



# Chat and Chew Focus Group Study

June 2024

A statewide Focus Group Study to meet the Title V needs assessment requirements related to the Delaware Division of Public Health (DPH) Maternal and Child Health program.

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Goeins-Williams Associates, Inc. for  
A B & C

**Table of Contents**  
**A B & C**  
**DDPHIM TITLE V NEEDS ASSESSMENT**  
**CHAT AND CHEW FOCUS GROUP STUDY**  
**JUNE 2024**

<b>Executive Summary</b> .....	<b>1</b>
Introduction.....	1
Major Findings - Adolescent Boys and Girls .....	6
Conclusion .....	12
Consultant’s Recommendations .....	13
Major Findings – Fathers/Partners General Health .....	14
Conclusion .....	23
Consultant’s Recommendations .....	24
Major Findings – Women’s General Health.....	25
Conclusion .....	37
Consultant’s Recommendations .....	38
Major Findings – Preconception .....	40
Conclusion .....	49
Consultant’s Recommendations .....	51
Major Findings – Children and Youth with Special Health Needs .....	52
Conclusion .....	65
Consultant’s Recommendations .....	66
 <b>Attachment: Focus Group Questionnaires and Discussion Guides</b> .....	 <b>68</b>

**A B & C**  
**DDPHIM Title V Needs Assessment**  
**CHAT AND CHEW**  
**FOCUS GROUP STUDY**  
**JUNE 2024**

**Executive Summary**

**Introduction**

AB & C engaged Goeins-Williams Associates, Inc., (GWA), the Consultant, to plan and conduct a total of 14 focus groups statewide to meet the Title V needs assessment requirements related to the Delaware Division of Public Health (DPH) Maternal and Child Health program. DPH requested that ABC follow the format *Chat and Chews* Focus Group project that was completed by ABC with some assistance from GWA in 2019. The project start date was in February and the last focus group session was completed May 13, 2024. Dr. Devona Williams, Principal, GWA, led this study with the assistance of Executive Assistant, Jayden Carr, GWA Associate, Catalina Natalini.

GWA conducted fifteen statewide focus groups to meet the specifications of DPH. The focus groups included teens, fathers/partners, mothers of children and youth with special health needs, Black women without children, and women with children. Three focus groups were conducted in Spanish. Five groups were canceled and rescheduled because of the inability to recruit enough participants or failure of enough participants to attend once recruited. Two sessions were rescheduled as Zoom sessions to address challenges of participants in finding day care or transportation. The chart below summarizes the details for the focus groups and the required specifications:

Group Description	Group Makeup	County	Location	Dates and Times	Confirmed Recruits	Respondents
<b>Women’s General Health</b>	Spanish speaking women with children, ages 18 to 44 who meet Federal income guidelines and reside in specified zip codes.	New Castle	Rt. 9 Public Library, New Castle	3/12/24, 6:00 pm to 8:00 pm	12	11
<b>Teens General Health</b>	Adolescent girls, ages 13 to 17 who reside in specified zip codes in the county	New Castle	H. Fletcher Brown Boys & Girls Club. Wilmington	3/14/24, 4:15 pm to 5:45 pm	10	11

<b>Children and Youth with Special Health Needs</b>	Spanish speaking mothers of special needs children with physical and behavioral health diagnoses, ages birth to 18 who reside in the county.	New Castle	Rt. 9 Public Library, New Castle	3/18/24, 6:00 pm – 8:00 pm	9	8
<b>Fathers/Partners General Health</b>	Fathers/Partners, ages 18 to 44 with children ages birth to 8 who reside in specified zip codes in the County.	New Castle	Rt. 9 Public Library, New Castle	4/2/24, 5:45 pm to 7:45 pm	9	8
<b>Teens General Health</b>	Adolescent boys, ages 13 to 17 who reside in specified zip codes in the county	Sussex	Boys and Girls Clubs, Seaford	4/3/24, 4:30 pm to 6:00 pm	11	9
<b>Women's General Health</b>	Women with children, ages 18 to 44 who meet Federal income guidelines and reside in specified zip codes.	Kent	Dover Public Library, Dover	4/4/24, 5:45 pm to 7:45 pm	8	8
<b>Children and Youth with Special Health Needs</b>	Mothers of special needs children with physical and behavioral health diagnoses, ages birth to 18 who reside in the county	New Castle	Rt. 9 Public Library, New Castle	4/9/24, 5:45 pm to 7:45 pm	9	7
<b>Preconception</b>	Black women ages 18 to 44, not pregnant, without children, who meet Federal income guidelines, have certain health conditions, and reside in the County*	Kent/Sussex	Milford Public Library, Milford	4/11, 4:45 pm to 6:30 pm	6	3

<b>Women's General Health</b>	Women with children, ages 18 to 44 who meet Federal income guidelines and reside in specified zip codes in the county.	New Castle	Rt. 9 Public Library, New Castle	4/16/24, 5:45 pm to 7:45 pm	13	13
<b>Children and Youth with Special Health Needs</b>	Mothers of special needs children with physical and behavioral health diagnoses, ages birth to 18 who reside in the county.	Kent/Sussex	Dover Public Library, Dover	4/17/24, 5:45 pm to 7:45 pm	12	9
<b>Children and Youth with Special Health Needs</b>	Spanish speaking mothers of special needs children with physical and behavioral health diagnoses, ages birth to 18 who reside in the county.	Sussex	Georgetown Public Library, Georgetown	4/18/24, 5:00 pm to 7:00 pm	8	8
<b>Preconception</b>	Black women ages 18 to 44, not pregnant, without children, who meet Federal income guidelines, have certain health conditions, and reside in the County.	New Castle	Henrietta Johnson Health Center, Wilmington,	4/24/24, 5:00 pm to 7:00 pm	11	8
<b>Fathers/Partners General Health</b>	Fathers/Partners, ages 18 to 44 with children ages birth to 8 who reside in specified zip codes in the counties.	Kent/Sussex	Milford Public Library, Milford	5/8/24, 4:45 pm to 6:30 pm	11	10
<b>Women's General Health (Rescheduled as a Zoom meeting)</b>	Women with children, ages 18 to 44 who meet Federal income guidelines and reside in specified zip codes in the county.	Sussex	Zoom meeting	5/9/24, 6:00 pm to 8:00 pm	10	9

<b>*Preconception (Zoom make-up session)</b>	Black women ages 18 to 44, not pregnant, without children, who meet Federal income guidelines, have certain health conditions, and reside in the County.	Kent/Sussex	Zoom meeting	5/13/24, 6:00 pm to 8:00 pm	8	7
<b>TOTALS</b>					<b>136</b>	<b>129</b>

One hundred thirty-six participants/respondents were recruited and confirmed by GWA through community networks and screened to verify their eligibility to participate in each of the focus groups. GWA worked with the ABC team to coordinate and develop appropriate recruitment flyers for the different focus groups. One hundred and twenty-nine individuals participated as respondents in the focus groups with a goal of having ten respondents participating in each group. Respondents were provided with a \$150 cash incentive and boxed meal (in-person only) for their participation. The general demographic characteristics of each focus group is included in the Major Findings for each of the focus group categories: Teen General Health, Fathers/Partners General Health, Women’s General Health, Preconception, and Children and Youth with Special Health Needs.

The Consultant prepared comprehensive discussion guides for each of the focus group categories which were approved by the client. A survey questionnaire was included in each discussion guide. The focus group discussion guides and questionnaires were translated into Spanish after approval. After the first three focus groups, the Consultant worked with the client to revise all of the discussion guides and survey questionnaires (in English, only) to streamline information collected from the questionnaire and allow more time for discussion. This added about a two-week delay in the scheduling and recruitment for the focus groups. The focus group guide topics included: Introduction, Healthy Behaviors, Experiences of Fathers During and After Pregnancy, Relationships, Resources in the Community, Mental Health, Transition to Adult Care, Mentoring, Bullying, Social Determinants of Health, and Wrap-up. The topics and questions for the discussion guides varied based on the categories. (The focus group discussion guides are contained in the attachment).

Dr. Devona Williams, Principal, GWA, and author of this report, moderated the English focus group discussions using the question guides, asking additional probing questions as appropriate, and resourced the three groups that were conducted in Spanish. Jayden Carr, GWA Special Assistant, co-moderated the teen boys focus group and acted as the virtual and onsite resource, assisting with registration, observation of the process, and note taking for the focus groups. Catalina Natalini assisted with the recruitment of Spanish speaking women and moderated the three focus groups in Spanish, co-authored the Spanish focus group reports which were translated back into English and finalized by Dr. Williams. Toni Sinibaldi, Krissy McMahon, and Alex Parkowski of AB C managed the project and were also



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observers in the focus groups along with DPH clients who attended different focus group sessions. The focus group discussions were recorded and transcribed, and participants were advised, accordingly.

The next section of the report includes the Major Findings for each category of focus groups with a conclusion and recommendations.

## Major Findings - Adolescent Boys and Girls

### General Characteristics of the Focus Groups

New Castle County - Adolescent Girls	Sussex County - Adolescent Boys
<p>The focus group was held on March 14, and was composed of 11 girls recruited by the Boys &amp; Girls Club of Wilmington in partnership with GWA with a parent or guardian’s permission. The focus group was held on site at the Fletcher Boys and Girls Club in Wilmington. Everyone participated but the younger girls were somewhat intimidated by the older girls and quiet. The girls were somewhat reserved early in the discussion and grew more comfortable with the conversation as time progressed. All girls completed the questionnaire prior to the discussion.</p>	<p>The focus group was held on April 3. And was composed of 9 boys recruited by the Boys &amp; Girls Club of Wilmington in partnership with GWA with a parent or guardian’s permission. The focus group was held on site at the Boys and Girls Club in Seaford. Everyone participated but the younger boys were quiet. The boys participated actively in the conversation which was more animated with the shortened questionnaire. All boys completed the questionnaire prior to the discussion.</p>

### Demographics

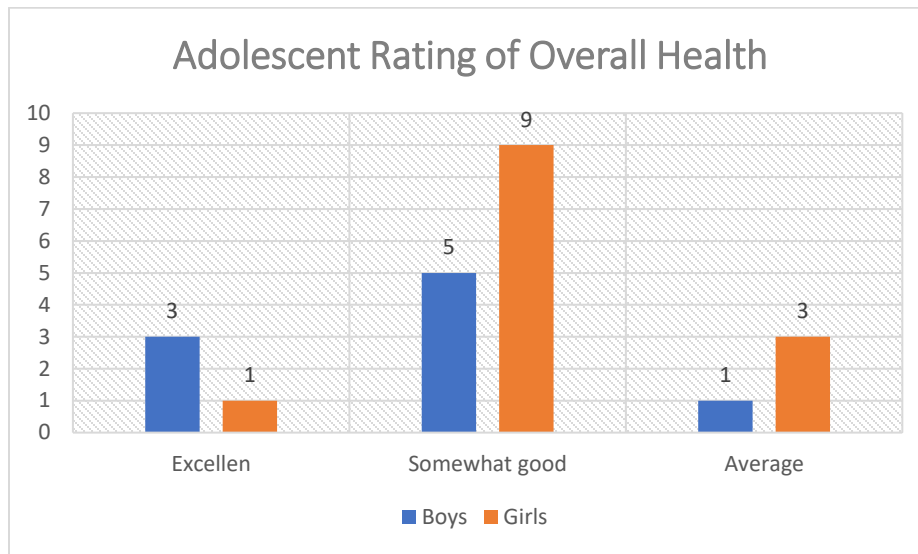
- Overall, fifteen to sixteen was the largest age group of the adolescent focus group participants (53%). All but two of the boys have access to a cell phone. Thirty percent of the adolescents work part-time. Three boys and three girls work part time.
- All teen participants were African American or Black.
- The girls were ages 13 to 17 and in grades 7 through 12. They reside in New Castle County from these zip codes: Wilmington 19802 (seven participants), and one participant each from Wilmington 19801, Wilmington 19805, Wilmington 19806, and New Castle 19720.
- The boys were ages 13 to 16 and in grades 8 through 11. They reside in Sussex County from these zip codes: Seaford 19973 (eight participants), and one participant each from Greenwood 19950. The boys were ages 13 to 16 and in grades 8 through 11. They reside in Sussex County from these zip codes: Seaford 19973 (eight participants), and one participant each from Greenwood 19950.

### Healthy Behaviors

#### *Rating of health*

- The adolescents rate their health from average to excellent with most who rate their health as somewhat good as shown in the chart that follows.





Two of the twenty adolescents reported having a chronic health condition.

#### *Meaning of healthy*

- The boys said healthy means staying in good physical shape and eating well. The girls identified several things they could do to improve their health such as sleeping and eating better, having a schedule, avoiding stress, limiting their time on the phone, and having an open mind.
- The girls responded that being healthy is taking care of ones-self physically, mentally, and emotionally. It also means taking care of your body and doing things to prevent illness, stay fit, eat healthy, avoid drugs, be in a safe environment, and have balance (mentally and physically).

#### *Actions they take to stay healthy*

- The boys join sport teams, try to eat healthy, drink water, are aware of their mental health needs, and stay away from bad people and drugs. The boys all agreed that they eat too much fast food. They feel they play too many video games and should not skip [sports] practice. They all agreed that they should avoid hanging around the *wrong people* who smoke, use, or sell drugs, and gang bangers.
- The girls responded they try to eat healthy, exercise, play sports, get proper rest, and stay away from drugs. The girls said to be healthier they try to limit snacking, increase their activity, drink more water, put the phone away, get more sleep, learn to set boundaries, and go to school every day.
- The boys suggested having a food stamp card, going to the gym more often, and going outside instead of playing video games would improve their health. They suggested having a safe recreational center or basketball court that is accessible in Seaford.

#### *Unhealthy things they do*

- The girls eat junk food, smoke, stay on social media, not exercise, and get poor sleep. None of the teen boys used tobacco products or vapes, and only one girl reported that she did.

#### *Support for being healthy*

- The teen boys and girls have support at home to be healthy. The boys said they go to a variety of sources for their health questions including their doctor, physical therapist, mom, dad, school wellness center, school sports trainer, and the Internet. The girls said they and their friends go to their parents or doctor, hospital, or wellness center.
- Fifty-six percent of boys and fifty-five percent of girls are aware that a School Based Health Centers (SBHC) is located within each high school in Delaware. Only forty-four percent of boys, and forty-five percent of girls are aware that the SBHC offers physical exams, treatment for minor illnesses and injuries, health screenings, young women's health, reproductive health, immunizations, nutrition, and weight management.

#### *Comfort discussing health issues with providers*

- Most of the boys were comfortable about discussing most of their health concerns with their health provider. About half of the boys were not comfortable talking with their health care provider about depression/anxiety/stress. They were also less comfortable discussing mental health issues and sexually transmitted diseases.
- Most girls were comfortable discussing personal questions with their healthcare provider regarding their weight, chronic conditions, and contraception. Almost half of the girls were not comfortable talking with their health care provider about tobacco use and half of the girls were uncomfortable discussing recreational drug use. Forty-three percent of the girls are not comfortable discussing depression, anxiety, and stress and nearly 30% are not comfortable discussing addiction services. Additionally, 20% of the girls were not comfortable discussing alcohol use, mental health issues, sexually transmitted diseases, or domestic partner violence.

#### *Family friendly provider*

- The few girls who responded to this question thought their health provider was family friendly. Eight of the nine boys said their health provider is family friendly. Reasons given were because they remember their names, ask questions, and the tone of their voice.

#### *Greatest influence*

- Almost all the girls said a family member (mom, dad, or sister) or coach is the greatest influence on their health and one participant said, "herself." Family members set examples of healthy practices and are straightforward and honest about what they should be doing to stay healthy.
- The boys' responses were mixed as to the greatest influence on their health. Two boys each responded they did not know, and that sports, and they personally have the most influence.

## Adolescent Transition to Adult Care

### *Term - Health Care Transition*

- None of the boys was familiar with the term and most girls were not familiar with the term. Nearly half of the girls thought it was pointless or did not matter to think about transitioning from adolescent to adult health care. A few of the girls thought it was important to think about it because of how the body changes and to know what is going on with the body.
- Only one girl was aware that her parent/guardian was transitioning her health care to an adult-patient model. Most of the girls said they do not know of any resources related to transitioning to adult health care.

### *Process of transitioning*

- Four of the boys said their parents had begun the process of transitioning their healthcare to adult centered patient care. They emphasized the importance of having to be financially responsible for their own needs.
- Many of the girls had not thought about transitioning to adult care and did not think it was important. The boys shared more thoughts and concerns about finances for buying a house, car, and insurance. They asked about the process for signing up for insurance and how to build credit and why it is important. The boys suggested their relatives as their primary resources for health care transition.

### *Changes to make*

- The girls did not think they needed to make any changes to transition to adult healthcare. However, the boys spoke primarily about their need to take on more responsibility and be more serious with school, their behavior, involvement in sports, faith, and help with siblings.

## Mental Health

### *How they feel*

- The girls said they felt okay, average, all right to good, amazing, and great. Almost all the girls said they have been depressed at one time. When they have been depressed, they manage by listening to music or playing basketball. One girl said she has no one to go to.
- Half of the boys said they were happy or felt good, but the remainder of the group said they were dissatisfied, bored, between happy and sad, or could encourage themselves more. One participant defined happiness as being able to *do the stuff you want, having money, not too many pressures. Money makes me happy.* Everyone in the group agreed that money makes them happy.

### *Feelings about their mental health*

- The boys have a strong sense of the meaning of mental health stating *feeling good for his age and having a strong mindset*. They feel that people around them and relatives can affect their mental health.
- The girls could use some improvement in their mental health. Three quarters of the group said they were stressed, and four participants agreed they feel “bi-polar.” The main causes of stress come from school, work, multi-tasking, becoming an adult, and scheduling. At least one participant is concerned about her future after graduation high school.
- More than half the boys rate their mental health as average and twenty-two percent feel overwhelmed, stressed, or anxious about school or their job or school. Twenty-two percent of the boys have considered seeking help and feel gloomy about half the time.
- More than half the girls also rate their mental health as average and fifty five percent feel overwhelmed, stressed, or anxious about school or their job or school. Thirty five percent of the girls feel gloomy about half the time and forty-four percent feel angry about half of the time.

