original Recommendations

Although the recommendations provided would certainly help the women in the focus groups, there are a few ways in which they may be amplified to better address their needs. The recommendations below better address the financial stress and insecurity and need for providers who are understanding and listen to their concerns.

- **Recommendation 5**, using community health workers and patient navigators, **and Recommendation 7**, providing facilitation for support groups, both advise there be support for the financial and insurance struggles that women encounter. However, it is likely that these solutions do not go far enough to address the underlying anxiety and real concerns women have with the heavy financial burden for care.
 - Go beyond support groups – have actual resources for help, such as financial assistance organizations
 - The cost of health care is an enormous problem well beyond this particular set of recommendations; however, could there be some engagement with insurance companies and possibly employers to rethink the co-payment structures for low income workers and people? At a minimum better explanations and tools (calculators, apps, handouts) and phone assistance (Hotline, etc.) to help explain benefits, restrictions, etc.
 - Provide these tools to practices in order for providers, or more likely their staff, to know which medications are covered for what.
- **Recommendation 1**, promoting the annual women's well visit, and **Recommendation 2**, the *Get up and Move* campaign, would certainly have a positive impact on women.

Fathers Focus Groups

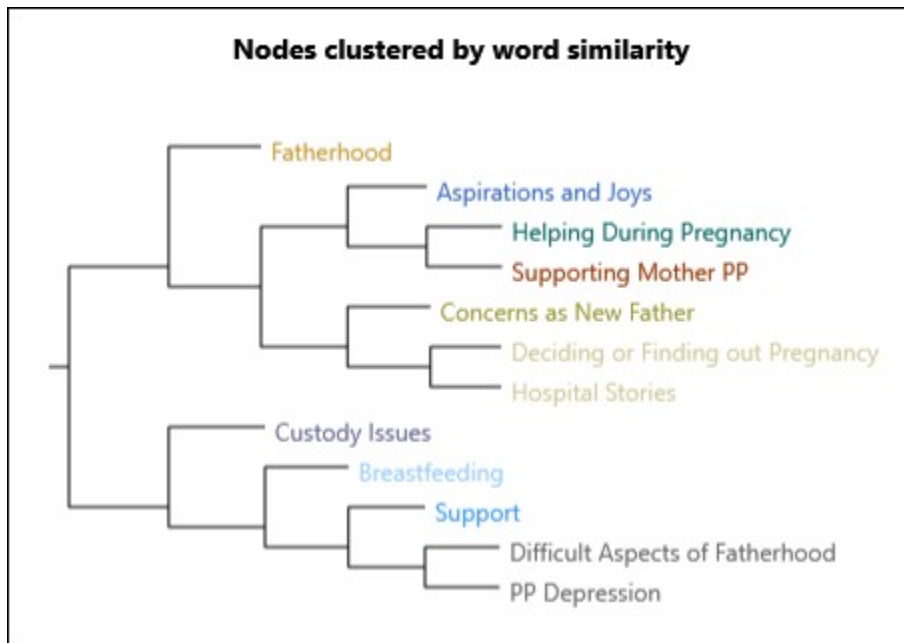
Tabulation of JSI Themes for the Fathers Groups

Name	Description
Thoughts on Becoming an Expecting or New Father	Being a responsible father was often mentioned - being able to make ends meet, and worried about bringing a baby into the world, given the state of things. Several talked about "turning a switch" were they went from worrying about these things to being ready for when the baby came with primary concern for his or her health and well-being.
Fatherhood	
Aspirations and Joys	Fathers described being amazed by their newborns, watching them change day-by-day, being affectionate with them, enjoying "the newborn smell". They wanted to help their kids to be successful, good people; they wanted to be good role models and give them good lives. Fathers who were told their children had mild Downs Syndrome, or prematurity that could affect their development, watched and helped their children grow and develop with abilities beyond what had been predicted by providers.
Custody Issues	For those who were not in a positive relationship with the mother, it was a shock to find out about the pregnancy. These fathers struggled with staying informed as to how the pregnancy was faring. For two fathers, it was weeks or months before they spent time alone with their infants; the babies did not recognize them or seemed to feel uncomfortable around them, which was painful for the fathers. Another father was granted full custody after the baby was born and the mother moved away.
Difficult Aspects of Fatherhood	Worried about making ends meet and unexpected expenses. Having to balance working and being tired when they got home and feeling guilty over not doing enough with the kids. Worried about their kids' health and safety, especially for newborns with health issues. Making sure they are attending to each child's unique personality. Handling it when their kids or wives stress them out. Knowing how and when to discipline their children. For Wilmington group, concerns over social media- porn/predators, violence, and meanness impacting their toddlers and young children through videos or games.
Helping During Pregnancy	With the exception of two who could not due to relationship issues, fathers participated in a parenting class, took the mothers to appointments, were informed about and very concerned over the health of the fetus and mother. They were present at the delivery of their children (unless C-section).
Hospital and Provider Stories	Both groups of fathers had vivid memories of labor and delivery. However, the memories of fathers in the downstate focus group had specific details about interactions with providers and hospitals. Two sub-themes – hospitals and providers - are based on this one focus

	group. They are also specifically talking about difficult, high risk deliveries that they experienced.
Hospitals (Labor/Delivery/NICU)	The fathers observed these complex deliveries and noticed instances of lack of coordination among providers, flawed decision-making, and poor communication with parents. Fathers were sometimes left in the dark. The consensus of the group was that they got higher quality and more personal care (more personal care may have been from nursing and other staff) at upstate hospitals than at local hospitals downstate.
Providers	During the prenatal period, being told by providers that they were a high-risk pregnancy, being sent for additional testing or genetic counselling were very stressful. Particularly difficult was news from specialists about a birth defect or prematurity. One father noted that the specialist did not listen to his wife’s questions. Especially in the hospital, fathers felt anguish and guilt: needing time to process the information and what it meant; concern the specialist was judging their child as “less” and having a lack of hope for the child’s future. Note that an example of a specialist with “poor bedside manner” occurred at an upstate hospital as well.
Supporting Mother Postpartum (PP)	After the birth, fathers continued to help get mothers to appointments, give mom “alone time”, and also helped with feeding. They pitched in more for chores, especially if mother had PP depression. They spent time holding their babies and getting to know them. Appreciative of family members that helped out as well.
Breastfeeding (BF)	Most fathers noted that a lactation consultant provided guidance on breastfeeding in the hospital. Some recalled BF follow-up calls or appointments. It seemed all of the mothers tried breastfeeding, and many really wanted to do it. Some who could not get the baby to latch were able to pump. Some had to switch to formula. Fathers were involved in prepping bottles, cleaning pumps, making sure there were clean towels; they acted as BF coaches. It was difficult and/or stressful when BF was not successful.
PP Depression	Maternal postpartum depression was common, as were wives having to recover from C-sections, and other pregnancy or birth related complications. Sometimes difficult for fathers to know exactly the extent of the depression and how to respond to it. Not knowing how common it was for women to have this condition (being in the focus group helped some realize that), or where to turn for help in serious situations. Having to do more around the house while still working/ensuring making ends meet (especially with wife not working).
Ideas for Supporting Fathers	Strong recognition that there is no choice but to step into fatherhood and start doing the work on one's own. Fathers had a lot of information about labor & delivery, breast feeding, car seats, and possibly safe sleep (indirect mentions). Could use more information about what to expect as children get older, yet recognize there is only so much that they can take in. Videos in hospitals were mentioned by a couple of fathers; very difficult to absorb because they were tired

and drained. Greater interest in advice than information per se; conversations with peers who've been through or are going through what they are going through as fathers. Time and space dedicated for groups for men; Chat & Chew sessions as example. A father noted that watching sports or similar activity with his friends is not generally considered a time for this type of (in-depth) discussion. Another said that groups and websites and information most often seems geared to women. Suggested names for such groups – Daddy Time, Father Time.

Dendrogram of Fathers Groups Themes



Synthesis and Analysis

We agreed with the thematic analysis of the two fathers’ focus groups provided in the original consultant’s report. There were a few areas in particular that stood out, and some additional insights about them are provided.

Ways to support fathers and provide information or resources for them. Consistent with what we heard from various women’s groups, there is a desire **to connect with peers**; in this case, to have **discussions** about fatherhood, relationships, and the health and development of their children. **Fathers are interested in advice rather than information.** The Chat and Chew format was very successful and participants held it up as an example of something they would consider participating in. We agree that fathers would like to see additional topics covered during prenatal parenting class. We noted the mention of shaken baby, but did not see quite as strong emphasis on this topic as the original analysis. We agree that postpartum depression, and caring for and coping with a newborn/dealing with stress of a crying or sick baby, would be great additions.