### *Access to mental health treatment services*

- Two boys have access to a school counselor and one boy participates in the man-up program which he finds beneficial because of the man’s life experience.
- Eight of the eleven girls have used the Wellness Center when they have need mental health treatment and they have found it effective. Other sources of help mentioned are Christiana Care for therapy, a school safe space group, mom, and guidance counselor.
- Forty-four percent of boys and twenty-two percent of girls do not feel comfortable discussing their emotional health with a counselor or mental health professional. Forty-five percent of the girls do not feel they have support of friends and peers regarding their mental health compared to only eleven percent of the boys.

### *Experience with bullying*

- Five girls in the group have been bullied. Two participants shared they were made fun of or bullied for being annoying to other people.
- The boys have experienced bullying through the Internet from strangers and friends with name calling and insulting jokes. One boy commented that this type of bullying has become too normalized, and another said it does not make one feel good after it has happened. Bullying is experienced through cyber bullying and texting.
- The girls said that social media plays a role in anonymous bullying where someone posed as them on social media to attract men.
- Some boys responded that listening to music, getting off the Internet and learning how to block people (on the Internet) would help to reduce cyber bullying.

### *Social media*

- Eight of the nine boys said they use social media, reporting they use Instagram, Tik-Tok and X, but also Face Book and Snap Chat. The boys said they are on social media five hours a day, for the entire day. The boys shared that social media can negatively affect their mental health, hurting their productivity and desensitizing them to negative information. The girls said they are on social media “24/7”, all day long, every day. The girls said they are addicted to social media and stressed out by it.

### *Most important mental health issues for teens*

- The boys feel that bullying, depression, decision making, boredom, interactions with family, and moodiness are the most important mental health issues for teens today. When prompted, participants further agreed that they would be depressed or bored without their phone.
- The girls thought they could take additional actions to manage their mental health including staying to themselves, finding someone to talk to, being more self-aware, and not taking things personally. The girls responded that depression, stress, abandonments, relationship issues, drugs, suicidal thoughts, and internal conflicts are important issues for teens.

### *Mental health stigma*

- Three of the boys had no one to talk to and one said he was not comfortable talking about mental health. The boys said that there is a stigma associated with being a male because one has to be strong, and people could take having mental health issue as a weakness. The boys shared that they have someone to talk to – mostly parents or friends.
- The girls said that teens have problems, are judged, and stereotyped. They said adults and teens are stressed, and Black teens are stereotyped for being angry. The girls suggested better communication and outreach, more understanding and empathy, being less judgmental, and meditation.

### *Available services and resources*

- The boys suggested a recreation center or YMCA in Seaford they could go to. The Boys and Girls Clubs, a teacher, sports, and music were also resources that are available.
- The majority of the girls were not aware of the services and resources that are available.

### **Mentoring**

- Almost half the boys thought that having a mentor would help improve their health and wellbeing because they steer one in the right direction and provide support outside the family. Male mentors give perspective and advice when a dad is not present. Several of the boys indicated they did not have a dad in the home. The boys found mentors through relationships with other children, and through sports. Two of the boys would like to have a mentor. One boy said he does not want to talk to anyone.

- Only two of the girls said they had a mentor. They said mentors motivate them to be better, provide honest feedback, and help them deal with uncertainties. Five girls would like support and guidance from a mentor who they trust and could talk to. Two girls did not think they needed a mentor said either they are fine or can rely on themselves.

## Social determinants of health

### *Current housing situation*

- Although most of the girls said their housing situation was stable, their standard of adequate housing seemed low for some. As one girl said, having a place to sleep at night. Two participants said their housing was not stable and two others reported a health concern of a grandmother and neighborhood safety issue. All the boys responded that their current housing situation is good.

### *Access to healthy food choices*

- For the girls, school appears to be the best source of healthy food choices. Seven of the nine boys said they have healthy food choices. One participant added that he relies on his family to provide healthy food choices.

### *Everyday concerns and worries*

- The boys worry about their families, their future, how to achieve and set goals, money, girls, and other people. Two of the boys do not have any worries. The girls who chose to speak are worried about their safety, being on their own, and their future.
- The boys shared their final concerns about their future and things like getting into college or finding a job. They suggested having a group to discuss their future and how to succeed in life.

## Conclusion

The teens are aware of what it means to be healthy physically and mentally. They are also aware of what to stay away from in order to remain healthy including drugs and junk food. The teens feel that they could do some things to improve their health including for boys hanging around the right crowd, playing less video games, and eating less fast food. For girls getting more sleep, exercise, and staying off of the phone were mentioned.

Both boys and girls have support to stay healthy and are influenced by family members, coaches, and other adults who role model healthy behaviors. The greatest influence on staying healthy for boys appears to be sports, which is also one of their biggest outlets. Girls appear to have higher levels of mental health issues, are depressed, stressed, and have less people to talk to about their issues. Unhappiness for boys appears to be tied to finances and they worry about money. Girls also have fewer resources and are less aware of what is available to them. Girls more than boys are less comfortable discussing mental health issues with their health care providers.

Girls and boys have you used school-based health centers but a significant number of them are not aware of the services that are provided. Teens are on their cell phones and social media constantly. The

girls say they are addicted to their phones and the boys are playing video games. Teens are experiencing cyber bullying which is a source of stress.

The biggest issues for the teens are their mental health and lack of access to free, safe recreation, or people they can confide in. Some of the teens feel there is a stigma associated with seeking help for mental health issues and males and Black girls are stereotyped and judged.

Teams recognize that mentors can be a source of support and provide them with someone to talk to, most of the teens do not have mentors.

For the most part, teens are not aware of what is needed to transition to adult healthcare. This is an area where healthcare providers do more to engage with teens and their parents.

The teens worry about their future, and their safety, and staying away from the wrong crowd and drugs. The boys expressed a greater need to have more access to free recreation facilities. The girls need greater access to and more awareness of the resources that are available to help them with their depression and high levels of stress. The teens could benefit from having group discussions that focus on their future where they learn about finances, opportunities for college, and life skills.

#### **Consultant's Recommendations:**

1. Increase awareness of services offered by the School Based Wellness Centers to teens and make information available on social media where teens would receive the information.
2. Explore the possibility of creating a community center or recreational facility for young males to engage in sports and other activities.
3. Consider providing resources for reducing cyber bullying and promoting mental health in the community that is "stigma-free."
4. Provide greater access to mentors and support systems for those who expressed a need for them.
5. Healthcare providers should do more to initiate conversations with teens and their parents about what is needed for them to transition to adult health care.
6. Provide opportunities for discussion groups for adolescent boys and girls to discuss their futures with different topics such as getting into college or post-high school training, life skills, and financial management.
7. Dr. Devona Williams will consider coming back to discuss health topics or any other topics that the participants find beneficial.

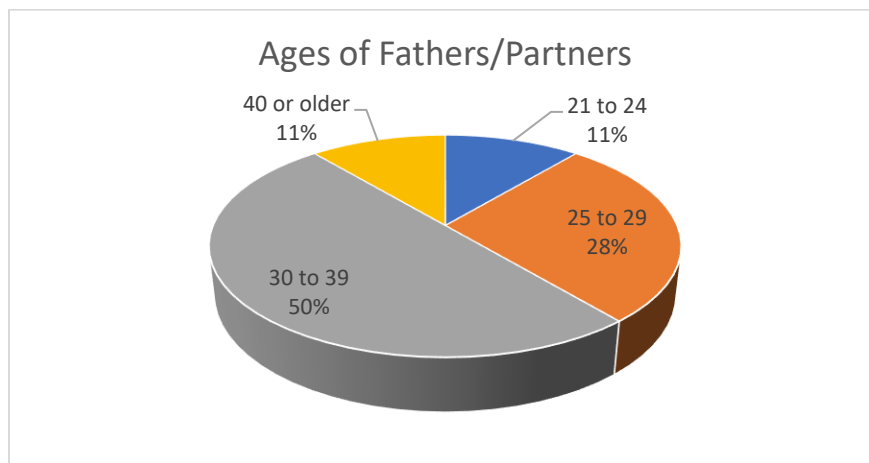
## Major Findings – Fathers/Partners General Health

### General Characteristics of the Focus Groups

New Castle County	Kent/Sussex Counties
<p>The focus group was held on April 2 at the Rt. 9 Public Library in New Castle with eight men from New Castle County. The men were ages 25 to 39 years of age with children ranging in age from infants to teenagers. Five of the men were single parents and not living with a partner, one was married, one lived with his partner, and one did not specify. The fathers had from one to four children each. Two of the fathers had wives or girlfriends who were currently pregnant. The group was racially diverse with five African Americans, two Hispanics, and two Caucasian men. Annual incomes ranged from \$10k to less than \$75k. Educational levels ranged from some high school to college graduates. Everyone completed the questionnaire at the start of the session. The men were honest with their responses and became more open and conversant as the group went on. They enjoyed participating in the discussion and valued what they learned from each other.</p>	<p>The focus group was held on May 8 at the Milford Public Library in Milford with ten men from Kent and Sussex Counties. The men were ages 22 to 44 years of age with children ranging in age from infants to teenagers. The men were both married and unmarried and had from one to four children each. No wives or girlfriends were currently pregnant. Eight of the ten men were African American, one was Hispanic, and the other was South African. Annual incomes ranged from less than \$10k to over \$75k. Educational levels ranged from some high school to college graduates. Everyone completed the questionnaire at the start of the session. The men were forthcoming in their conversation and shared openly with the group. They enjoyed participating in the discussion.</p>

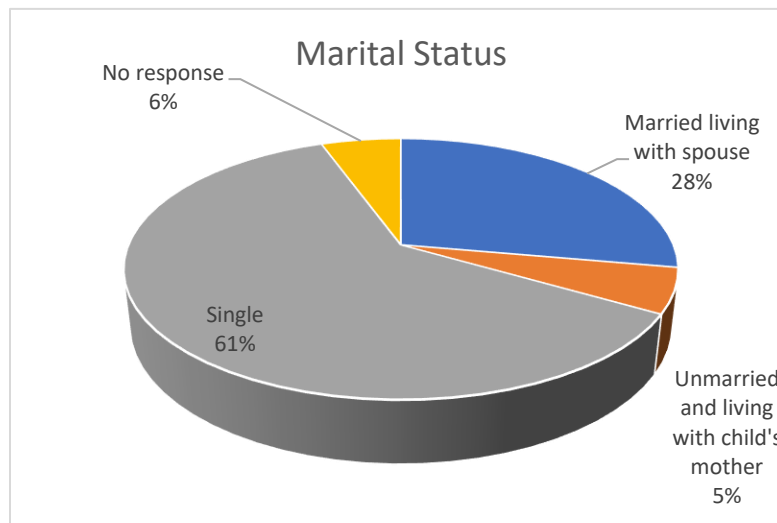
### Demographics

- Ages of fathers and partners are shown in the pie chart below. Half of the participants were between the ages of 30 and 39.

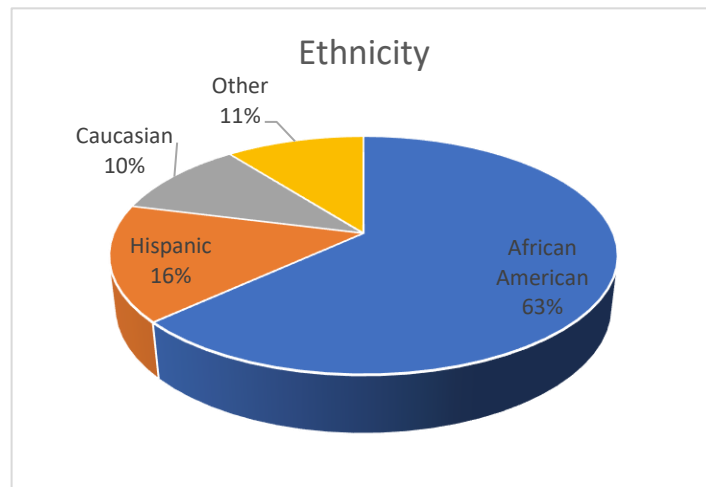




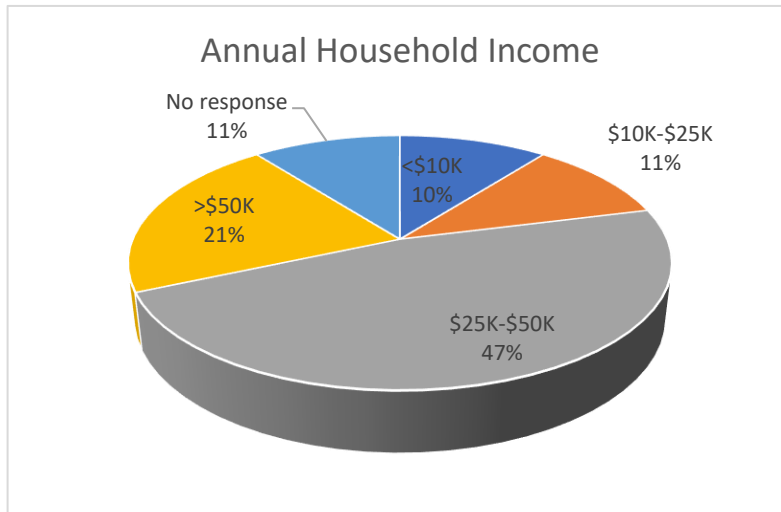
- The zip codes for the New Castle County group: 19802 (5 participants), 19801 (1 participant), and 19720 (2 participants). Zip codes for the Kent/Sussex Counties group: 19901 (3 participants), 19904 (1 participant), 19973 (4 participants), 19933 (1 participant), and 19947 (1 participant).
- All respondents in both groups have a cell phone.
- Marital status - Sixty-one percent of respondents are single fathers, not married to the child's mother. Only twenty-eight percent of respondents are married and living with their child's mother.



- Ethnic breakdown: Sixty-three percent of respondents were African American. The other ethnicities were Haitian and South African.



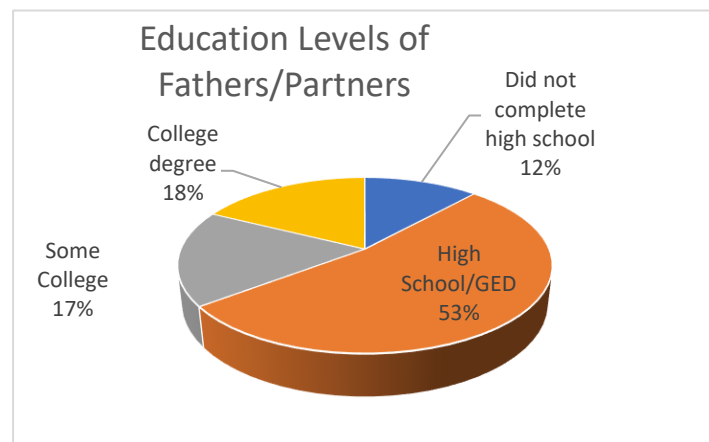
- Annual household income.



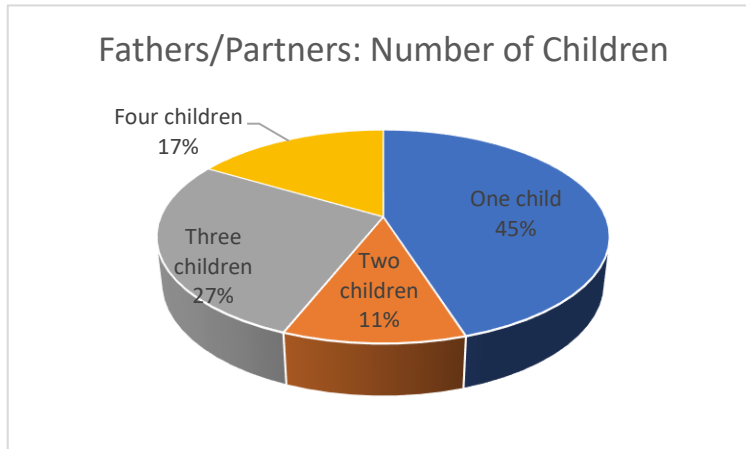
Two respondents' annual household income is less than \$10k and two reported incomes of \$10,000 - \$25,000. Nine respondents have annual household incomes of \$25,000 - \$50,000. Four respondents earn more than \$50,000 annually.

- Employment situation.
  - Sixty-one percent of respondents are employed full-time.
  - Twenty-two percent of respondents are employed part-time.
  - Eleven percent of respondents are unemployed.
  - One percent of respondents are attending school.
- Occupations: Sales associate, social worker, plasma table operator, overnight Walmart employee, flagger, service supervisor, front desk coordinator, IT product manager, customer service, warehouse associate, public safety officer, utility worker, Door Dash/Grubhub driver, software engineer, and car salesperson. One unemployed respondent was recently incarcerated.
- Education levels: Fifty-three percent of the fathers/partners completed high school or earned their GED. The breakdown by percentages is in the chart and number of respondents are below.

- Three respondents are college graduates.
- Three respondents have some college.
- Nine respondents, or half the group have a GED or are high school graduates.
- Two respondents did not complete high school.



- Tobacco use: Twenty-two percent of respondents reported using tobacco products.
- Children: Respondents have between one and four children each for a total of 41 children. Forty-five percent of the fathers/partners have only one child. The breakdown is below:



Six respondents have one child.  
Four respondents have two children.  
Five respondents have three children.  
Three respondents have four children.

- Current pregnancies: Only two respondents in the group have a spouse or partner who is pregnant.
- Ages of children eight years old or younger. Respondents' children who are eight years and younger range in age from 7 months to age 8. The breakdown is as follows:
  - Two infants, 7 and 11 months
  - One child 1 ½ years old.
  - Two children aged 2.
  - Five children aged 3.
  - Five children aged 4.
  - Two children aged 5.
  - Three children aged 7.
  - Two children aged 8.

## Experiences during and after pregnancy

### *Feelings about the pregnancy*

- The pregnancy was unintentional for eleven respondents and intentional for seven respondents.
- For both planned and unplanned pregnancies, the men of both focus groups shared they were excited and nervous about being an expectant father. The young and first-time fathers were nervous because of the changes it would bring to their lives and not knowing how to be a dad.

### *Concerns*

- Participants expressed concern over finances, if their relationship with the child's mother will continue, where they will live, managing the new baby while working, the health of the baby in

utero, their social life, and how to be a father. A father of multiple children suggested that worries lessen with the second child.