- *“It’s just nice to be able to listen to the experiences of others. You know what I mean? Stuff like this. Once a week, my son’s going through this. Mine did this too. Or just someone that’s been through it that can help give the advice and the guidance would be helpful.”*
- *“I went to all the classes I could, [name] and I. I didn’t have a father figure in my life, but just because you see and you experience fathers doesn’t mean you know anything, so I did that. And kind of did that also because her doctor wanted to do the more class you get, the more points you get, a better store program. So, he’s like, “I’m going to give you points.” I went to all the classes. I wish I was in more classes. I mean I know they’re geared to the mother, but I wish there had been some for the father of the child, especially with discipline and stuff.”*
- *“We need pamphlets. When you go to the hospital, all those pamphlets are for the woman. Ain’t nothing there for you.”*

Post-partum depression was commonly noted by men in both focus groups. It was not always easy for them to recognize, at first, the difference between recovery from delivery and a more substantial problem, nor to know what to do about it. Several mothers were also recovering from C-sections and other complications of labor and delivery. PP depression put additional stress on the partner’s relationship, added more chores or child-care giving responsibility on the father. In a few seemingly really serious cases, it was not at all clear where to seek help – the local MH hospital seemed a bit too much, but urgent care seemed inadequate (one participant suggested giving out magnets with who to call in a MH emergency).

- *Trying to be kind of supportive because my wife, she went through -- a lot of people don’t understand it, but it’s real, that -- what do they call that -- postpartum. That can get a person to the point where they’re almost out of their mind. Now that time, I had to do everything. You laughing.”*
- *“But like you were saying with the postpartum, I don’t think a lot of people talk about it, but I think it’s a lot more common than not. For the support thing you were saying, I think guys just do things they think they’re doing well, but it may be backfiring.”*
- *“But there’s been times even with the baby, when she had the postpartum with my eight and seven-year olds, my four-year-old, she was fine. I would just, when I seen her, turn, because if anyone ever dealt with postpartum, you can see them turn that corner. So, I just said, “You know what? Just go in a room. Play you some Reason [rap artist]. I got the baby.”*

Memories of labor and delivery were vividly recalled by all the fathers. Especially insightful and vivid were memories of fathers of children who were born prematurely or had other types other complex, high-risk pregnancies/deliveries. These insights were provided by the Milford focus group. Specialist providers were called out as doing a really poor job of delivering “bad” news: no time to absorb the information or discuss the news, not realizing that parents felt like they did something wrong or providing little sense of hope for the future of the child, and giving complicated follow-up instructions that were difficult to remember. Based on their experience in these complex cases, fathers were concerned about the overall quality of care at downstate hospitals compared to upstate hospitals.

Quality seemed to be considered both in terms of how they and the mothers were treated as people, as well as the coordination/communication/clinical skills of, and among, staff.

- *“I was going to say I was excited [about child birth], but the worst part for me was when our first born, we needed to go the NICU right away because she was four weeks early and she wasn’t breathing real good so they took her to the NICU. For me, that was the hardest part. You try to hold your emotions, but my daughter was six pounds premature, which is still a big baby, but I was more scared because NICU you think the babies are extra sick. The doctor scared me; you know what I mean? He said your wife’s pregnant, you’re 35, you’re pretty high risk. It’s scary from day one because you got your neck disorders, and you measure the femur, and the femur’s the wrong size. It’s supposed to be a joyous occasion, but I think the doctors, they do more harm, scaring you.”*
- *“That was one of big issues with my wife’s first pregnancy, was the doctors down here. She had a doctor who kept saying, “Oh, baby’s fine. You’re fine.” Wouldn’t help her or nothing. Go to Beebe or even Milford, they give her a bag of IV fluids. You’re fine. Baby’s okay. You’re good. Then by the time she went to Christina finally, she was already in multiple organ failure. They finally decide to keep her and tried to help her. By then, the baby was already -- they couldn’t find the heartbeat.”*
- *“Yeah. It was crazy. But the one birth that I did have at an upstate hospital, they are so professional. It seemed like they’re more concerned about the father the mother, and the child. They come to me, “Are you okay, sir?” I’m like, “I’m fine.” When you go around here, man, they might tell you to go stand outside and go somewhere. Man, it’s my wife.”*

Suggestions Regarding Recommendations

We find that the three recommendations provided in the original report make sense and are consistent with the results of the focus group thematic analysis. Some further suggestions/refinements are provided below:

Regarding **Recommendation 1**, partnering with the health care system to ensure greater attention is paid to the father during the birthing process: A **quality improvement framework** might allow for quicker changes toward a more patient-centered approach (coupled with better training). A learning collaborative model could be effective for hospital delivery/NICU units and specialists willing to engage in addressing both systems and staff levels of poor communication and coordination for high risk pregnancies. There may already be an existing collaborative to build upon. **Pamphlets (or posters) that are designed for fathers** that include links to local resources are a great idea for placement at prenatal classes or OB/GYN practices. Pamphlets (or posters) could also be placed in hospitals, sent home after the delivery for reference. Labor and delivery are intense times; some fathers noted it was difficult time to process detailed information (e.g., watching videos).

Regarding **Recommendations 2**, services for fathers: There was strong **interest in places where fathers can get together for advice, in a conversational format, with peers; facilitated groups would be welcomed**. The groups need to meet at convenient, familiar locations and be marketed to fathers so they feel welcome to participate (Daddy Time or Father Time were offered as suggested names). Fathers

feel responsible for providing for their family financially. While not discussed in the father focus groups, further thought could be given to the state providing leadership in working with practices, insurers, and/or employers to come up with ways to create payment plans, waiving co-payments, or providing coupons for necessities. **Recommendation 3** is addressing the important and complex issue of father-baby bonding when the parents are estranged. It is innovative to consider ways the health and legal systems could share information on resources, or perhaps even collaborate.

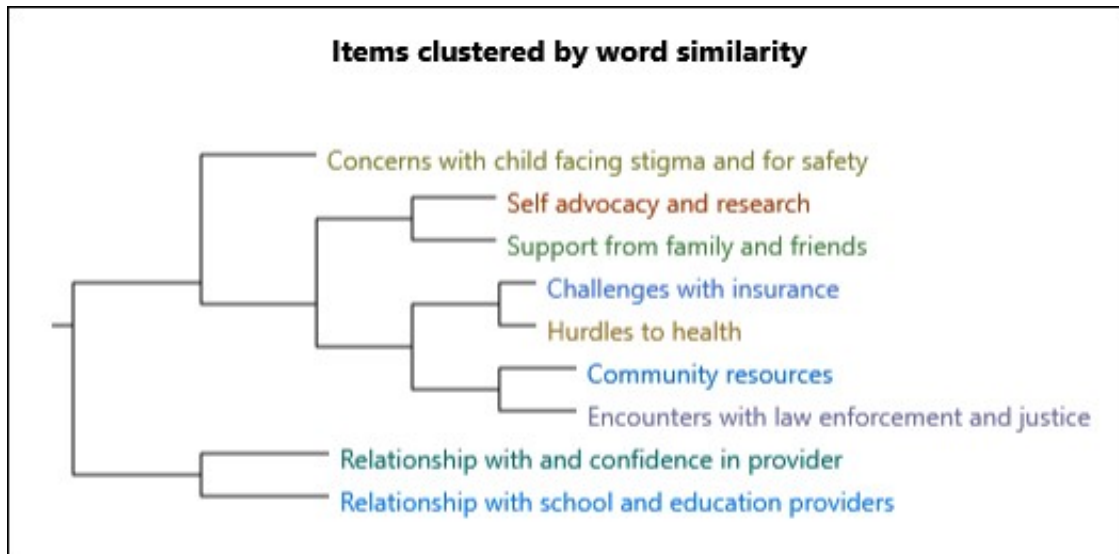
Parents of Children and Youth with Special Health Needs (CYSHN)

Tabulation of JSI Themes for the Parents of CYSHN Groups

Name	Description
Community resources	This theme describes how participants described the support and resources (or lack of) from community sources. Participants described several community sources that provided resources that were helpful to them, their children, and their families. For example, one participant cited that community events and health fairs often had useful connections and information. People also connected with other families dealing with similar issues. On the other hand, participants also discussed the frustration with the lack of certain community resources. One participant specifically brought up the lack of a substance abuse program for children which is desperately needed. Other areas that needed attention are residential treatment centers and respite care. The lack of respite care, in particular, was very taxing on participants.
Concerns with child facing stigma and for safety	This theme describes the concerns and anxieties that parents felt for their children associated with safety risks. One aspect of this was their fear that their children with special needs would not understand dangerous situations and therefore get hurt. The other side of this fear included the stigma their children would face associated with their behavioural issues on top of other characteristics that could lead to bias against them. This theme is also connected to the encounters with law enforcement, explained below.
Encounters with law enforcement and justice	This theme describes in greater detail the fears and frustrations that parents had with law enforcement and the justice system's encounters with their children with special needs. Parents specifically voiced that they felt law enforcement needed to be better trained and equipped to handle special needs children. There was also anger regarding how the judicial system was ineffective in providing their children with the resources they needed. The parents felt that the lack of adequate training for law enforcement put their children in danger and set them up for failure in an unjust system.
Hurdles to health	This theme looks at the main barriers to care that women reported facing. Several parents mentioned the high cost of care and copays. Other difficulties included accessing care due to social circumstances,