- Respondents were concerned about financial support and being young, and/or inexperienced. They worry about the unknown future, the pressures, and responsibilities of fatherhood, and not having examples in their own lives as role models.

#### *Support during pregnancy*

- The fathers said they provided emotional support and accommodated the mood swings from the pregnancy. They helped with cravings, provided physical comfort, took on more hours at work and attended different classes related to pregnancy.
- Respondents undertook various actions to bring comfort and support to their wives and partners by “providing acts of service,” emotional and physical support, taking responsibility for other children, running errands, cooking, going to doctors’ appointments.
- From the questionnaire, fourteen respondents were very involved with the pregnancy and three respondents were somewhat involved with the pregnancy. One respondent did not answer.

#### *Attendance at labor and delivery classes*

- No one in the New Castle County group attended labor or delivery classes.
- All of the men of the Kent/Sussex Counties’ group attended prenatal visits, were present for delivery of their babies. One of the men expressed empathy toward his partner for the difficult delivery she had giving birth to their child.

#### *Attendance at prenatal visits*

- All participants of both groups attended the prenatal visits. One participant responded that it’s important to take vitamins.

#### *Offer of advice on safe health habits*

- Participants in the Kent/Sussex Counties group stated that they had to change their health habits including eating habits, stopping the use of marijuana, smoking, and drinking. It was also suggested to lessen time at work and take vitamins.
- All but one respondent to the questionnaire answered yes to advising the mother of safe health habits during pregnancy.

#### *Pregnancy and their relationship*

- For half of the New Castle County group, the pregnancies came at a time when the relationship with the mother of their child was not stable, or it was recreational.
- Regarding timing of the pregnancy for members of the Kent/Sussex Counties group, three of the men said it caused them to change their behavior. Two of the men said they “had to get their lives together” and one said he had to be more focused and present.

### *Support for their partner*

- One respondent shared that he raised his son the first year of his life because the baby's mother was ill. Other participants commented that they provided some support. When prompted, four respondents said their partners complained about breastfeeding.
- The men discussed how they adjusted to their partners after the babies were born by being sensitive to their emotional state, being of service, helping out with the babies, practicing some skills (like diapering) ahead of the birth. As one respondent said, 'stay out of the way.'

### *Experience during delivery*

- Responses from the questionnaire revealed that all respondents were able to be present at their child's birth. After the birth, all respondents were able to visit their child and the child's mother in the place the child was born. All respondents' names were placed on the child's birth certificate.

### *Postpartum depression*

- The majority of respondents had partners who experienced postpartum depression. Respondents said they offered reassurance. They helped by being positive and being reassuring. They also received family support and sought outside support from church. They tried to be supportive during emotional moments their partners were having. One of the men suggested more resources are needed to help fathers through this period. One respondent suggested therapy, and another did not know what post-partum depression is.

## **Experiences with newborn**

### *Experiences immediately after the child was born*

- The fathers expressed their joy and elation at having their newborn and for some it was different than they expected. They expressed their lack of knowledge and anxiety they had for the newborn. They shared how they cared for the baby and adjusted the schedule to care for the infant. One respondent "he buys stuff and is there for the mom but doesn't mess with them."
- Having a newborn impacted the behaviors of the fathers who said they had to slow down or stop running the streets, and their sleep was affected. Being a dad caused one respondent to examine the relationship he had with his dad who was not married to his mother. Fathers shared that they were bonding with their infants and wanted to be good dads. They shared their emotions that being a new father was fun, scary, but brings happiness.

### *Taking care of the infant*

- Almost all respondents were able to take care of their child during the first year and were available three hours a day to twenty-four hours a day. Thirteen of the eighteen respondents' surveys shared a great deal of responsibility for raising their children. Five respondents shared some responsibility.

#### *Best things about having a newborn*

- The fathers liked seeing themselves reflected in their newborns, telling others, and the experience. The fathers enjoyed talking about their newborns. They shared that it was a great experience to be a dad. Newborns are simple to take care of and they like holding the baby. Having a baby gave one father something to live for.
- Several of the men who did not have a father present in their own life want to be better dads and have influence in their children's lives.

#### *Worst things about having a newborn*

- The fathers agreed that the worst things about having a newborn are the lack of sleep, dirty diapers, calming them down when they are crying, dealing with a fragile baby, cleaning up poop, the potential for SIDs, waking up at night, and getting peed on. One respondent also mentioned the cost of daycare.

#### *Help given to their wife or partner*

- All participants in the Kent/Sussex Counties group helped their wife or partner care for the infant. The examples given were to do small things like giving gifts of positive affirmations or giving their partner space.

#### *Breastfeeding*

- Most of the fathers had partners who breastfed. Two of their partners had a breastfeeding coach in the hospital. Some of them stopped because of drinking alcohol, pain, or the inability to produce enough milk for twins.

#### *Help for breastfeeding*

- Seven of the eight participants of the New Castle County group and 2 participants in the Kent/Sussex Counties group had a lactation consultant. Two respondents shared the negative experiences they had with the lactation consultants who they found to be pushy, and inappropriate with their comments and behavior toward them.

#### *Information dads need*

- Fathers do not get information they need after the birth of their children to be a good parent, and information is geared toward mothers. Those who had additional children learned on the job through their mistakes. They suggested having fathers who are role models from whom they could learn. One participant suggested creating a business for fathers that would provide all of the information a father needs. Information needed includes setting expectations on what is normal, books to read, advice on when to call a pediatrician, the placenta, the whole birthing process, what to expect in the hospital, a C-section, and what to do with a diabetic child or premie. It was suggested these topics could be made into videos that could be shown in the hospital.

#### *Information on safe sleeping conditions*

- All participants received information on safe sleeping conditions for their infants. All participants agreed that they had to learn how to do without sleep.

#### *Ability to take time off work*

- Only three of the fathers of the New Castle County group but eight of the Kent/Sussex Counties group were able to take time off work for the birth of their children. The men were able to take three days to three months off of work which included one family leave request.
- Two of the men had to quit their jobs in order to support their partners and one was told he would be fired if he took off from work. Other participants were in the military or could not afford to take the time off. Participants who were given time off took from three days to three weeks off. It was suggested that a father's assistance program be put in place.

### **Current relationship with the child**

#### *Relationship with their child(ren)*

- Several fathers of the New Castle County group feel close to their children, while some want to improve their relationships by getting to love their child more, get closer or know more about how they think and feel. One father struggle with the mom's environment.
- The participants of the Kent/Sussex Counties group believe that they have good relationships with their children. They spoke of their roles as fathers, being more straightforward, firm, or disciplinarians.
- Most participants rated all the factors related to being a good father on the questionnaire as very important.
- The majority of participants live with their children and the child's mother. Their children also see other family members regularly. Only one respondent seldom sees his child. Additionally, only one respondent's child seldom sees other family members.
- Twenty-two percent of respondents are making any ongoing child support payments and twenty-two percents of fathers are receiving government assistance such as Medicaid, WIC, and food benefits.

#### *Relationship with your child's mother*

- Some fathers are not close to their child's mothers and have strained relationships. In fact, two of the fathers said they should not have children with the mother. One of the fathers has a really close relationship with his child's mother.
- Some fathers have managed to work out cooperative co-parenting relationships with their partners. The fathers mentioned the difficulties of the child support system and custody agreements.

#### *Satisfaction as a father*

- A number of participants generally expressed their satisfaction with their experience as a father, but many thought they could do more as a father. The fathers spoke of the poor parents they had growing up and the lack of having a father which motivated them to be better fathers. One

of the fathers would like to communicate better with his child's mother. One of the participants commented that he and his fiancée did things backwards and a two-parent household is healthier.

#### *Input they have with their children*

- The participants all believe they have the most input on discipline, their child's physical activity, and safety. They see differences between how they discipline compared to their children's mothers. Where the child lives, and custody arrangements influence the decision making and input parents have as shared by participants. The fathers shared their view on types of discipline. Four of the fathers support talking, timeouts and restraining, as opposed to physical discipline. Most fathers share custody and parenting with their partners.

### **Difficulties in dealing with fatherhood**

#### *Challenges being a father*

- The participants said their biggest challenges to being a father are relationship issues including with their children's mothers, and the need for them to work as a team when it comes to their children. They are concerned with the impact of the environment on their children, finances, children's changes as they grow up, child support, other children's parenting, and workload.
- Participants indicated the challenges that interfere with their ability to participate in parenting activities with their child. financial difficulties, relationship issues with the child's mother, incarcerated or trouble with the police, unemployment, responsibility, and skills needed to be a father.

#### *Resources for new fathers*

- The participants spoke about the support and comfort they felt with one another in the focus group and suggested father's support group as a resource where fathers can learn from one another and grow and progress as fathers. They stated that fathers need equal treatment and someone to talk to and the importance of sharing each other's stories. The fathers would like financial management resources, information on homeschooling, therapy, counseling, and fatherhood.

#### *Everyday concerns and worries*

- The fathers expressed concerns about the state of the government, their faith in God, and current state of the world, their child's illnesses, and becoming sick, managing their children as they grow older, their children's safety, finances, schooling, raising daughters, and outside influences.

### **Wrap Up**

- The men enjoyed the focus group discussions and felt they benefited from being in a group of fathers. They suggested having fathers who are role models to demonstrate fathers and



leadership. Additionally, they would like to see more focus groups for fathers to include expectant fathers. One father suggested starting a business that would provide services to fathers.

## Conclusion

The questionnaire showed the diversity and complexity of the family situations for the fathers/partners. The completion of the questionnaire was followed by discussions on experiences during pregnancy, supporting partners during pregnancy and postpartum, experiences of new parents, breastfeeding experiences, fatherhood and parenting, discipline, co-parenting, and resources necessary for new fathers. The participants shared personal insights and experiences, highlighting the complexities of becoming a parent and the challenges faced by fathers. The discussion emphasized the need for support groups, therapy, and unbiased opinions from peers as essential resources for fathers.

The participants shared their diverse range of emotions felt upon learning about their partner's pregnancy, including nervousness, excitement, and fear, as well as the various concerns and worries they had, such as finances, relationships, and support during pregnancy. The discussions also touched on the support provided after the birth of the child, with one participant sharing their experience of raising their child while their partner was unwell, and the challenges of postpartum depression. The discussions emphasized the importance of being present and supportive of their partners.

The fathers shared experiences with newborns, including personal anecdotes and reflections of both the challenges and meaningful moments they have encountered including parenting a newborn, dealing with allergies, fears of SIDS, and the exhaustion of caring for a baby. The groups shared their experiences with breastfeeding and societal pressures around breastfeeding and the difficulties in accessing adequate support. Fathers do not feel that information and resources are readily available for them to be parents and suggested more informational videos and information geared to fathers be made available from pregnancy, through birthing process, and infant care.

Fathers discussed the complexities of non-physical discipline and the need to adjust disciplinary methods as children mature, explored the differences in raising sons and daughters, and touched on the role of mothers in teaching daughters and the influence of parental behavior on children's development. Participants sharing insights on the importance of teamwork with the mother, addressing disrespectful behavior, and navigating custody issues and its emotional impact, and the need for effective communication and cooperation for the well-being of the child.

Challenges of fatherhood include relationship difficulties with the children's mothers, finances, lack of role models, and lack of resources and information to help them develop parenting skills. Some fathers had challenges with getting time off from work and the conversations touched on the impact of work commitments on their ability to be present for their children, highlighting the importance of parental leave.

The discussion emphasized the importance of creating a supportive environment for fathers to share experiences and learn from each other, and the need to provide a network of resources to help fathers in their parenting journey. The participants expressed the need for support groups, therapy, and unbiased opinions from peers. Participants acknowledged their need for ongoing growth and progress in their development as fathers.

### **Consultant's Recommendations:**

1. Identify fathers who could serve leaders and mentors for fathers who grew up without a father that can serve and role models and provide advice to new fathers and fathers of young children.
2. Develop information and resources geared toward new fathers on all aspects of pregnancy, childbirth and delivery, infant care, relationship management, navigating custody and child support issues, co-parenting, and other related topics. Information should be in the form of short videos that can be viewed on social media, especially You Tube, and Tik Tok. Fathers should be provided with this information upon first learning of a pregnancy, and at various times through their parenting journey through health care providers and State agencies.
3. Support groups for fathers could be offered through agencies like Children & Families First that could be accessible online or in person to discuss relevant topics for fathers/partners. The groups could be participant led.
4. Develop information for fathers/partners who raise daughters, and how to adapt one's parenting style as children grow older. Information and advice could also be developed to provide guidance on effective disciplinary techniques. This information can also be made available in the form of videos or short handouts that can be accessed through social media, healthcare providers, or State agencies.
5. Financial management tips or short videos and information geared to fathers/partners on budgeting could be made available to young and new fathers/partners.
6. Develop a need-based stipend or financial assistance program to help new or young fathers who are unemployed or recently incarcerated meet financial demands so they can be a better support to the mothers of their children.

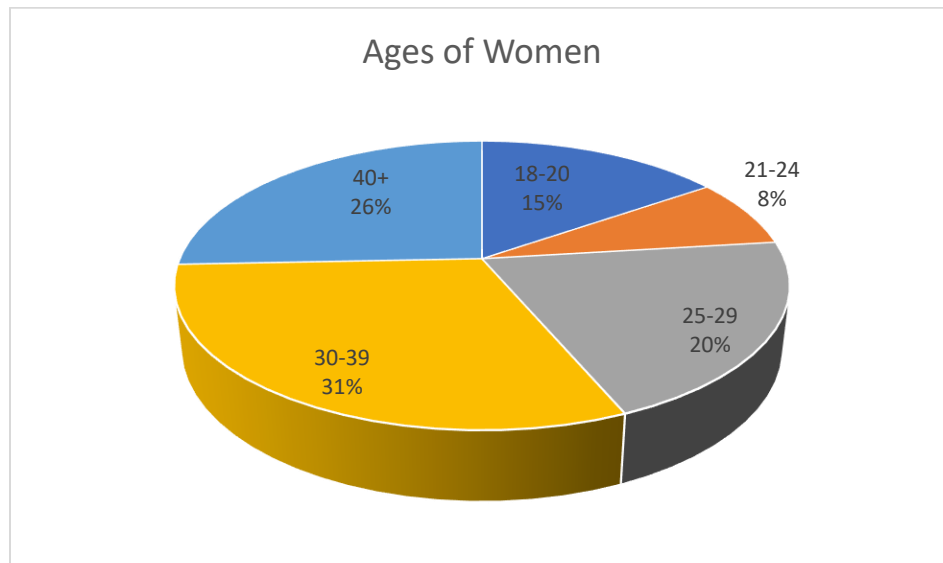
## Major Findings – Women’s General Health

### General Characteristics of the Focus Groups

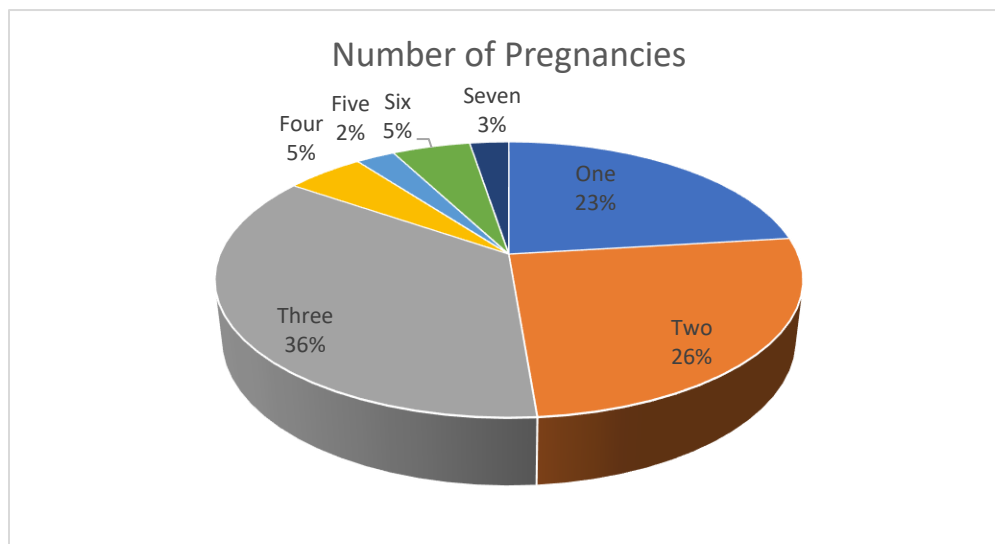
New Castle County - Spanish	New Castle County
<p>Twelve Hispanic women participated in the focus group held on March 12 at the New Castle Public Library. The group ranged in age from 18 to 40 and included four college graduates, two participants with some college, five high school graduates, and one with a few years of high school. Reported annual income was from less than \$20K to \$52K. The participants were from Wilmington, Newark, Newport, and New Castle. Their children’s ages ranged between 1 month old and 21 years old. Eight mothers reported having a family doctor and four did not. No one reported the use of cigarettes, and the household number of residents ranged from 3 to 8. The group responded to all the questions and enjoyed participating in the discussion.</p>	<p>The focus group met on April 16 at the Rt. 9 Public Library and was composed of 12 women participants. The women were ages 18 through 43 and had a combined total of 29 children with one to seven children each, from infants to adults in their twenties. Educational levels ranged from GED to post graduate. Three quarters of the group had a family physician and eight visit their doctor at least annually. One fourth of the group uses tobacco products. Everyone participated actively in the conversation and completed the questionnaire prior to the discussion.</p>
Kent County	Sussex County
<p>The focus group was composed of eight women participants, seven of whom attended the Dover meeting and one participated as the sole participant in the Georgetown focus group on general health which was held on April 8. The women were ages 23 through 44. Six of the women were African American and two women were Caucasian. The women had one to six children, from infants to adults, five months to 24 years of age, and a total of eighteen children. Educational levels ranged from some high school to some college. Six of the women had a family doctor and all but one participant visits their doctor at least annually. Only one woman in the group uses tobacco products. Everyone participated actively in the conversation and completed the questionnaire prior to the discussion.</p>	<p>The focus group was composed of nine women participants on general health which was held on May 9 virtually, via Zoom. The women were ages 18 through 40. This session was scheduled as a Zoom meeting to address transportation and childcare barriers so the women could attend. Eight of the women were African American and one was Haitian-Creole. The women had one to four children, from infants to adults, five months to 18 years of age, and a total of twenty children. Educational levels ranged from some high school to college degree, but most of the women were high school graduates. Only four of the women had a family doctor and they visit their doctor at least annually. Two women in the group uses tobacco products. Everyone participated actively in the conversation and completed the questionnaire prior to the discussion.</p>

## Demographics

- Age of respondents. The forty-one respondents ranged in age from 18 to 40. The largest group of respondents were aged 30 to 39 at 31%. The breakdown of ages is in the chart below.



- Number of pregnancies. Most of the women reported having two or three pregnancies with the number of pregnancies ranging from one to seven as shown in the chart below.



- Cell phones: Only one person out of forty-one respondents did not have access to a cell phone.
- ZIP codes of your permanent residence:
  - New Castle County Spanish: Two out of twelve respondents reported living in zip code 19702, four in zip code 19804, two in 19805, three in 19720, and one in zip code 19808.

- New Castle County: Five respondents reside in zip code 19801, three reside in zip code 19805, two reside in zip code 19802, and two reside in zip code 19720.
  - Kent County: Three of the respondents reside in zip code 19901, four reside in zip code 19904, and one resides in 19934 zip code.
  - Sussex County: Five of the respondents reside in zip code 19973, four reside in zip code 19933, and one resides in zip code 19947 zip code.
- Age and sex of the children:
    - Respondents had a total of 94 children ranging from one month old to 27 years of age. Respondents had one to six children each. Fifty two percent of their children are males and forty-four percent of the children are female. Four percent – no response.

## Health Habits and Practices

### *Improvement of health habits*

- The majority of participants who responded would like to improve their health habits with respect to their exercise, weight, stress reduction, and daily folic acid/multivitamin. Three women who responded want to improve their mental health. Participants do not feel they need to improve in their use of tobacco, alcohol, recreational drugs.

### *Access to contraception or birth control*

- Twenty-three percent of women who responded to the questionnaire do not have access to contraception or birth control. Twenty seven percent of respondents reported they were not able to afford contraception or birth control. One woman reported discrimination as a reason.
- Half of the Spanish speaking respondents were not able to afford contraception or birth control after the delivery of their infant. There were one to two respondents in each group who also could not afford contraception.

### *Access to advice on health habits*

- Ten respondents did not have access to advice on health habits such as nutrition, and the dangers of alcohol, tobacco, or recreational drugs.

## Family Support and Partnerships

### *Help and Support*

- Responses from the questionnaire revealed that most respondents had friends or relatives they can rely on to help with care and have people they can talk with about the issues/challenges you face. The Spanish speaking women had family friends, therapists, and their babies' fathers help them with the care and counsel for their children and help with transportation. The New Castle County group had family friends, therapists, and mentors who helped them with the care and counsel for their children and with transportation. Most of the women in the Sussex County group do not have anyone to help with care, talk with about issues, or help with transportation.

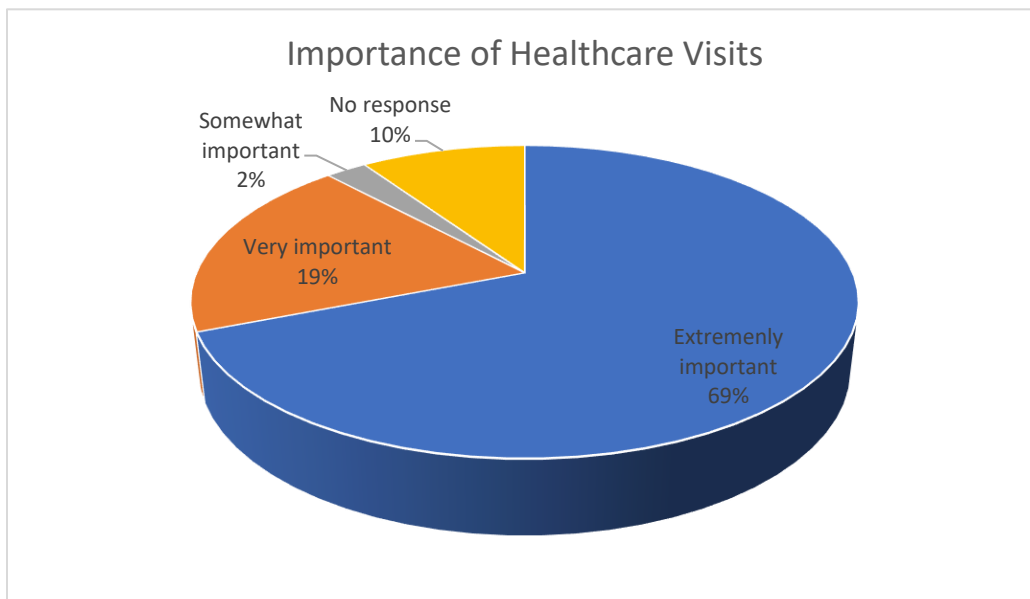
- Nearly twenty percent of the women did not have friends or relatives to help with care or transportation. Additionally, almost twenty percent of the women reported that they did not have anyone to talk to about challenges or issues.

#### *Internet and Social Media Use*

- Almost all respondents with the exception of the Sussex County focus group reported they used the Internet and social media to find resources to help care for their child. There were a few women in every group who did not use the Internet or social media as a resource.

#### **Access to General Healthcare**

- Importance of healthcare visits. Sixty-nine percent of respondents felt healthcare visits are extremely important. The breakdown of all responses is shown in the chart below.



- Annual preventive health/wellness checkup.
  - Only half of the women in the Spanish speaking and Sussex County focus groups reported that they get an annual preventive health/wellness checkup.
  - All participants of the New Castle and Kent County focus groups get an annual preventative health/wellness checkup.
- Affordable Care Act Eligibility for Annual Well Woman Visit.

Fifty-one percent of participants were aware that, under the Affordable Care Act, they are eligible for a no-cost preventative health/well woman annual visit.

- Healthcare providers.

Sixty-three percent of the women have a primary care doctor, forty-nine percent have an OB/GYN, and only forty-three percent of the women have a pediatrician. Only twenty-five percent of the Spanish speaking women have a primary care doctor, OB/GYN, or pediatrician.

- Trouble paying for healthcare.

Forty-one percent of the women have trouble paying for healthcare or their health needs.

#### *What they look for in a healthcare provider*

- Spanish speaking respondents shared that they do not want language to be a problem. They want their healthcare provider to treat them well, to provide detailed explanations and shorter waiting times. They also want payment options.
- Participants want a doctor that is trustworthy, listens and understands them and their children, allows them to ask questions without judgement. They also want a dependable, reliable, compassionate doctor who is convenient, provides resources, and works in partnership with them. It is important to have a stable relationship with a doctor. Participants look for doctors who have positive reviews on the Internet or recommendations from family members. They want doctors who are knowledgeable, consistent, treat them well, and have effective communication. Participants look for doctors with whom they are comfortable, are comfortable treating Black women, and are knowledgeable, honest, trustworthy, and positive. A participant wanted an OB/GYN doctor to have firsthand experience.

#### *Where they go for healthcare*

- Spanish speaking respondents use West Side Family, Complete Family Care, Nemours Hospital for Children, St. Francis Hospital, and Christiana Care.
- New Castle County participants use Bayhealth family care or ChristianaCare.
- Sussex County women go to their primary care doctors and OB/GYNs at various locations in Sussex County at locations in Milford, Seaford, and Salisbury, Maryland. They mentioned walk-in and urgent care offices, Tidal Health, LaRed, Nemours, Ambient care, and Dedicated to Women. One respondent mentioned she did not have a primary care doctor, but only an OB/GYN. Walk-ins are preferred for fast and same day results and urgent care.

#### *Barriers to healthcare*

- From the questionnaire, 71% of the respondents have healthcare insurance. However, forty-two percent of Spanish speaking women do not have healthcare insurance. The lack of and type of insurance for healthcare was identified as a barrier in every focus group discussion.

- Additionally, respondents mention the following barriers for them to get the healthcare they need: communication, making appointments was difficult because they get no answers when calling and are told to go in person to make an appointment, transportation, high copays, lack of childcare, and discrimination for being immigrants (for Spanish speaking), the need for babysitters, the cost of medication, timing and coordinating appointments around work schedules, and lack of trust in the healthcare system.
- Participants stated that Medicaid only does extractions, some providers will not accept Medicaid, and it takes a long time to approve prescriptions with Medicaid. The incomes of two participants were too high to qualify for Medicaid. One of these respondents said she was struggling to pay her bills.

#### *Comfort discussing personal questions or concerns with healthcare providers*

- The majority of respondents to the questionnaire are comfortable discussing personal questions with their healthcare providers. They are less comfortable discussing addiction issues, intimate partner violence, and immigration concerns. There are a few respondents who were not very comfortable or not at all comfortable discussing most topics with their providers. Most respondents understand the answers given by providers to their health-related questions.
- Respondents shared that their level of comfort with their doctor depended on the treating doctor. They commented that some doctors were very blunt, not empathetic or rushed them through their appointments. They also mentioned that communication was easier with women doctors, and pointed out that having different doctors every time they went for a follow up prevented them from sharing their personal questions or concerns as it was hard to build rapport with the different doctors. It was also mentioned that doctors minimized problems they shared with them, and finally respondents agreed that interpreters were not qualified. For Spanish speaking women, having a doctor that spoke Spanish was an advantage.
- Some women were not comfortable discussing abuse in the home or emotional issues. One respondent suggested that with matters of abuse, the State [of Delaware] gets involved.
- Most respondents say they felt comfortable are comfortable discussing questions about reproductive and sexual health, and contraception with their providers. Some of the women who are not comfortable with their doctors are looking for another doctor and one respondent said her doctor has a language barrier. Some of the women from the Kent County focus group, who are on Medicaid have difficulty obtaining contraceptives through Walgreens and CVS where the prescriptions are delayed, partially filled, or generic versions filled.

#### *How well health providers answer their questions or concerns*

Respondents had mixed responses to how well providers answer their questions and concerns. The Spanish speaking respondents said that they get short answers and there is not enough time for questions and concerns to be addressed. They wished providers would not play down them symptoms or problems or say that it is normal rather than explaining what is happening. Providers should listen and analyze better what they are saying. And they also agreed that more personnel to help would be great. One respondent shared that she got help from doctors in her country she consulted by video-call



- Participants said their doctors answer their questions and some doctors do not. However, participants go to their family members, pastor, friends, and pharmacist who answer their questions.
- The women suggested support groups could help them with their personal questions or concerns, writing down questions before going to the doctor would help them get their personal questions and concerns answered, attending classes on health and social services, and using message groups on the Internet.

## **Prenatal and Postpartum, and Infant Care**

### *Access to prenatal care*

- Most of the Spanish speaking women did not have access to prenatal care and the majority responded that they lacked access to mental health services and support. There were some respondents of all groups who could not afford the cost of pregnancy related items, did not have transportation to health visits, access to prenatal care, or mental health services and support
- Everyone had access to prenatal care when they were pregnant. Participants reported mixed experiences with their prenatal care from having excellent care, great, good, and not being able to get a timely appointment, to perceptions of delays in procedures like ultrasound.
- The Sussex County respondents said they used doctors and midwives. Four of the women did not always see the same provider or midwife each time they went for an appointment. One woman who had switched her care to Dover because of her diabetes reported that she had a bad experience at Kent General Hospital and regretted her decision to go there.
- Respondents described the care they received as very good to acceptable. Respondents pointed out how the care combination of West Side and Christina Care worked well in some cases and in other cases some problems were overlooked due to lack of communication between the two.

### *Racial/ethnic discrimination*

- About twenty-two percent of the women felt they experienced racial/ethnic discrimination while getting healthcare during pregnancy, delivery, or during postpartum care.
- Spanish speaking respondents said that nurses lacked knowledge of phone translator apps to communicate basic information or to communicate with their relatives. One respondent shared about being isolated and without food because she had COVID, and the food was being left outside her room. Respondents believe that in many cases they were ill-treated due to being Hispanic and that what happened to them would not have happened with another person.
- One to two participants in the New Castle, Kent, and Sussex Counties groups described incidents where they experienced bias or were not treated fairly regarding their race or ethnicity during the delivery of their child.

*Dangers of tobacco, alcohol, and recreational drugs on your unborn baby*

- All participants were told about the dangers of tobacco, alcohol, and recreational drugs on their unborn baby.

*Pregnancy or birth complications*

- Twelve of the forty-one respondents had a child that was born prematurely. More than half of the respondents experienced pregnancy or birth complications.

*Challenges in acquiring healthcare related to pregnancy*

- Most Spanish speaking respondents reported having difficulty getting the first appointment and up to the third month because there was no availability. Access to healthcare during pregnancy was difficult due to the lack of transportation.
- Two participants had major health issues with preeclampsia. One participant came to Delaware pregnant and had to wait to get insurance coverage. One participant delivered a set of twins unexpectedly.
- One participant commented that she did not have Medicaid for the first part of her pregnancy, stating that her insurance was turned off and it took about 5 months for her to be re-instated.

*Developmental screening, childhood vaccinations, physical activity, or preventive dental care*

- Spanish speaking respondents all agreed that their health care provider gave them information about vaccinations, and that having a bilingual doctor helps them understand their doctors better.
- New Castle County participants had difficulty recalling if they had received developmental screening for their children and most were unsure. Participants named various conditions their children were screened for including blood test for genetic testing, autism, speech. One participant stated that her doctor screens for her son meeting his milestones. Only two participants received advice from their doctors about vaccinations, but most were given a paper with information about vaccinations from their doctors, not advice. About a third of the group were given information from their doctors on preventive dental care.
- Kent County participants who responded spoke out against vaccinations for their children and did not offer an explanation.
- Sussex County participants spoke about the amniocentesis test they were offered with their babies in utero. At least four of the women said they were offered the test but declined because they were told their babies could die. They took their chances, and their babies were born without defects.

*Post-partum experience*

- The majority of respondents went to a postpartum visit after their child was born. About half the respondents experienced post-partum depression. Several women in each focus group did not have access to treatment.

- Most participants who could remember had their first post-partum visit said it was from three days to six months after they had their babies. Three participants chose not to go to her post-partum visit. Two participants had birth control procedures, a tubal ligation and depot shot.
- Respondents with delivery problems had their post-partum visits two to three weeks after giving birth. One woman had a C- section and the other had a piece of sponge left inside of her.

#### *Discussions with providers on mental health or contraception*

- Spanish speaking respondents said that they talked about both mental health and contraception. One respondent did not share what she was feeling with her health care provider because she was afraid her children were going to be taken away from her if the provider knew she was feeling depressed. Language and the sex of the provider influenced how respondents shared about these topics with their providers.
- The providers discussed mental health and contraception with all but one of the respondents. One respondent said she was not educated on postpartum depression and her doctor breezed through both topics.

#### *Breastfeeding*

- All Spanish speaking participants said they breastfed their children. Respondents shared they breastfeed their babies between one week and three months. Many of them said they did not know how and had to rely on their own experience or relatives to show them how. Some of them found the experience painful and stressful.
- Participants shared their positive and negative experiences. Participants shared that they learned how to breastfeed with the help of classes, a lactation consultant, hospital, nurses, and a doula. One participant shared that the lactation consultant was not helpful, and another participant shared that she was scared and wished she knew more as a young mother of only 16 or 17 years old.
- The women said they stopped nursing because their milk ran out, or the baby could not latch, they lacked adequate milk supply, were not comfortable, or no one told them how to hold the baby.

#### *Safe sleep practices for baby*

- Respondents said that their healthcare provider advised them about safe sleep practices for their baby. They reported they were told not to lay the baby on their stomach or put the baby on the bed. Despite being told, one participant said she still let her baby sleep wither.
- One participant stated she was told how to lay the baby down, and not to put the baby in bed by her doctor. She watched an instructional video before leaving the hospital. This participant also shared that her 12-year-old daughter had a baby and was going through postpartum depression.

#### *Changes experienced after baby was born*

- The majority of participants who responded experienced changes with their intimate relationships or experienced financial instability after their child was born. Respondents were not sure of the best resources for getting the support they needed and lacked access to resources. They had difficulty affording child related costs, and experienced isolation.
- Only one of the respondents out of forty-one participants had thoughts of harming their baby. Only one participant in each focus group had difficulty bonding with her baby.

#### *Help from friends and relatives*

- The participants had help from community resources, friends, and family, doctors, nurses, hospitals, and program resources for help with obtaining WIC, safe sleep practices, and a safe home environment. They had less help with breastfeeding and WIC.

### **Social determinants of health**

#### *Community conditions affecting their children's health*

- Respondents shared concern about distribution of drugs, bullying, smoking, unsafe play areas and parks due to consumption of marijuana or alcohol. Some have experienced shootings in their neighborhoods, and some find the information about Hispanic women and children disappearing worrying and upsetting. They all believe this affects their children's health.
- Respondents shared they liked the opportunity to listen to other moms' experiences and find so much common ground about the topics discussed. They also said that they had not had an opportunity to be heard in this way as a Hispanic group. They were grateful for the opportunity and asked for all their feedback to be considered.
- Participants spoke of the drugs, violence, and crime in their communities, making it unsafe for their children to go outside of their homes or play in city parks. One participant said there are many positive things in the community including free programs that are available. One participant who lives near Concord Pike said that she did not have any drug, violence, or criminal issues. Another participant spoke of the poor quality of the school lunches which caused health problems in her children and since she started packing their lunches, their health issues have subsided.
- Participants focused mostly on poor air and water quality caused by pollution. One participant said her son had undiagnosed asthma from the poor air quality. One other participant commented about the shared air vents in her current housing situation.
- The Spanish speaking women have problems/challenges with transportation either not having a car, sharing a car, not being able to drive, or being far from the hospital.

#### *Current housing situation*

- From the questionnaire, twenty-eight percent of the women from the English-speaking focus groups experienced an issue with their housing over the past year. The Spanish speaking women experienced unstable housing over the past year. Reasons given included seasonal employment, weather conditions making a home unsafe, and lack of income.