	such as lack of transportation. Specific challenges related to insurance are explored below.
Challenges with insurance	Several participants described the challenges they encountered with insurance, beyond the high costs, in relation to their children. Parents always felt like they were ‘fighting’ for medications to be approved and covered. This has been further exacerbated by diagnoses changing – further hindered by the testing being delayed by insurance bureaucracy. Insurance companies identified were Medicare, Blue Cross and Blue Shield, Medicaid, Primark, and Aetna. Participants also explained how certain specialists that children needed may be out of network, thereby exacerbating the frustration and financial burdens.
Relationship with and confidence in provider	This theme looks at what parents looked for in their providers and their interactions with these providers. Parents mentioned that they appreciated when a provider cared about them, their children, and their families, and were particularly knowledgeable about special needs. Parents felt as if they could trust these providers more, especially because getting the right diagnosis and medication was challenging. However, several parents mentioned that it took them some time to find a provider they liked, as many providers lacked the necessary knowledge of special needs, and often brushed aside concerns. Parents also received many resources for help from providers.
Relationship with school and education providers	This theme encompasses both the challenges and support that parents and children received from schools, including individual educators, the school system, and other peers. Participants reported receiving support and resources from their schools and from Head Start that they found particularly useful. However, parents also had negative experiences with educators who lacked patience with their children. Parents also indicated worrying about their children being bullied because of their specific challenges.
Self advocacy and research	This theme describes the resources and support that the participants described as having found themselves. Several parents explained that in their interactions with providers, law enforcement, and schools, they had to be their own advocate for the needs of their children. Several parents also explained using online searches and resources to connect with others and find programs that would be helpful.

Dendrogram of Parents of CYSHN Groups Themes



Analysis and Synthesis

While our synthesis and analysis of the focus groups of the CYSHN groups resulted in similar themes as the original report, the following finding may change the emphasis of the recommendations suggested in the original report.

- 1) Participants were deeply concerned with the safety of their children, particularly teenage boys, given the stigma they would face from others, and particularly from law enforcement. The participants described harrowing events that traumatized both them and their families, indicating clearly that they did not feel safe relying on the judicial system to help them.
 - a. *I deal with a lot of police with my son and I think they need to be aware and trained how to deal with kids...that have special needs. You know what I mean? Dealing with a lot of stuff...Learn how to approach them. They approached him not knowing the state of mind that he's in. He hears voices, he sees them. So when they approach him, they don't look for them... I think the cops need to know -- they need to be trained how to cope with kids like with him. And adults.*
 - b. *I called a lot of people, but when you just going through so much at one time you don't know who to call. I always had the cops at my house. Like one time I had nine state troopers and two cops in front of my house for one child.*
 - c. *Parents press charges on them, but then when you press charges on them, if they have a mental health diagnosis why are we pressing charges on someone who we have documentation saying there is a mental issue, it's not a criminal issue? But we want to press charges on them which then starts another issue I have because now you are building them up to go into the judicial system so when they turn 18 they no longer have a mental health issue, they now have a criminal issue when all along we should have*

been dealing with the mental health issue at hand. The state of Delaware has done a huge disservice to every family represented.