- Overall respondents said that their housing situation was safe except for the consumption of marijuana by neighbors and presence of lead.
- Several participants said that their housing situation was inadequate and did not meet their current needs. One participant who lives in an apartment complained about her neighbor's problem with mice and roaches and mice now entering her home. One participant referred to her landlord as a slum landlord, while another participant said her home was too small and she lacked a kitchen. Three participants live in a Habitat for Humanity home. Others commented that Kent County does not have adequate housing.
- Participants complained about the cost of rent.

#### *Access to healthy food choices*

- Respondents said that WIC, food banks and churches gave them access to healthy food.
- Participants said they do not have access to healthy food, and they cannot afford it. Participants said they are eating processed food, making food stretch, trying to grow their own food, or getting food without preservatives. Seven of the participants agreed that they have to go out of the area to buy healthy foods from locations outside of Wilmington like Wegman's, Aldi, Market Fresh, The New Castle Farmer's Market, and Sprout.
- Participants said they go to select grocery stores like Redner's, Trader Joes, Aldi's, Safeway, and the New Castle Farmer's Market to get healthy food. However, they said that healthy food, or "good food," is expensive and fresh food does not stay fresh long. One participant spoke about her research on healthy food. Participants shared information on opportunities to receive vouchers for fresh food and locations.
- Participants said they go to Redner's, Aldi's, Lidl, the Food lion, and Walmart, and have used vouchers for the Farmer's Market to get healthy food. They use WIC and the food banks. They commented that food is expensive.

#### *Food access*

- Twenty-five percent of women reported on the questionnaire that over the last 12 months, their children have experienced some issues with accessing enough food.
- Respondents agreed that there was a lot of help with food. Three participants said they would rather stay hungry and make sure their kids have enough food to eat. One participant says she needs more food and resources to feed her grandson. One participant said that she cannot afford food stamps because she works.

#### *Community resources*

- Most of the Spanish speaking women reported they did not use any community resources to help with care and two said they did and mentioned: the Latin American Community Center and Harper's Heart.

- New Castle County participants have used including the parenting programs, food closets, the library, Duffy's Hope, Harper's Heart, the Diaper Bank, Doors of Hope, and PAL.
- Kent County participants have used community baby showers, social media groups, church, and food banks, and specific programs including WIC, Black Doulas, Highmark, Medicaid, and ChristianaCare portal. They said a place like a community center for parents where they could come together to play, and learn from one another without their children, is missing.
- Sussex County participants have used home health nurses, purchase of care, a speech therapist, chat groups on Facebook, Champions group, home visiting program, Westside Family Health ambassador program, Children and Families First, Parents as Teachers, and Easter Seals.

#### *Issues in the community that are affecting the community's health*

- Respondents mentioned lack of empathy among neighbors because each one lives without caring what happens to the others. Plumbing was also mentioned. And one main concern was transportation to school when the school was out of the district.
- Two of the participants do not allow their children to play outside because of safety concerns, outside influences, and the behavior of other children. One respondent is planning to move because the neighborhood is unsafe. They also discussed that children may become sick at school or daycare because other parents send their children there when they are sick.

#### *Methods to ease access vaccinations for children*

- Spanish participants do not believe in getting non-mandatory vaccinations or flu shots because of family beliefs, lack of trust, belief that shots cause ill health, and their own research. One person suggested that in-depth conversation with a doctor would make access to vaccinations easier.
- Participants get vaccinations for their children because they must work, or children need to go to school. They expressed some skepticism about the need for vaccines because of their experience with Covid and what they know about chicken pox. Participants suggested providers give more information about vaccines and why they are important. One participant who got behind on vaccination schedule for her son was given a chart by her doctor with a schedule for each age which she found informative and helpful.

#### *Everyday concerns and worries*

- Participants expressed common concerns about their futures, their mental and physical health, the health, and safety of their children, raising their children, and if they are doing their best as a parent. They struggle with depression and anxiety, worry about finances and lack of income, their housing stability, work and work life balance, and transportation. They worry about having enough milk and diapers, finding a doctor, and being able to get medicine, and paying medical bills

#### **Wrap Up**

- Participants enjoyed the focus group meetings, opening up and relating to one another, finding support and common ground with one another. They would like to see more groups for mothers

to provide support for them raising their children, and topics for single women with children regardless of their age.

## Conclusion

The discussion on women's general health covered a range of topics, including access to healthcare, family situations, and community impact on health. The participants shared their experiences and insights on the qualities they seek in healthcare providers, barriers to accessing healthcare, comfort level in discussing personal questions or concerns with their healthcare providers, prenatal and postpartum care, child development and healthcare, postpartum visits and breastfeeding experiences, community conditions affecting children's health, health and nutrition concerns, improving access to childhood vaccinations, community resources, and everyday worries and concerns of mothers.

The survey responses and conversation highlighted the impact of various barriers to accessing healthcare, including insurance limitations, transportation issues, disparities in treatment based on insurance type, language, challenges with pharmaceutical coverage for contraceptives, and long wait times in emergency rooms. The participants also shared their experiences with prenatal care and the varying levels of care they received, as well as their interactions with healthcare providers, including instances of feeling unfairly treated based on race or ethnicity. Participants expressed varying levels of comfort discussing personal health concerns with healthcare providers, highlighting the importance of open communication and the need for improved support and care from healthcare providers.

Participants discussed their healthcare provider preferences and access to healthcare services, comfort level in discussing personal and reproductive health with health providers, prenatal and postpartum care, and the potential impact of community conditions on children's health. Participants shared their experiences and challenges in accessing healthcare, managing chronic conditions, and finding doctors who accept Medicaid or are open to taking on new patients. Walk-in clinics are meeting needs that traditional primary care providers cannot offer, such as flexible appointments and immediate results.

The discussion highlighted the importance of effective communication and education to address vaccine hesitancy and improve access to essential vaccinations for children, as well as the need for community resources and support for parents to enhance their children's learning and development. It also revealed that everyone does not have family support or someone to talk to about their concerns and issues which is important to relieving stress and anxiety.

Respondents share the community resources they utilized and their experiences. Missing resources in the community, particularly for parents, emphasize the need for a community center for parents to access mental health support and parent training. The conversation also covered the everyday worries and concerns of the participants, including the challenges of parenting, work-related stress, financial worries, and the desire for improvement in programs and services.

The groups explored the potential impact of community conditions on children's health, focusing on housing situations, access to healthy food choices and the difficulties of accessing affordable healthy food in their communities, and transportation issues.

Overall, the focus groups provided valuable insights into the experiences and perspectives of mothers in Delaware, shedding light on the complexities and disparities within the healthcare system for their care and the challenges faced by parents in accessing resources and support for their children's well-being.

The meetings concluded with participants expressing gratitude for the focus group discussions, suggesting having more frequent meetings, to continue the support and connection.

## Recommendations

1. Women want to improve their health in the area of exercise, weight management, stress, and anxiety reduction, and taking vitamins. The medical practitioners can easily initiate these conversations since the women are already motivated and receptive.
2. Increase access to contraceptives by ensuring coverage through Medicaid and increasing affordability through subsidies for lower income women.
3. Establish support group opportunities, both virtual and in-person, for women to be able to discuss health issues and concerns and share with one another. This will provide an opportunity to gain information and relieve stress for women who do not have support of family members or friends to talk to. The groups should be offered for Spanish speaking and in English and also feature speakers who can share information on community resources.
4. The Division of Public Health should ensure that information is disseminated to healthcare providers and state agencies that women are eligible for a free annual well-women visit through the Affordable Care Act.
5. Greater efforts need to be made by community medical providers to increase access to prenatal care for low- and moderate-income women and especially Spanish speaking women. More outreaches should be done to increase opportunities for low- and moderate-income women to have insurance coverage.
6. Medical practitioners should have greater sensitivity and awareness of cultural differences and their interactions with Black and Brown women. Training videos for practitioners and written communication reminders of how patients should be treated could improve these interactions. More bilingual medical professionals and people of color are needed.
7. Primary care physicians could benefit from training to learn how to improve interactions with women patients by listening more and helping in the behavioral health to address mental health, anxiety, and depression. Medical professionals should be able to make on the spot referrals to community resources for mental health issues. Guidelines on how to talk to women on uncomfortable topics including sexual abuse, partner intimidation, and mental health would help medical professionals. Likewise, guidelines for women on how to talk to their health professionals about these topics would be helpful.



8. The Division of Public Health or the Delaware Academy of Medicine could develop a vaccination milestone checklist in English and Spanish with an explanation why immunization is important and needed. Videos with this information that could be shown on social media or in doctor's offices might also be helpful.
9. Social determinants of health are impacting the health of mothers and children. More should be done to address food insecurity that is impacting women and their children. Affordability is a big issue for low-income women who do not qualify for Medicaid. Consider expanding a voucher program for women to use for food at farmer's markets, and for transportation to medical appointments.
10. Encourage pediatricians to provide developmental screening for infants and encourage mothers to ask physicians about the screening for their infants and children.
11. Community Centers and family support organizations can create resources for parents to come together, learn about mental health, and receive parent training.

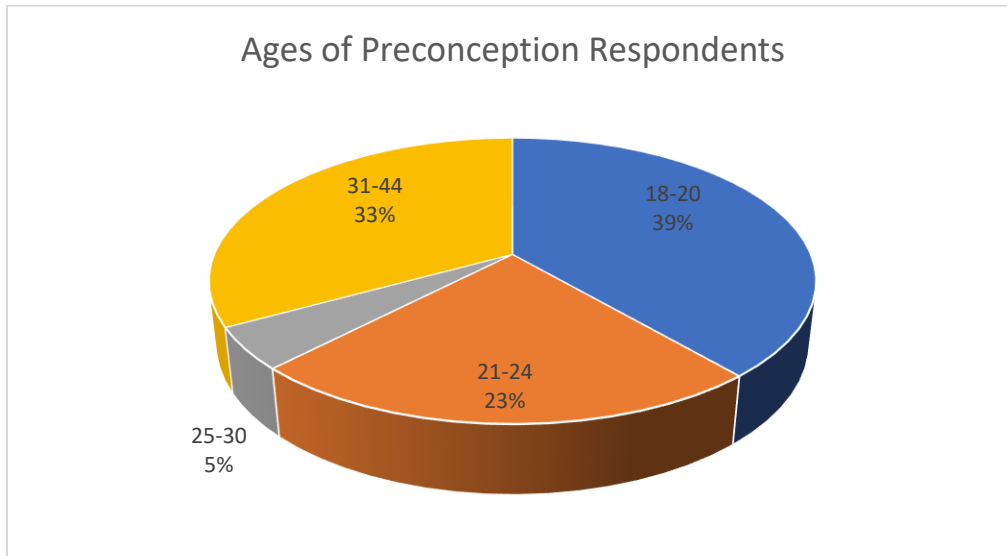
## Major Findings - Preconception

### General Characteristics of the Focus Groups

New Castle County	Kent/Sussex Counties
<p>The focus group was held on April 24 at the Henrietta Johnson Medical Center in Wilmington with eight African American women from New Castle County. The women were ages 18 to 44. When screened, all of the women said they did not have children and they were not pregnant. However, a woman in her forties revealed in the focus group that she had a daughter. One woman who was in her forties was a walk-in and lied about being screened. They reside in zip codes 19805 (4 participants), 19802 (2 participants), 19801 (1 participant), and 19720 (1 participant). Three of the women were overweight. The women had high stress, depression, pre-diabetes, and high blood pressure. Most of the women lived with other family members or roommates and annual household incomes were from less than \$15K to \$20.4K. Everyone completed the questionnaire at the start of the session. The women responded to the questions and the older women in the group tried to give advice and counsel to the younger women. The women participated actively in the discussion.</p>	<p>A focus group was held on April 11 at the Milford Public Library in Milford with two African American women and one African woman from Kent and Sussex Counties. Three women who were recruited did not attend. The women were ages 21, 22, and 30. None of the women had children or were pregnant. They reside in zip codes 19973 (2 participants), and 19901 (1 participant). The women had high stress levels. Their annual household incomes were from less than \$15K to \$28.4K. Everyone completed the questionnaire at the start of the session. Even though the group was small, the women were very talkative and participated openly and actively in the discussion.</p> <p>Because of the small size of the Milford group, a make-up focus group was held via Zoom on May 13 with eight African American women from Kent and Sussex Counties. The women were ages 18 to 42, did not have children and were not pregnant. They reside in zip codes 19901 (4 participants), 19904 (3 participants), and 19947 (1 participant). The women had high stress, depression, asthma, ADHD, and one was overweight. Their annual household incomes were from less than \$15K to \$55K, with households of one to 5 people. Everyone completed the questionnaire at the start of the session. The women gave serious thought to their responses, were very talkative, and enjoyed participating.</p>

### Demographics

- Age of respondents. The respondents were aged eighteen through forty-four. The percentage breakdown of ages is shown in the chart that follows.



- Access to a cell phone. All participants who responded have access to a cell phone.
- Respondents' zip codes of their permanent residences.

New Castle County residents: 19805 (4), 19802 (2), 19801 (1), 19720 (1)

Kent/Sussex County residents: 19901 (4), 19904 (3), 19973 (2), and 19947 (1).

### Health Habits and Practices

- Personal habits to change before planning to have a child.

The women want to change their exercise, tobacco use (New Castle County group), stress, mental health, and weight, before they have a child.

- Daily multiple vitamins
  - Thirty seven percent of respondents take multiple vitamins.
  - Fifty eight percent of respondents do not take multiple vitamins.
  - Five percent of respondents did not answer the question.
- Knowledge of which vitamins to take to become pregnant.
  - Seventy two percent of respondents (13) did not know which vitamins to take if they want to become pregnant.
  - Seventeen percent (3) of respondents did not know.
  - Six percent (1) respondent knows
  - Six percent (1) respondent did not answer the question.

- Level of comfort discussing personal questions with healthcare providers.
  - The New Castle County women are very comfortable discussing most personal questions with their health provider especially birth control, sexually transmitted diseases, and intimate partner violence.
  - The Kent/Sussex County women are very comfortable discussing most personal questions with their health provider on tobacco, alcohol, drug, and addiction questions. They are also very comfortable discussing routine wellness care. To a lesser extent, they are very comfortable discussing chronic conditions, obesity/weight control. And contraception. Only a few people responded to questions related to sexually transmitted diseases, intimate partner violence, and pregnancy plans.

## Overall, Health and Wellness

### *What is important about their health*

- Respondents shared their efforts to exercise more, change eating patterns and eat healthier, engage in self-care, drink more water, go outside more, sleep, take breaks, listen to music and journal. Respondents said that work schedules create pressure and stress. They are concerned about the homeless population and the lack of access to affordable, healthy food choices, and the ability to take walks safely.

### *Barriers to doing healthy things*

- Respondents said time, finances, work, children, and lack of motivation, and the pressure of day-to-day living, make it hard for them to be healthy. The exposure to food including eating fast food and junk food, and preparing food they like to eat, seeing commercials for food and Tik Tok recipes also make it difficult. Participants' inability to make appointments with healthcare providers, and lack of transportation are barriers. With respect to finances, the cost to join a gym is expensive and access to places to exercise for free or low cost is limited. The women said it is expensive to buy healthy food and mental and physical health must also be in balance.

### *Who helps them be healthy*

- The women said they have to self-motivated do healthy things and make healthy choices. Friends, family members, coaches, doctors, and community-based services provide support.

### *Who do you talk to about health?*

- Most of the women prefer to talk to God, close family, friends, partners, or boyfriends about their health who tend to be empathetic and listen to their concerns. They will talk with their doctors or therapists about their health concerns when it is a serious or difficult matter. A couple of the women said they keep their concerns to themselves. They stressed the importance of having a supportive partner. They also use Tik Tok and Google for health information. Not all of the respondents have support.

### *Managing stress levels*

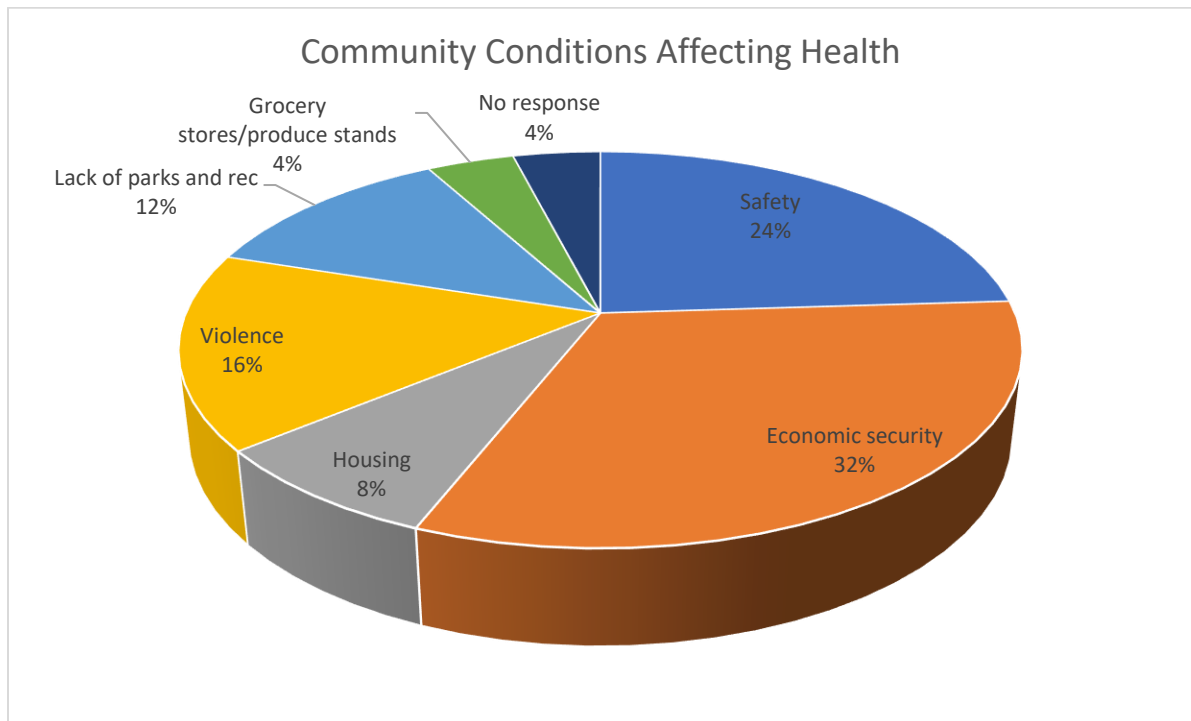
- Several of the women admitted to struggling with high stress levels. The participants said they pray, listen to music, journal, talk to friends, go for walks, find ways to be productive, go to the gym and work out, sleep, slow down, watch videos, or talk to someone, or use aromatherapy. One respondent mentioned that once she leaves work, her stress levels go down. As one respondent stated, *no one really understands the gravity of the stress I feel inside*. Six of the eight New Castle County respondents said they smoke (marijuana or cigarettes) to reduce their stress levels.

### *Healthcare provider encouragement to be healthy*

- Respondents said their healthcare providers can give them ideas and resources. Respondents spoke of the care they received from pediatricians and the hard transition it has been to less caring adult health care providers. They suggest the need for a transition program for younger people from child to adult care. One respondent expressed the need for a Black female doctor and another respondent said that she does not feel encouraged by healthcare providers as a Black woman and there is a racial barrier to which another respondent agreed. Finally, the group shared numerous negative experiences of Emergency Room and hospital care of Bayhealth and Christiana Care. They experienced excessive wait times, no treatment, or lack of concern.
- Respondents said their healthcare providers have helped them with medical issues, encouraged one woman to quit smoking and to lose weight. Another respondent said she did not like the advice she was given to change her diet in order to reduce her blood pressure.

### *Community conditions that affect health*

- Respondents in the New Castle County group said the community does not promote healthy activities and there is no motivation. One woman mentioned she would like to start yoga. Two of the women said drug addicts who are outside limit their ability to go outside and to the park. A respondent mentioned body shaming on social media as a deterrent.
- Respondents are motivated by their communities, music, and seeing friends, family, and coworkers who are making healthy choices or doing healthy things, achieve results from their efforts. They are also motivated by seeing exercising and dancing on Tik Tok, seeing public figures who go to the gym, or reading and hearing things about women's health.
- Respondents spoke of the need to exercise self-control and make good choices when it comes to healthy eating. Respondents also stressed the importance of being consistent and balancing mentally and physically.
- From the questionnaire, economic security and safety are the top community concerns that affect women's ability to do healthy things. Responses and the breakdown of other community conditions are in the chart below:



*Greatest concerns related to their health and well-being.*

- The greatest concerns of respondents were financial security, and public safety, having a supportive partner, mental health, family and community support, access to fitness centers, food insecurities.

*Healthcare providers offices*

- Three participants complained about their doctor's being mean, cool, or having too many other patients to see. They spoke of the need to find new providers.

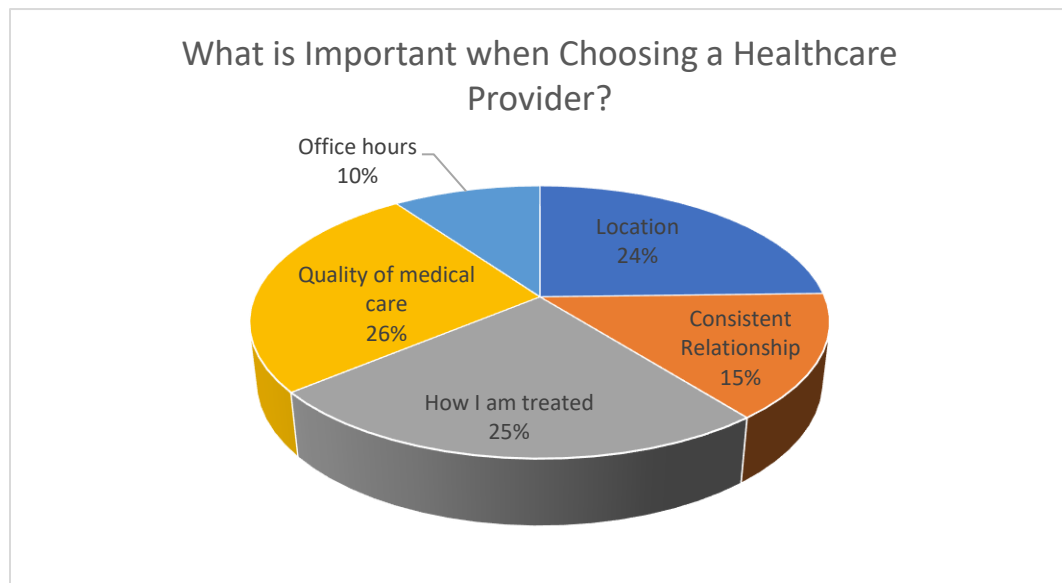
*Services available in the community*

- The New Castle County group has used services from St. Francis, Wilmington Hospital, Henrietta Johnson Medical Center, Porter State Service Center, and the Claymont Community Center. Four of the women had their wisdom teeth pulled at Wilmington Hospital's Women's Center. Two participants did not think there were services available in the community to help with personal questions and concerns.
- Most of the women in the Kent/Sussex Counties groups expressed concern about not knowing about services the community or where to go for help. They also talked about the services that are available that could be more engaging. Two college students receive services through the university, and they have a lot of information about programs and services in the community. Respondents suggested different strategies for marketing the programs so people would receive the information such as making it easy to understand.
- Respondents said services in the community that are missing are doctors who are engaged in the community, and information about places where one can go for free physical activities.

## Access and Quality

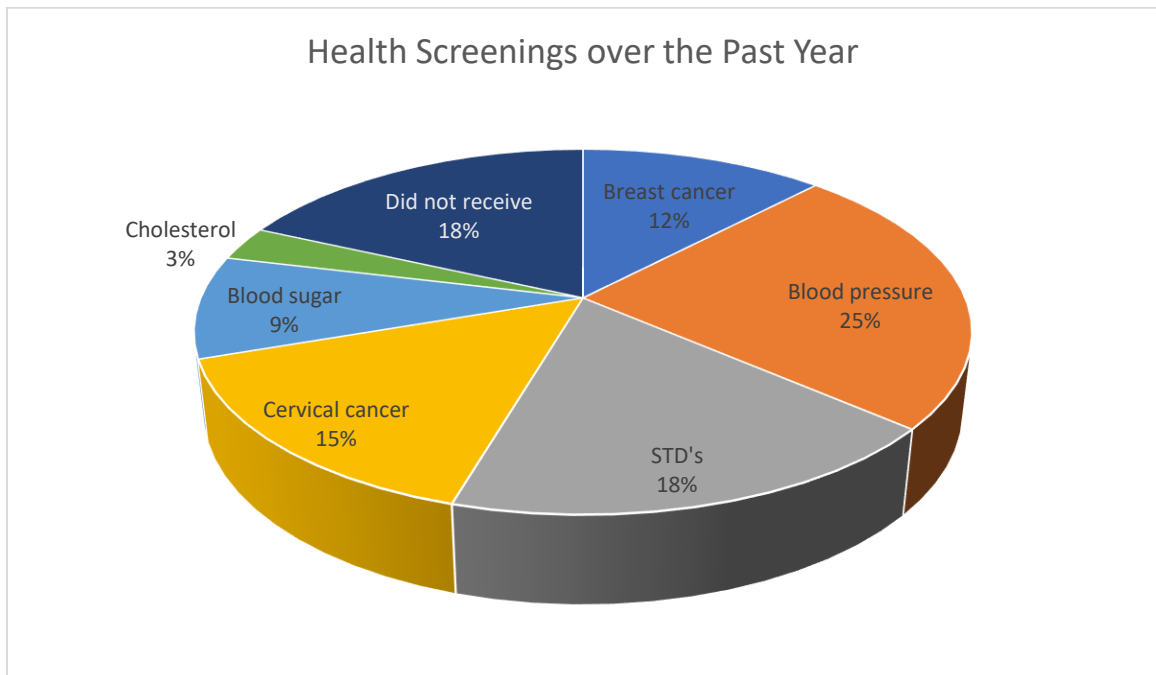
### *Importance of are healthcare visits*

- The women believe that healthcare visits are important to know one’s body, and practice preventive care which can be lifesaving and contribute to living a healthier, longer life.
- Several women are not able to go to the doctor because of their lack of insurance and affordability of visits and cost of medications. One woman shared that her visit to the doctor made her feel worse and when she stopped going, she felt better.
- Questionnaire responses revealed the quality of medical care, how respondents are treated, and location, are most important to them when choosing a healthcare provider. Less important are consistency of relationship and office hours. The breakdown of responses is shown in the chart below.



### *Health screenings*

- Respondents received multiple screenings over the past year. The most popular screening was for blood pressure. Eighteen percent of respondents did not have a health screening. The percentage breakdown of health screenings is shown in the chart below.



#### *Where respondents go for healthcare*

- New Castle County respondents: Henrietta Johnson Medical Center, Emergency Center, Doctor. (2 participants), Caring Minds. St. Francis Hospital. (3 participants), and Trinity Healthcare. Kent/Sussex Counties: Walk-in clinic (3 respondents), Primary care doctor (3 respondents), Urgent care, and Milton or Dover.
- To get to their appointments, respondents drive their cars. The New Castle County respondents have other options including public transportation, walking, friends or relatives or Uber/Lyft. Kent/Sussex County respondents, besides driving, rely on friends and relatives, and also use Uber/Lyft.
- Participants go for healthcare twice a year to annually. They will also go for healthcare when sick, or when they need a check-up.

#### *What they liked about their healthcare provider*

- Respondents shared the positive experiences they have with their healthcare provider. Their providers are timely, listen, answer their questions, take notes, give pamphlets, concerned, and respectful. One woman said her doctor pushed for her to get insurance when they were not going to pay. Another respondent shared that her doctor was a Black woman that the respondent thought was concerned and more empathetic.

#### *What they did not like about their healthcare provider*

- The participants do not like the attitude of staff who are rude or long waiting times. They do not like doctors with language and cultural barriers, or not getting enough information during an exam and feeling rushed. The participants shared examples of medication being forced on them, a doctor leaving a practice and that information not being shared, and a lack of care in the



hospital. Respondents suggested teaching nurses to be more empathetic, addressing structural racism, and implementing cultural competency.

#### *Ideal health care place*

- Respondents suggested the ideal healthcare place would be accessible, free, have a warm, safe, and welcoming atmosphere with a diverse pool of respectful doctors, nurses, friendly faces, and good time management. They liked the health care app that one of the respondents mentioned that sends and receives messages about refills.

#### *Challenges to getting healthcare*

- One respondent shared that when she needed a cortisone shot her insurance denied it. She was given a gel injection shot instead. None of the participants in the New Castle County group was aware that, under the Affordable Care Act, you are eligible for a no-cost preventive health/well-woman annual visit?

#### *Level of comfort with healthcare providers*

- All participants said they are comfortable discussing personal questions or concerns with their providers. One participant said that she lied to her provider about smoking marijuana.
- Only two participants out of eleven women in the Kent/Sussex County groups said they are comfortable discussing personal questions or concerns with their providers.

#### *What should be included in a Well Woman Visit?*

- Most of the group would like to see mental and emotional health included in the Well Woman visit. About half the group would also like to see nutrition counseling, chronic disease management and preventive screenings. Responses follow:

## **Reproductive Health**

#### *Reproductive life planning*

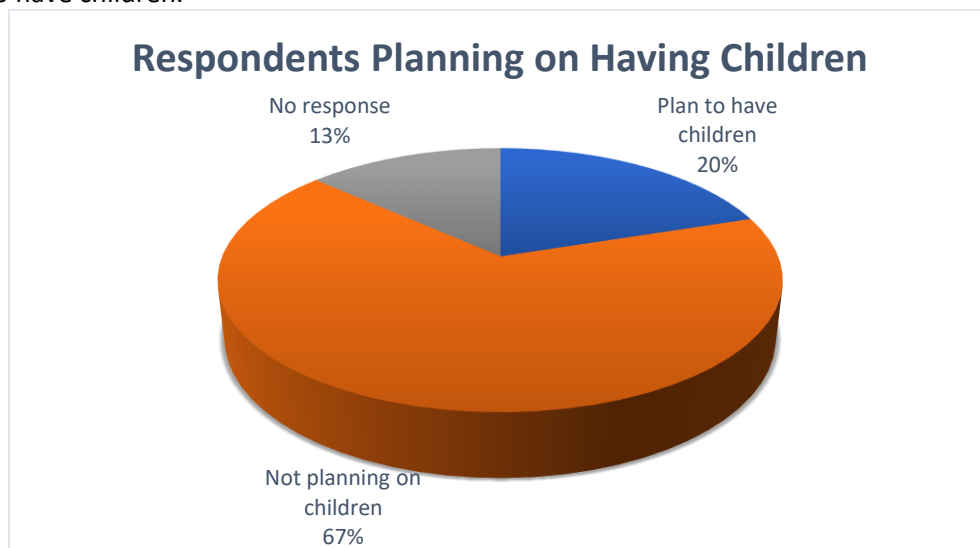
- Only two women out of both groups have heard of reproductive life planning and their providers have discussed a reproductive life plan with them.

#### *Comfort discussing contraception with healthcare providers*

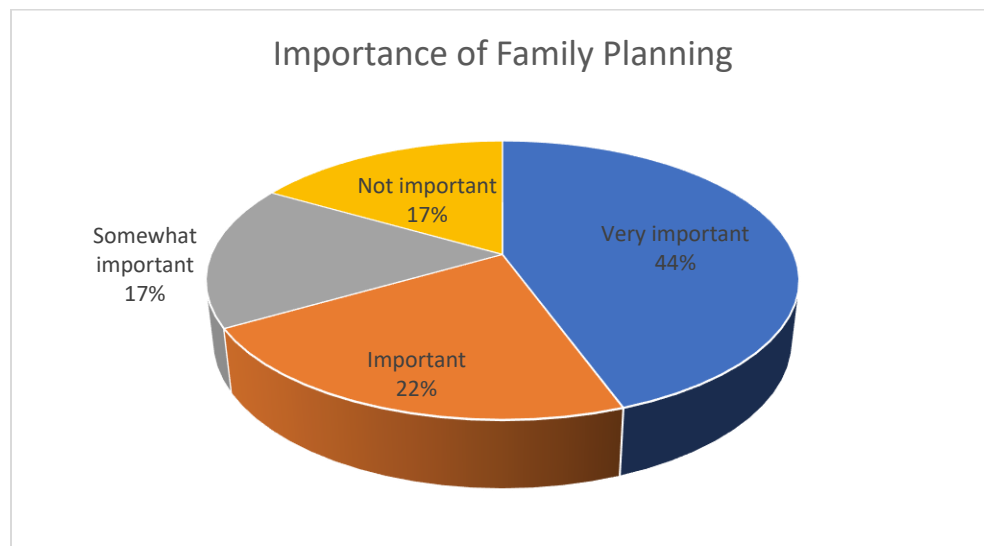
- Participants all have access to contraceptives but two of the youngest women did not know what the word contraception meant. The women said that age, transportation, the conversation, and stigma about contraception may make it hard to access.
- Seven out of ten participants of the Kent/Sussex Counties groups have access to contraceptives. The cost and insurance coverage makes it hard to access contraception. The women discussed difficulty getting IUDs and obtaining birth control pills.

*Family planning*

- The respondents like the idea of planning a family and believe that it is important. However, they have not thought about it or are not ready to have a family. The women who want to have children prefer to wait until they are financially stable.
- Only two women out of 10 in from the Kent/Sussex Counties focus groups said they planned to have children. The participants believe the world is not safe for women or them as Black women causing them to do not want to bring children into the world. They shared concerns about finances, and the affordability of housing, rent, and the economy. One respondent suggested that gay women have more to consider when planning a family.
- Overall, only three women of sixteen women who responded to the questionnaire said they plan to have children.



- In response to the questionnaire, forty four percent (8) of the women think family planning is very important. The percentage breakdown of all responses is shown in the chart below.



Seventy eight percent (or 11 of 19) respondents were not aware of specific services or programs that would help with family planning.

#### *Health to become pregnant*

- The women have been told to get married before getting pregnant, choose one's partner wisely, and to be mentally and financially stable and in a safe environment before getting pregnant. They also raised concerns about safe childcare, better healthcare providers, and age being a factor in choosing to become pregnant.

#### *Encouragement from healthcare providers*

- Two respondents suggested losing weight, eating the right foods, taking vitamins, and eating healthy. The other respondent would want more personal care from healthcare providers including a home visit. She said she would prefer a midwife or doula.

#### *Reproductive health services*

- Some of the women said they feel fine with their current health services. However, they shared poor experiences they have had with birth control and felt their healthcare providers did not provide them with sufficient information about the use or side effects. One woman who is 35 said that age makes a difference in how they are treated.

#### *Additional experiences*

- The women said that the doctors do not care and suggested more black doctors and nurses in the community and cultural sensitivity by doctors when treating Black women. It was also suggested that medical professionals need to be "more genuine" or real in their treatment.

#### *Everyday concerns or worries*

- Respondents are concerned about their futures and their financial situations. They worry about their jobs, their weight, buying a house, stability, independence or having children, and growing older and still unmarried, and not being about to pursue their interests.

## **Conclusion**

The questionnaire and focus group discussion covered topics such as health habits and practices, health and wellness, stress management, healthcare providers, healthcare access, and reproductive health. The women shared their struggles with making healthy choices, citing issues such as the difficulty in finding the right foods, the temptation of unhealthy options, and the high cost of healthy eating. The conversation on health and wellness explored participants' proudest self-care achievements, including exercise, dietary changes, quitting smoking, and drinking more water. They also discussed the impact of community conditions, highlighting safety concerns in certain neighborhoods, and addressing the heavy drug problem and homeless population in Delaware. The discussion also highlighted barriers to healthy habits, such as work schedules, transportation challenges, and lack of motivation in their communities., as well as the impact of social media on body image and self-esteem.

The respondents emphasized the significance of consistency, dedication, self-control, and seeing results as key factors in maintaining healthy habits. Additionally, they discussed the challenges of making healthier food choices, the struggle to diversify meal prepping while considering financial constraint, and the importance of self-motivation in staying healthy.

The participants shared their experiences with expensive gym memberships and the challenges of cancellation policies. They suggested free workout classes on a consistent basis to make fitness more accessible, especially for those facing financial hardships. Additionally, they highlighted the inconvenience of limited operating hours at certain fitness facilities.