- 2) *Participants uniformly had difficulty with insurance: restrictions, out-of-pocket expenses, and delays accessing needed care until needed approvals were received.*
- a. *“See, my only problem is that if [name] goes to see one doctor and this doctor and that doctor, they have a \$50 co-pay, for this doctor, \$50 co-pay for this doctor, and a \$50 co-pay for this doctor. So I can’t go see every single...I’m like, let me schedule one this week because I am getting a co-pay for each doctor, each appointment. So it’s easier when you have assistance.”*
 - b. *“Yeah, I think it’s because I just don’t mind it because [name] has my insurance and his dad is secondary, so whatever mine don’t cover his dad’s will cover.”*
 - c. *“Just the insurance companies in general are my biggest issue. There’s so much red tape. Just to get things approved. There’s special equipment or there’s special medication, whatever it may be. In most cases I would assume the doctor wouldn’t prescribe it if it wasn’t something that was needed. If your kid’s six-foot-tall and he needs a special brace to fit his frame how are you going to (inaudible) with an insurance company who says oh, he doesn’t really need that. Obviously, he does. So that is my biggest issue. I feel like I am always fighting the insurance company about something.”*

Appendix:

Recommendations Provided in the Original Consultant's Report

Women in the Preconception Period

Original Consultant's Recommendations

The consultant offers 10 recommendations based on the findings of this focus group study:

1. Continue to address walkable, bikeable issues in Sussex County and violence/safety concerns in Wilmington. Provide options until these environmental conditions change, such as forming mall-walking clubs or partnering with businesses to provide work-wellness programs.
2. Develop a campaign using a local African American celebrity spokeswoman who could demonstrate healthy lifestyle behaviors, food preparation, exercise options, and weight management, as well as provide encouragement and motivational tips, and show results. The spokesperson can be promoted via social media and engage followers.
3. Encourage health providers to ask their patients to view training videos that provide additional information they need. The above campaign could be accessed or recommended by health providers.
4. Some consideration might be given to developing telehealth options for women who are downstate and for women who commute out of state or are unable to get to doctors during regular office hours. This could cut down on women skipping needed appointments, dissatisfaction, or going to out-of-network doctors or walk-in centers for care.
5. Consider developing a shopping-center concept for African American women, following the suggestions of the groups. It could include all health providers, Medicaid resources, behavioral health specialists, and wellness coaches. Consider working with Federally Qualified Health Centers, like Henrietta Johnson Medical Center in Wilmington and La Red Medical Center in Sussex County to operate these women's centers, perhaps as satellite locations. The health centers could also market the annual well-woman visit and encourage women to receive these checkups. The women's centers could provide more options for women to have health providers of color, who will speak with them about their reproductive life plans as well as issues and concerns pertaining to sexuality.
6. The Division of Public Health can follow up with the women of the focus groups by providing them with more information on the annual well-woman visits. In addition, greater promotion of this option should occur in communities, targeting African American women (shopping centers, movie theaters, day cares, churches, community centers, colleges and universities, public libraries, etc.).
7. Doctors could be encouraged to develop payment plans for some patients to address costs issues. Eventually the patients will have to pay. Perhaps the Division of Public Health could partner with a foundation to establish a fund with foundation dollars for working women who meet certain eligibility criteria to defer some of their costs.
8. It may be helpful to develop a campaign to promote self-care and options for mental health to address the stigma in black community of behavioral health disorders and treatment.

9. Encourage the development of peer support groups for African American women in Delaware. Partner with existing groups like the National Coalition of 100 Black Women — DE Chapter, the Wilmington Urban League, The Links, sororities, and large churches who could help sponsor or host these groups. Different support groups are needed: support groups for women on life planning, health and wellness, and mental health, as well as support groups for families who want to learn more about specific chronic illnesses like asthma, diabetes, etc.
10. Encourage institutions of higher learning to develop a certification in trauma-informed approaches in health care.

Mothers

Original Consultant's Recommendations

The consultant offers 7 recommendations based on the findings of this focus group study:

1. The Division of Public Health (DPH) should consider doing more to promote the annual women's well-visit eligibility and what is covered. Promotions can be made online since the women use the internet, or with a cellphone app since all women have access to cellphones.
2. DPH should consider revitalizing the campaign that DHSS launched a few years ago — *Get up and Move*, but geared toward women and reaching them where they are with a cellphone app or on the internet, to address weight management, exercise, stress, anxiety, and depression. In addition, other sources of the information should be made available to women who do not have cellphone or Internet access, to promote the concepts and ways for women to track their progress or get feedback. Information should be made available in Spanish and English, with women spokespeople of different ages, ethnicities, and cultural backgrounds.
3. Some thought could be given to establishing one-stop medical offices geared toward women, which can also include more women health providers and specialists, as well as offer a safe place for undocumented women to seek health care.
4. Physician training could be offered to help providers increase their attentiveness, listening skills, and cultural sensitivity. With male doctors, some training could also be offered to help them learn how to have conversations with women patients on issues related to their sexuality so that comfort can be increased between patient and provider on these topics.
5. Community health workers could be engaged to help women who need help getting to their medical appointments with low-cost/no-cost transportation options. Health navigators should be put in place to provide assistance to English- and Spanish-speaking women on insurance questions or for help resolving complex insurance eligibility problems. A hotline could be established for this purpose.
6. Community safety is a major issue for women in Wilmington and Sussex County. More needs to be done to ensure safe recreational opportunities for women and their children. Partnerships with the counties to provide safe parks and recreational areas similar to the Bear-Glasgow park as well as subsidies for Boys & Girls Clubs for single working women could be a help. The state could do more to invest in community centers with free programming for women and youth.
7. Financial insecurity and high cost of living are concerns for all women, along with concerns about the well-being of their families. Support and discussion groups could be sponsored by the DPH — perhaps a women-wellness series — where women could drop in for free facilitator-led discussion groups or workshops on topics related to these issues and ways to manage stress, anxiety, depression, health and wellness, finances, etc. There may be opportunities for women who are interested to receive training on how to moderate a group. These support/discussion groups should be offered in communities and locations where women can go with their

children, such as the Boys & Girls Clubs, Children and Families First, Latin American Community Center, First State Community Action, the Federally Qualified Health Centers (Henrietta Johnson Medical Center, Westside, and La Red Health Center), public libraries, and other similar community locations.

Fathers

Original Consultant's Recommendations

1. The Division of Public Health should partner with the health care system to ensure that greater attention is paid to the father during the birthing process, in the period immediately following delivery, and perhaps through the first year.
 - a. DPH could encourage training for doctors to improve their bedside manner when interacting with fathers. Pamphlets and training videos geared toward fathers could be developed and placed in hospital delivery rooms.
 - b. Pamphlets should also include where fathers can go for additional resources, like the Fatherhood and Family Coalition (www.dffcdads.org) and the Money School (www.dfli.org) for free financial management workshops, as well as current resources such as the Delaware Thrives website (<https://dethrives.com>), which offers information on developmental milestones.
 - c. Finally, parenting classes could be expanded to include post-partum depression and other important topics, including caring and coping with a newborn, shaken baby syndrome, discipline, developmental milestones, internet safety, new family dynamics, and health and nutrition.
2. DPH could partner with existing organizations to understand the services that currently exist for fathers with respect to parenting, education and training, and support groups.
 - a. DPH could encourage the formation of appropriate support groups on suggested topics, to include but not necessarily limited to post-partum depression, discipline, dealing with teenagers, communication with children, family relationships, dealing with financial stress, and managing in a digital world.

Collaborations between DPH and community-based organizations such as Children and Families First, Brandywine Counseling, the Fatherhood and Family Coalition, and Delaware Reinvestment Action Council are suggested. DPH could work with these organizations to provide support groups for fathers that are accessible statewide, perhaps even through libraries or state service centers.

DPH could review the social and legal services available for single fathers, to encourage their ongoing support and involvement with their children. This may include developing specific marketing materials that promote services that may be helpful to single fathers, such as legal resources and relationship counseling.

Parents of Children with Special Health Needs

Original Consultant's Recommendations

The following recommendations are suggested by the consultant based on the findings of these focus groups:

1. More specialists are needed downstate. More information about specific special needs should be made available for parents of special-needs children. There may be an opportunity to develop videos or apps about specific conditions as well as internet resources that parents could seek, in both English and Spanish.
2. Doctors and health care providers can have greater awareness and sensitivity of the number of referrals and cost of co-pays. This may be something that Community Health Workers or Health Navigators can assist with. Services can be provided in English and Spanish.
3. Cultural sensitivity training should be provided to health providers to improve relationships between Latino women and the care of their children.
4. Consider expanding public transportation services for women with special-needs children who have multiple children, so they can make their appointments.
5. Consider establishing a medical facility where parents can receive multiple medical services for their children as well as support and discussion groups and medical information.
6. Consider partnering with Federally Qualified Health Centers and other community agencies to provide respite services and support/discussion groups. It may be helpful to form a service like the Parent Information Center or Voices in downstate locations.
7. Training should be provided to public safety officials regarding adult children with special health needs, to ensure the youth are not wrongfully prosecuted.
8. As with earlier recommendations, greater investment needs to be made in public safety for residents and more recreational programs and community services for parents of special-needs children and youth.