Participants highlighted the impact of having a supportive partner or family member in maintaining health and weight management. Participants spoke about the challenges of discussing health and weight with others, especially in a society that places emphasis on physical appearance. The women also shared their personal experiences with managing stress, and their struggles with various coping mechanisms they have tried. They raised their concerns about the limitations of healthcare providers in addressing stress and the challenges of transitioning from pediatric care to adult care.

Respondents expressed the lack of awareness and promotion of available services, emphasizing the need to make these resources more accessible and understandable for low-income people and engaging with the community through hands-on activities and demonstrations to share health information more effectively.

The women expressed frustration with the complexities of health insurance, the high cost of healthcare, and the lack of support for medication expenses. The discussion on healthcare providers emphasized the importance of respectful and helpful treatment from healthcare providers and the impact it has on individuals' overall healthcare experiences. Participants express dissatisfaction with their providers due to instances of rudeness and language barriers. The conversation also touched on the ideal healthcare experience, emphasizing the significance of respectful and welcoming healthcare environments, efficient time management, and the convenience of accessing comprehensive information through an app. The discussion reflected a focus on patient-centered care and the importance of addressing barriers to healthcare access and the need for more representation of black doctors and nurses in the community.

The women had various levels of awareness of preventive health services under the Affordable Care Act, comfort in discussing personal concerns with healthcare providers, and access to contraception with some sharing experiences of inadequate information and understanding about contraceptive care. Participants shared their experiences and thoughts on planning for family and the number of children they want to have. The women felt financial stability, mental preparedness, and the need for a strong support system were factors to consider when having children. The impact of the current world situation is influencing their decision to have children, and they expressed concerns about the challenges of raising children in today's society.

Participants have anxieties about health, financial stability, and the unknown future. The discussion touched on the stress of managing expenses, the desire for financial security, and the fear of the unknown.

## Recommendations

1. Provide opportunities for women to have greater access to mental health services to address high levels of stress, anxiety depression. The Division of Public Health could partner with libraries and community agencies to provide support group opportunities and provide referrals to therapists and counseling services.
2. Provide vouchers for low and moderate income to participate in gyms and exercise facilities like the YMCA. DPH could work with community agencies to develop free pop-up exercise dance sessions in the community.
3. Work with the Department of Public safety to patrol public parks to ensure their safety so that women and children feel safe to exercise. Eliminate drug activity and marijuana smoking in public parks.
4. Develop a healthy food campaign with short videos that can be shown on Tik Tok and You Tube to show preparation of low-cost, healthy, delicious food options. The videos could also encourage healthy food choice alternatives.
5. Improved communication on contraception and birth control needs improvement on the part of health care providers. The term *contraception* should be clearly defined in all communications. Doctors, other health care practitioners, and pharmacists should explain the use of birth control pills and the side effects.
6. Health systems should be more aware of customer service and how they are interacting with patients from the reception desk to care givers. More can be done to communicate the wait times in ERs and hospitals. Medical staff should be trained on cultural competency and be aware of the behaviors that may result in negative interactions with Black women.
7. Healthcare providers need to improve their level of communication with women to be more empathetic, and actively listen.
8. Public Health Advocates can work on improving access to healthcare services and promoting the importance of healthcare visits for overall health and wellness.
9. The DPH could partner with community-based organizations to provide information on resources for financial planning and stability. Similarly, participants could benefit from having information on the housing market and resources for home ownership through partnerships with such organizations as Habitat for Humanity and Reach Riverside.
10. Individuals should advocate for themselves and ask questions during healthcare visits to ensure they receive the information and care they need. A tip sheet for women to remind them to ask questions would be helpful.
11. Public Health should continue to develop engaging activities or incentives to encourage participation preventive programs to increase response rates. Community health related organizations can increase visibility and accessibility of services to the community through hands-on activities, demonstrations, and role modeling.

## Major Findings – Children and Youth with Special Health Needs

### General Characteristics of the Focus Groups

New Castle County - Spanish	Kent/Sussex Counties
<p>Nine Hispanic women participated in the focus group held on March 18 at the New Castle Public Library. The group ranged in age from 21 to 49 and included one college graduate, one participant with some college, five high school graduates, one participant with a few years of high school, and one participant with less than elementary school. Reported annual income was from less than \$20K to \$40K. The participants were from Wilmington, Newark, and Newport. The women have one to three children each and they range in ages from 7 months to 17 years. Their children were diagnosed with Down’s syndrome (two children), autism (three children), autism/developmental delay and one child each with Trisomy 18, deafness/limited hearing, and ADHD. The group responded to all the questions and enjoyed participating in the group discussion.</p>	<p>A focus group was held on April 17 at the Dover Public Library with a diverse group of nine women from Kent and Sussex Counties who were mothers of children and youth with special health needs. Two of the women were Caucasian, five were African American, and one was Hispanic. The women ranged in age from 21 to over 49. Their children ranged in age from four months to twenty for a total of seventeen children. The mothers each had one to six children and one of the women was pregnant. Their children’s disabilities were wide ranging including ADHD, autism, developmental delay, spina bifida, Beckwith bleeding syndrome, Down’s syndrome, asthma, and deaf. Most of the children had multiple health issues. Two of the mothers have multiple children with disabilities. All but one respondent had college with an educational range of the group from high school graduate to post doctorate. Their annual household incomes were from less than \$20K to over \$75K. Everyone completed the questionnaire at the start of the session. The group participated openly and appeared to enjoy the session.</p>

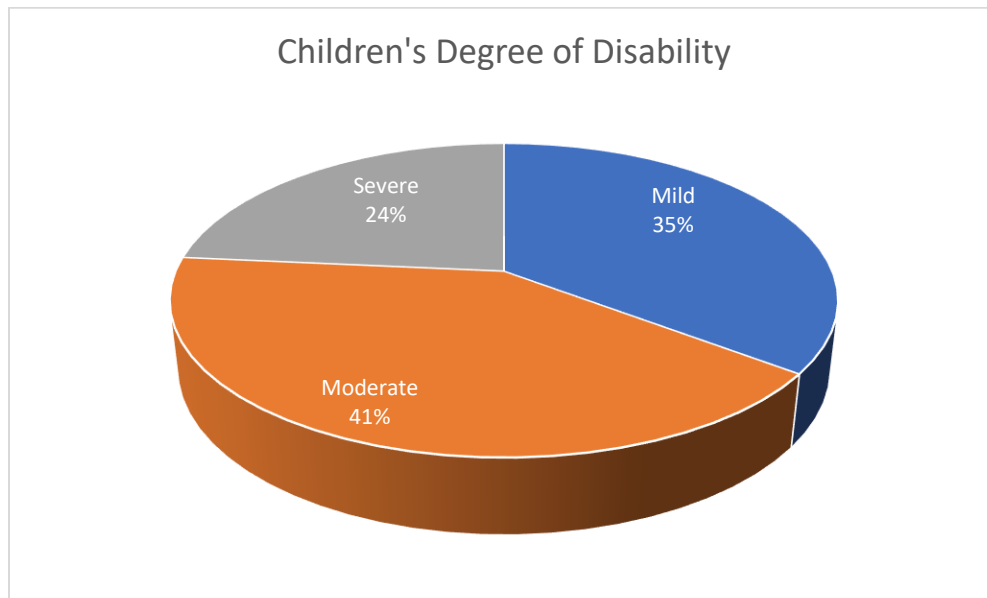
New Castle County	Sussex County - Spanish
<p>A focus group was held on April 9 at the Rt. 9 Public Library in New Castle with a diverse group of seven women from New Castle County who were mothers of children and youth with special health needs. Two women who were recruited could not participate just before the session because of a health emergency with a child and a nurse who canceled her stay with the child. Two of the women were Caucasian, three were African American, and two were Hispanic. The women ranged in age from 25 to over 50. Their children ranged in age from one to twenty. The mothers had one to three children. Three of the mothers have multiple children with disabilities. Their children's disabilities were wide ranging including apraxia, dyslexia, autism, ADHD, developmental delay, heart defect, epilepsy, language and speech delay, asthma, and limited hearing.</p> <p>Most of the children had multiple health issues. All but one respondent had college with an educational range of the group from high school graduate to post doctorate. Their annual household incomes were from less than \$20K to over \$75K. It should be noted that two of the women quit their jobs to be eligible to receive Medicaid. Everyone completed the questionnaire at the start of the session. The group was someone reserved with their responses and one Hispanic woman needed simultaneous translation to English by another respondent. They participated openly and at least two women shared contact information with one another after the session.</p>	<p>Eight Hispanic women participated in the focus group help on April 18 in the Georgetown Public Library. The group ranged in age from 25 to 49 and included three participants who completed high school, one participant with a few years of college, and three participants who only completed elementary school. They were from Mexico, Puerto Rico, and Honduras.</p> <p>Reported annual income was from no income to \$75K. The participants were from Georgetown, Milford, Lewes, and Lincoln. The respondents had children ranging in age from 20 months to 19 years. They had from two to five children each for a total of 22 children. Their children were diagnosed with epilepsy, autism, non-verbal autism, speech delay (two participants), ADHD, developmental delay, defiance disorder possibly autism, and downs syndrome. Four of the women had more than one child living with them with a special health need.</p> <p>Four women came very late to the group because of childcare and transportation issues. One woman who came late and brought her four children with her. The lateness and disruptions delayed the start of the group by 30 minutes and the end was cut short because the library closed. As a result, some of the questions at the very end of the discussion were left unanswered. The women who came late completed their questionnaires in the library courtyard. The group enjoyed participating in the group discussion and remained afterwards in the library courtyard to continue their conversation and exchange phone numbers to stay in touch.</p>

## Demographics

- Age of respondents.
  - New Castle County – Spanish: age range 21 to 49
  - New Castle County: age range 25 to over 50
  - Kent/Sussex County – age 21 to over 50
  - Sussex County – Spanish: age range 25 to 49
- Zip code of respondents' permanent residence
  - New Castle County Spanish speaking group: 19804 (3), 19805, 19808 (2), 19720 (1), 19713 (1)
  - New Castle County: 19720 (3), 19805 (2), 19801 (1), 19711 (1).
  - Kent/Sussex County: 19904 (4), 19977 (2), 19901 (1), 19950 (1), 19975 (1).
  - Sussex County: 19947 (5), 19963 (1), 19958 (1), 19960 (1).

- Children’s primary disabilities. Respondents identified their children’s primary disabilities. Many of the children have multiple disabilities. The most frequently identified disabilities are autism, ADHD, and speech delay. The disabilities diagnoses are listed in the chart below with additional number of children diagnosed with the condition, where applicable.
  - Apraxia
  - ADHD – 6 children
  - Asthma -2 children
  - Autism – 10 children
  - Beckwith Bleeding Syndrome.
  - Bipolar disorder.
  - Conduct disorder
  - Defiance disorder possibly autism
  - Developmental delay – 3 children
  - Delays in physical, language, and other areas
  - Down’s syndrome – 4 children
  - Dygraphia
  - Epilepsy
  - Food restrictions.
  - Global motor planning delay
  - Immune deficiency
  - N-G tube dependent.
  - Nonverbal autism
  - ODD
  - PTSD
  - Deafness/limited hearing – 2 children
  - Sensory processing disorder
  - Social and emotional.
  - Speech delay – 6 children
  - Spina bifida.
  - Trisomy 18
  
- Children’s degree of disability. Respondents for the New Castle and Kent/Sussex County focus groups indicated on their survey questionnaire the degree of their children’s disabilities. For those who responded. As the chart illustrates, forty one percent of the children have moderate disabilities, thirty five percent have mild disabilities, and twenty four percent have severe disabilities.





- Children's enrollment in education or training programs

Almost all participants had their children enrolled in education or training programs. Many services are delivered in schools with children having an IEP. Physical, occupational and speech therapy services are mentioned most frequently. The following are the services mentioned for each child:

- Early childhood intervention in school and psychologist every week
- Speech therapy, feeding/eye therapy, and physical therapy
- Physical therapy
- Speech therapy (mentioned twice).
- Occupational therapy (mentioned twice).
- School and childcare.
- Brennan School offsite program.
- Jennie Smith School DAP program
- Nemours Beckwood – speech therapy, feeding therapy.
- Physical therapy, occupational therapy, speech therapy, and feeding therapy.
- Birth to Three Program – speech therapy.
- Colwyck – occupational therapy, speech therapy, physical therapy.
- Nemours – occupational therapy, physical therapy.
- Private – speech therapy.
- Birth to Three Program – ECE, speech therapy.
- Medical daycare, IEP with Capital School District. Part time occupational therapy, SLP audiology, TDD, LSL, ASL.
- Birth to Three Program
- Education program, Smyrna Middle School speech, physical therapy, occupational therapy.

- Special Olympics, Autism Delaware, PBA
  - IEP in school (mentioned twice)
  - Stockley Head Start.
  - Child Development Watch
  - IEP and separately, speech, occupational, behavioral, and feeding therapy.
- 
- Access to a cell phone.

Not all respondents answered the survey question. Out of the four groups, only two people did not have a cell phone.

## Medical Home Information

### *Difficulties finding a good physician*

- The women had mixed experiences from excellent care they receive by their doctors to challenges they had with transitional care, and proper diagnoses and treatment. They have taken their children to Al Dupont Hospital, the Children’s Hospital of Philadelphia (CHOP), Delaware Pediatrics, Children’s Secret Garden, and Christiana Care. They have received therapeutic services from Easter Seals and Nemours. The women shared how they struggled to find the right care for their children and. In cases with improper treatment or diagnoses, the mothers had to advocate for their children or find another doctor. Sometimes it meant going against doctor’s orders to advocate for what they thought was best for their child.
- Respondents also shared that they have had good experiences with Nemours and the doctors there. Spanish speaking respondent also said that Nemours provides great support and there are bilingual doctors and interpreters.
- Spanish speaking respondents have not had difficulties in finding a good physician. However, they shared how difficult it is to get an appointment with a pediatrician especially when it’s the first time, and also for referrals. Early childhood intervention is very important, but it takes three months to get an evaluation. There is a long wait for evaluations, and there are many mothers who have children with special needs and do not know it. Most satisfactory interactions are with doctors who speak Spanish and who also have children with special needs. Advocacy and support with groups like the focus group are important. They feel a network of doctors they can rely on would be helpful, and if they speak Spanish that would be even better.
- Respondents think the Department of Health and Social Services’ webpage is complicated and moms give up looking for help. There is also language barrier related to their ability to speak English and the fact that doctors do not seem to pay attention to or understand parents’ concerns. Finally, there is also a lack of knowledge by respondents of the special needs’ world.

### *Relationship with doctors (from the survey questionnaire)*

- Spanish NCC – All respondents reported that their child’s physician always respects their wants, needs and preferences in receiving care and treats them and their children with respect and dignity. All respondents said they feel that their child’s doctor always makes sure care is

received in the right place, at the right time and in the manner that best suits his/her needs. All other services provided by the doctor were rated from good to excellent.

- New Castle County - Respondents find the relationship with their child and their treatment to be good to excellent. They rate their doctors' access to a professional team of providers highly. They also rate their doctor's provision of care from good to excellent. Responses varied from very poor to excellent to how good their doctor is at coordinating care, providing access for afterhours care, and helping respondents make informed decisions about their children's care.
- Kent/Sussex County - All but one respondent finds the relationship with their child and their treatment to be excellent. They rate their doctors' access to a professional team of providers highly. They also rate their doctor's provision of care from fair to excellent. Responses varied from very fair to excellent to how good their doctor is at coordinating care, providing access for afterhours care, and helping respondents make informed decisions about their children's care.
- Sussex County Spanish - The majority of respondents reported positive interactions, services, and experiences with their doctors especially with treatment and understanding of their child's disability. However, about a fourth of the group had less positive or poor interactions or experiences. Treatment of chronic conditions, preventative services, acute care services, and care coordination had some poor to fair ratings.

#### *Family centered care*

- Most respondents of the New Castle County Spanish speaking group agreed that they are receiving family centered care from their health provider. They shared that doctors ask them about family interactions, how relatives can support children with special needs, and that their health care providers care for their well-being and mental health.
- The New Castle County respondents did not think the care they receive from their health provider is family centered. Services are not set up with families in mind and there are not enough resources. Kent/Sussex County respondents said they receive family centered care from their health provider and the school districts.
- Sussex County Spanish speaking respondents agreed that doctors are too busy and that there is very little time to chat and get to know their children. They also shared the language barrier is a hindrance to have proper conversations and for doctors to learn more about the family and provide treatment. They further shared that as mothers there is wealth of knowledge, they have about their children that could speed diagnosis and treatment. However, the lack of communication between parents and healthcare providers is a big obstacle to achieving better outcomes for children with special needs.

#### *How health providers handle referrals*

All respondents have good experience with referral by health providers. Respondents shared that their health providers refer them and make the appointments for them. For example, one person shared, when someone in her family hit her head, they took care of everything. At

Nemours and St. Francis, doctors are very committed. Most of the respondents have to follow up after referrals are made to ensure they are properly coded for insurance purposes. *Referrals are fast, efficient, and effective from Nemours and CHOP.*

#### *Experience with care coordination*

- Overall, respondents find care coordination to work well, and they have good experiences.
- Respondents in the New Castle County Spanish speaking group shared their positive experiences. A participant shared that when her child has acid reflux, she only needs to leave a message in the Nemours app, and she is quickly called back. She uses the translator and puts the message in the app to communicate in English. Many respondents said that their doctors take care of everything. They have a direct number to their doctor and can call at any time. This is true also for their cardiologist and pulmonologist. Parents can directly contact all of them. One respondent shared she had a bad experience with the people from information in the area of gastroenterology. She said the receptionist made fun of her saying, “These are the kind of people we have to deal with sometimes,” but nurses and doctors are all very good.
- The respondents from the New Castle County group found some coordinators very helpful who decide for their children and communicate well. However, they experience turnover with their care coordinators which makes it hard to establish a consistent relationship. The mothers have been told that their children have graduated out of particular programs but without explanation. There does not seem to be a system in place for prolonged treatment or service. The respondents spend considerable time trying to determine if services or supplies are covered by insurance. A respondent without a case manager said she felt lonely and had no one to answer questions. The respondent with private insurance did not have a case manager. It was suggested that Google and Facebook groups provide additional support.

#### *Doctor discussions of community resources available*

- Respondents of three of the four groups said that doctors do not provide community resources that are available. The mothers might receive information if they ask but are generally left on their own to find resources by asking around, or through school or state agencies.
- Respondents shared that social workers help them get diapers and with insurance that includes transportation. They also mentioned that there is no one to explain all the insurance benefits. They have to ask around to get the information.
- Additionally, respondents said that services below the canal are not available and people in their communities are underserved. There are no services for the deaf downstate.

- Respondents of the Spanish speaking Sussex County group shared that doctors do not talk about community resources. They focus on the diagnosis, and they do not share information. Respondents are mostly uninformed about basic information that everyone seems to know about like where to sleep when you spend the night at the hospital. Respondents expressed they come by information by chance or on their own. They have to educate themselves on the disability, the healthcare system in the country, the language and they find there is no one to trust. The New Castle County group shared that their doctors were very supportive of resources, especially those concerning actual help and support for parents and caregivers. They mentioned places like the Latin American Center, Harpers' Heart, Social Security, and schools where they get support.

#### *Developmental screening*

- Respondents said that community services, not the health care providers, made information available to them for developmental screening. Community services mentioned were Child Find, daycares, Parents as Teachers, and schools. Respondents said their children did not get developmental screening early on. Three participants' doctors screened their children for meeting developmental milestones

#### *Physical activity, or preventive dental care*

- Respondents shared that they received dental information and sometimes they did not. They commented that it was hard to get a dentist because dentists do not want to service children with special health needs. Dentists are a great need, but they do not understand the children's behaviors. Mothers need to explain when children are afraid of needles, cry or get upset, and need to calm down children so they can receive dental care.
- Mothers must support dentists in their work because dentists are not prepared to provide services to children with special needs. A respondent shared that there is always the fear that the child will have a convulsion. She's had very bad experiences with dentists in Delaware and noted how the dentist was nervous during their first visit. It is hard for mothers to get referrals for a dentist.
- Respondents also mentioned that there is no support for physical activities for her child who is obese. Her child only sees the nutritionist. It was also commented that for eye-doctors, the mothers need to go to Lewes or Rehoboth because there are no specialized eye-doctors. Children with autism have a hard time being in a foreign place many times with limited space environments and feel very stressed. Doctors are poorly informed about children with special needs.

#### *Changes they suggest in the health care system*

- Respondents expressed the opinion that better qualified personnel regarding special needs should be available. Children with special needs have very specific needs depending on the condition. More programs to teach moms how to take care of their children are needed. They also wished to be heard more on what they know about their children's condition when it comes to referrals

- The mothers complained about the insurance coverage limitations placed on services and supplies for their children and lack of healthcare providers. They suggest increasing accessibility and flexibility in the health system, which needs more providers who read the charts of their children and conduct assessments early.
- The women would like to see care coordination, easier access to resources, and greater access to disability Medicaid. They suggested travel reimbursements or stipends to help with travel costs. The state website is not user friendly or up to date. Parents understand each other and share resources better than what is provided through other sources. Delaware Autism was mentioned as an agency that provides information and connects people with resources.
- Respondents agreed that overcoming language barriers and getting information about the healthcare system, resources available, education on their children's special needs would enormously help them manage issues and challenges. It was mentioned many times how little help and support parents with children with special needs get. There is a great need for more networking support groups and easy access to information localized in one place.

## Family Support and partnerships

### *Topics they felt positive about*

- Respondents are positive about the Internet resources, schools and teachers, and husbands who provide additional support. They felt good about their connections through social media and their use of the Internet. They liked being asked questions from a parent's perspective. Delaware Autism is viewed as a positive resource.

### *Topics they felt negative about*

- Respondents shared that sometimes they get more support from strangers than from their own family. *They did not have family support or a husband to help them. One shared she only had her mom, and another shared she only had her husband and the nurse as support.* Also, it was mentioned that no one can watch their children every day, and when they do watch their children, it may be just for a while. They share that they were afraid to leave their children with other people because of their special needs, and only nurses know how to take care of them. Sometimes their friends are scared of the equipment their children need.
- Respondents felt that they are given advice that they do not understand. One respondent stated that teachers compare her autistic child to other children his age. They also complained that the family does not know how to manage and there is no help from doctors or family.
- The women spoke of the difficulties they have being the sole caretaker. They are alone with their children all the time, have no downtime, and do not get time off. One respondent suggested respite services offered by the Delaware Division of Social Services.
- From the survey questionnaire, sixty five percent of the respondents have a second adult who lives in the household who can help with caring for their child or children.

### *Experience with bullying*

- Respondents shared about two types of bullying: in the classroom and from strangers. In the classroom most bullying happens from the lack of understanding that peers and teachers have about the children’s special needs.
- Mothers feel bullied by strangers who look at the children as “sick” or even question them on their choice to have a child with special needs. Mothers worry about their children being called names or being bullied or pitied because of their condition.
- Mothers experienced their children being bullied by other children or rude comments from parents at school or electronically. They shared examples including a post on social media by a parent who did not want their child in the same classroom as a respondent’s child.
- Mothers reported their children were bullied at school. One of the women said that parents are not instructing their children about disabilities and bullying, but parents are also pointing at and talking about her child.
- Respondents mentioned incidents during transportation in the school bus even though these are school buses for children with special needs. Bullying is not seen by teachers and administration and many times when children with special needs report bullying, nobody in the school believes them. Special needs children have difficulties to communicate this too. Respondents agreed that it’s important to listen to children when they report bullying instead of minimizing it.
- A respondent had to take her child out of school because of the bullying. Respondents suggested increased communication about bullying in schools, showing videos, and having classes for the parents and the offending child.

### *Community resources*

- The majority of the Sussex County Spanish speaking group do not use any community resources to help with their child’s care. Three respondents said they do use community services and mentioned: Respite Care with Medicare, Sussex Consortium, schools, and Easter Seals.
- The New Castle County Spanish speaking respondents shared that Medicaid help was most important otherwise they would not have help with medicine and treatments. However, it is difficult to renew it. There are objections and if something is missing, they have to come back. If they ask to speak to someone is Spanish, the workers respond angrily, are disdainful, and ill-spoken or make fun of them. One respondent shared that she tried to renew in the Medicaid webpage, but it did not go through. She had a confirmation number but was told they had not received anything. Another shared that hers was cancelled because she had not added the children and needed a social worker to help her with this, which was a lot of trouble.
- Respondents stated that schools, Delaware Autism, Birth to 3 programs, Easter Seals, and Parents as Teachers, and Down Syndrome Association of Delaware were valuable in caring for their child. One respondent received was not able to receive services from the Birth to 3 programs. One respondent shared that she had heard SSI is good but has not applied for help for the children with autism and the social worker says they ask for too many things.

- Spanish speaking respondents in the Sussex County group found valuable text messages from the school regarding a Department of Education monthly meeting with parents whose children have special needs with doctors and specialists as speakers. They also shared that medical insurance covers help with children so that parents can have time to rest and breathe. They need to apply and sometimes it takes a long time to get approved. A respondent shared that a social worker referred her to a Respite program that offers her 285 hours of care for each child. She found a person she trusted with her children and this person is paid through this program. Another respondent shared that someone who had children with autism explained to her about Social Security Disability. She applied and the process took two years. Respondents suggested more conferences where SSI benefits and Medicaid for children can be explained. Parents overall agreed that they don't know about resources, and they need people who are sensitive enough to work in the entities that provide these services. The mothers feel the system makes things difficult for them and so they give up.

#### *Internet use and resources*

- The survey questionnaire revealed that ninety one percent (or 29 of 32 who responded) have access to the Internet. Ninety one percent of respondents (29 of 32 who responded) use the internet and social media to find resources to help care for your child and one out eight does not.
- Respondents mentioned the Latin American Center provides information on nutrition and divorce. They also mentioned the Down Syndrome Association, Embrace, the American Society for Deaf children, and other links for groups of parents who share experiences and problems. Respondents identified Google, You Tube, and Facebook groups as valuable resources. They said that You Tube was a good resource, and one mother shared she learned how to put the tube for her daughter from watching it. Another participant shared by searching in You Tube she found a trisomy group in Mexico and one in California and Arizona.

## **Social determinants of health**

#### *Services in the community*

- Spanish speaking respondents in New Castle County mentioned transportation difficulties like uncooperative drivers to help and also being left last when transported home. They shared their neighborhoods felt safe overall with police patrolling at night. Some mentioned that youth hanging on at the corner, dogs that are threatening, and cars driving by fast on the street, are concerns, making it unsafe for children to play outside. One participant mentioned the support at work during her pregnancy. Some found their neighbors friendly and helpful whereas others had no contact with them.



- Respondents felt that the community lacks resources and information is not readily available. The mothers find support from other mothers through shared experiences, and with a community that has similar issues. Respondents do not allow their children to play outside because of fear of human trafficking, and violence. Respondents in Smyrna, Greenwood, and Dover said they feel safe in their community. They said the communities lack activities and resources. DART public transportation service is limited downstate
- Spanish speaking respondents in the Sussex County group agreed that they can get transportation with Medicaid to take them to their appointments. One respondent shared that she had a bad experience travelling to Wilmington with her child that had a tracheotomy, and a man started smoking, so she stopped using the service. Regarding services in general, respondents shared that in their area services are limited. They feel people do not want to help Hispanics or provide them with information. Additionally, they feel there is no support in their community. They believe there are plenty of resources that are not shared with them.

#### *Current housing situation*

- All participants believe that their current housing situation is adequate.

#### *Access to healthy food choices*

- Respondents mentioned the Latin American Center, WIC, SNAP, food banks, and the farmer's market as sources of food, and 211 for food and information about housing. One respondent shared her children had applied for stamps and that was the only resource she had now. Respondents said sometimes the food bank gives food that has expired, and it is not set up for special health needs. A couple of respondents commented that healthy food is expensive and does not last long as other sources of food.

#### *Having enough food to eat*

- Most respondents said that they and their children had enough to eat. The Spanish speaking women shared that daycare and the Latin American Center, and food stamps helped them. All participants believe they and their children have enough food to eat, although one respondent said she had experienced not having enough food before.

#### *Community Conditions Affecting Their Children's Health*

- New Castle County Spanish - Five out of eight said there is no one who understands the healthcare system or the social services systems and can help respondents in dealing with them. Most reported it was somewhat easy to very easy to find the health care resources they need to care for their child. Six out of eight respondents said it was somewhat easy to very easy to find the social services they need to care for their child. Three out of eight respondents reported it was somewhat easy to very easy to transport their child to doctor appointments or treatment centers. However, three reported it was somehow difficult.
- New Castle County - Three and four of seven respondents find it somewhat difficult to difficult to find the healthcare resources and social services they need. The majority of the respondents have no one who understands the healthcare or social services systems. The respondents that

do have help receive assistance from a case worker, Parents as Teachers, and friends. All but one respondent feels safe in her community, but half of the group do not feel their children are safe playing outside. Half of the group is not very secure in the income coming into the household. None of the respondents have struggled with drug or alcohol dependency.

- Kent/Sussex County - Three and four of seven respondents find it somewhat difficult to difficult to find the healthcare resources and social services they need. The majority of the respondents have no one who understands the healthcare or social services systems. The respondents that do have help receive assistance from a case worker, Parents as Teachers, and friends. All but one respondent feels safe in her community, but half of the group do not feel their children are safe playing outside. Half of the group is not very secure in the income coming into the household. None of the respondents have struggled with drug or alcohol dependency
- Sussex County Spanish – Seven out of eight respondents said it was somewhat difficult to very difficult to find the health care resources they need to care for their child. Only one reported it somewhat easy. They also responded it was somewhat difficult to very difficult to find the social services they need to care for their child. One said it was somewhat easy. Seven out of eight said there is no one who understands the healthcare or social services systems who can help them. Only one respondent said there was one and mentioned care coordinator. Four out of eight respondents reported it was somewhat easy to very easy to transport their child to doctor appointments or treatment centers. Four reported it was somewhat difficult to very difficult.

## Transition care

- None of the mothers of older children had pediatricians who have spoken to them about transitioning their children to adult services.
- One mother said her daughter is well prepared to transition to adult services because her daughter's therapist helps her with decisions. Another mother said her child *is fearful of the transition*.
- Some respondents who answered the question did not see any major barriers to their children transitioning to adult care. The research they do on their own appears to be adequate. Other respondents identified barriers to their children entering adult care as communication challenges with the transitioning patients and finding adequate providers.

## Wrap Up

### *Everyday concerns and worries*

- Participants worry about the state of the economy and their financial situation, and the well-being of themselves and their children. They worry about childcare and the difficulty getting daycare when one is not working, holding on to their jobs and how hard is to keep a job when unexpected things happen to their children, and how all the money they get goes to babysitting. They also worry about taking care of their homes, buying diapers and toys for their children, and their children being misunderstood safety and them getting into trouble.

*Additional comments (from notes on questionnaire)*

- New Castle County Spanish - Participants suggested training and mental health programs for mothers of special needs children. They also expressed concerns about not being able to continue to take care of their children as they grow, and they become sick or are unable to work and care financially for their children. Lastly, a participant shared her concern about poor customer service when making phone calls that go unanswered, lost paperwork, and being treated rudely when asking for someone who speaks Spanish.
- Sussex County Spanish - Respondents concerns and challenges were the language barrier, difficulty qualifying their child for medical care or finding providers who understand autistic behavior.

## Conclusion

Participants shared their experiences and challenges in caring for children and youth with special health needs. The survey questionnaire and the discussions highlight the diverse experiences and health concerns of the participants, fostering an understanding of the range of child health issues within the groups. The participants discussed the challenges of finding a good physician and the importance of family-centered care in healthcare. They also shared their personal struggles and challenges as parents of children with special needs, discussing difficulties with healthcare providers, work-life balance, and accessing necessary services and support. Several participants openly shared their experiences as parents of children with special needs, including the emotional and practical challenges they face, as well as the importance of mutual support between parents in similar situations.

Participants have good experiences with referrals and care coordination especially with Nemours and Children's Hospital of Philadelphia. They also feel good about the support and help they receive from family and friends. However, both the New Castle County group and the Sussex County Spanish group had many mothers who did not have any help or support from family members.

Respondents face obstacles in dealing with insurance coding, emphasizing the critical role of proper coding for insurance coverage. They also talked about care coordination experiences for children with health needs, where parents shared their challenges and frustrations with the turnover of care coordinators. There are discrepancies in access to services and information and limitations of insurance coverage. The participants emphasized the urgent need for more early assessment of children's health conditions and needs by health care providers, and greater flexibility in support systems for parents with special needs children.

Participants shared personal experiences with the healthcare system, highlighting the lack of care and support for their children with special needs. The participants also face issues with records, misdiagnosis, and delayed treatment. They emphasized the need for parents to advocate for their children and trust their instincts, sharing their own experiences of having to fight for proper care. They want to build rapport with healthcare providers and consistent care coordinators, and seek out the best possible care for children, even if it means going out of state. The Spanish speaking participants face obstacles because of language barriers, lack of understanding and support from some doctors, and what

they believe is discrimination from health care providers. In addition, the mothers need greater sensitivity and understanding on the part of health professionals and more family centered care. The respondents said that they had not been asked about developmental screening for their children and suggested the assessments be performed much earlier.

Participants shared their experiences and challenges in accessing therapy and healthcare services for their children, including difficulties finding good therapists and navigating the referral process. Additionally, they discussed the lack of information on state and community resources from healthcare providers and the disparities in available resources in different regions citing community resources are less available downstate.

The families of children with disabilities face challenges when trying to access health care, and there is a lack of communication and support from health care professionals. They expressed frustration at not finding dentists and doctors trained to care for her son and noted the need for greater preparation and understanding from these professionals. In addition, the discussion highlighted the importance of educating doctors and dentists about the specific needs of children with disabilities to ensure equitable access to health care. They also face challenges with their children being bullied in school.

Community resources and social determinants of health that impact their children's well-being and respondents shared resources they value including schools, Birth to Three program, Internet resources, and assistance in transportation and respite care. The Sussex County Spanish group had little knowledge of community resources and had the least amount of support from friends and family, and the poorest relationship with their children's doctors. Parents worry about the safety of their communities and the adequacy of housing. The parents shared their experiences and challenges, highlighting the importance of finding support within their communities and the impact of financial accessibility on obtaining food.

The discussion on personal worries and concerns prompted participants to share their fears and anxieties. The conversation delved into the economic strain experienced by many, with participants expressing concerns about financial instability and the potential impact on their children. The group also discussed the challenges and support required for transitioning children from pediatric care to adult care, emphasizing the importance of improving maternal and child health services in Delaware, especially for children with special needs.

## Recommendations

1. Doctors and Specialists should improve communication and coordination with families to ensure more effective medical care.
2. DPH could develop a directory of resources and services for parents of children with special health needs and make it available on the State website but also through health provider offices and community agencies. The directory should list services by county and be available in English and in Spanish and accessible for people who do not have a cell phone or access to the Internet.

3. A list of support groups for different health conditions could also be made available so parents could more easily find a common disability community that would help them share information and concerns.
4. Improve the DHSS website to be more user friendly for parents of special health needs children.
5. Increase insurance access. Consider options to educate healthcare providers about proper insurance coding for referrals. The state should evaluate limitations of Medicaid for certain coverages for special health needs children. Ease the application process for parents of children with special health needs. Private health insurance should have greater options for case coordination, so mothers do not have to quit their jobs to take on public insurance to have greater access to services.
6. Healthcare providers who work with bilingual Spanish parents of special needs health children need sensitivity training and cultural competency to improve interactions with parents and their children. Training should be provided to all health care providers and in addition, front line staff, and people who answer the phones.
7. The School Community should implement policies and programs to prevent bullying and support children with disabilities in schools. Such programs can include education for parents and children, guidelines for bus drivers, and written and online information on bullying.
8. DPH should partner with LaRed Health Center, Community Health Workers to provide support to Spanish speaking parents of special health needs children to help them identify resources and navigate social and health care systems.
9. More bilingual health providers are needed to address language barriers of Spanish speaking parents of children with special health needs.
10. Offer workshops for parents of special health needs children on how to apply for Medicaid and SSI.



**ATTACHMENT: FOCUS GROUP QUESTIONNAIRES AND DISCUSSION GUIDES**