Data Highlights

Delaware Standards for Culturally and Linguistically Appropriate Services in Health Care (CLAS) Initiative
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Introduction

In 2005, the state legislature created the Delaware Healthy Mother and Infant Consortium to narrow and or eliminate racial and ethnic prenatal care differences. The Consortium’s mission is to provide statewide leadership and coordination of efforts to prevent infant mortality and improve the health of women of childbearing age in Delaware. To support this mission, the Consortium’s Health Disparities Committee, with support from the State Division of Public Health, sought input from consumers and health care practitioners (nurses, nurse practitioners, physician assistants and physicians) throughout the state. To this end, the Consortium contracted with Altarum Institute to undertake the following activities:

- Review available reports containing relevant secondary data on maternal and birth outcomes
- Administer a brief Web-based survey of providers serving the maternal and child health (MCH) population to collect information about cultural and linguistic policies and practices within their organization or practice
- Conduct focus groups with consumers to learn more about the health care experiences of women throughout state

This document presents the key findings of those data collection efforts, which will be used along with the results of the Stakeholder Forum on CLAS standards, to inform development of a plan for implementing standards for culturally and linguistically appropriate care for women, infants, and their families. The Consortium was commissioned by the Governor’s Infant Mortality Task Force to develop the plan; this data collection effort is one of several activities undertaken by the Consortium to gather input from providers and consumers as part of the development process.
A Health Capacity Snapshot

In a 2008 Health Capacity Studies with the Center for Family Health Research & Epidemiology and the Health Systems Bureau, the Consortium found that 7 out of 27 (26%) of Census County Divisions have a potential shortage, some shortage, or significant shortage of primary care physicians. I Of 737 full-time practicing primary care physicians, only 11% (83) are obstetricians/gynecologists, making a shortage of OB-GYN care practically unavoidable. II As Figure 1 illustrates, Kent and Sussex counties are the most underserved in OB-GYN practice sites, with many Census County Divisions having no OB-GYN practice to report. This is true for 14 of the 27 Census County Divisions in the state. The most overburdened practices are in the Millsboro and Greater Newark Census County Divisions, with a range of 7,001 to 26,841 women per OBGYN. III

Figure 1. Regions of Concern

Women participating in the Wilmington Consortium study described having limited options for preventive care in their communities. The provider shortage creates a real barrier for women seeking OB-GYN services. Other barriers include limited provider Medicaid participation and travel distance. OB-GYNs tend to be located near hospitals, which mean longer travel distances for women seeking OB-GYN services. IV

Pregnant and postpartum women reported using mobile clinic services or having to travel to access care at community clinics and hospitals. Insurance coverage—or lack of it—limited care options, especially for women who are unable to find a provider that accepts Medicaid. V VI This is consistent with a finding from the Perceived Discrimination Study, which found that lack of coverage delayed initiation of prenatal care by 4.3 weeks. V VII

There are 83 practicing OBGYNs in Delaware:

- 64% practice in New Castle
- 22% practice in Sussex
- 14% practice in Kent.
A Health Disparities Snapshot

In Delaware, the Infant Mortality Rate is significantly higher among African-American infants, ranging between two to nearly three times that of Caucasian infants.\textsuperscript{x} Delaware is the second smallest state but has the fifth highest infant mortality rate in the nation.\textsuperscript{x}

\textbf{Figure 2. Infant Mortality Rates by Race and County for Delaware, 2002-2006}

\begin{figure}
\centering
\includegraphics[width=\textwidth]{figure2}
\caption{Infant Mortality Rates by Race and County for Delaware, 2002-2006}
\end{figure}

\textbf{Figure 3. Leading Causes of Deaths among Caucasian and African-American Infants for Delaware, 2002-2006}

\begin{figure}
\centering
\includegraphics[width=\textwidth]{figure3}
\caption{Leading Causes of Deaths among Caucasian and African-American Infants for Delaware, 2002-2006}
\end{figure}

Factors in Mortality:

\begin{itemize}
  \item Inadequate health care services
  \item Lack of health insurance coverage
  \item Lack of access to appropriate health care services
  \item Maternal attitudes
  \item Sociocultural variables
  \item Inadequate access to early prenatal care\textsuperscript{xii}
\end{itemize}

The most common cause of infant mortality among Caucasians and African-Americans was prematurity and low infant birth weight. For African-Americans, the second leading cause was maternal complications in pregnancy, which can be prevented.\textsuperscript{xii} Efforts to reduce racial and ethnic disparities have emphasized the provision of culturally and linguistically appropriate care as an important strategy.
Cultural and linguistic competence is defined as a set of behaviors, attitudes, and policies that enables effective work in cross-cultural situations. 'Culture' refers to the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups. 'Competence' implies having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by consumers and their communities. (Adapted from the Office of Minority Health website)

Providers in Delaware define diversity broadly—in terms of race, ethnicity, language, age, health beliefs, and socioeconomic status. xiii

Cultural Competency and Providers in Delaware

The Delaware Department of Health and Social Services (DHSS) commissioned focus groups with health care providers in 2008 to assess their perception of the growth of diverse populations, including the effect of that growth on the delivery of care, and to identify strategies for meeting the demands of a growing diverse population. Providers are seeing an increasingly diverse caseload and, despite limited resources, are challenged to meet the needs of their most vulnerable populations.

Provider Survey Demographics (N=100)

<table>
<thead>
<tr>
<th>Profession</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Physicians</td>
<td>48%</td>
</tr>
<tr>
<td>Nurse practitioner/nurse specialist</td>
<td>46%</td>
</tr>
<tr>
<td>Other</td>
<td>6%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Practice Setting</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Community-based settings and health centers</td>
<td>37%</td>
</tr>
<tr>
<td>Hospitals/universities</td>
<td>35%</td>
</tr>
<tr>
<td>Private practice</td>
<td>23%</td>
</tr>
<tr>
<td>Other settings</td>
<td>10%</td>
</tr>
</tbody>
</table>

Source: Altarum Provider Survey, 2010

To gather additional information from a larger sample of health care providers, Altarum Institute administered a Web-based survey with 100 providers throughout Delaware. This survey collected information about training received, barriers and facilitators to improving cultural and linguistic competency, and the policies implemented around it.
Policies and Practices

Providers identified language access policies and practices (approaches taken to provide services for individuals with limited English proficiency) as the policy most commonly developed in their practices. This corroborates statements made by providers in a 2008 provider cultural competency training report by the DHSS in which providers identified linguistic competency as an important policy for their practices. In that report, physicians reported that they wanted to have bilingual staff, and some practices/centers even offered Spanish classes for staff.

Policies and practices in place related to the following domains:

Language access policies and practices – defined as approaches taken to provide services for individuals with limited English proficiency 91%

Provider and staff policies and practices – defined as implementing approaches to develop the knowledge, skills and ability of all staff to understand and address the needs of diverse populations. 75%

Organizational policies and practices – defined as incorporating cultural competence into the organizational mission, planning, policymaking and infrastructure activities within the health care organization or practice. 74%

Community focused policies and practices – defined as engaging community members and community partners, and using knowledge of a community to inform decisions within your health care organization or practice. 67%

Providers were also asked about the extent to which these policies and practices are monitored or evaluated. Few (9%) reported that policies and practices were monitored and evaluated to “a great extent” while 37% of respondents were unaware if any monitoring or evaluation was taking place in their practice.
**Cultural Competency Training**

Health care providers who participated in the 2008 focus groups recommended provider education and suggested that education on cultural and linguistic competency would be most beneficial if provided during medical residency. Half of survey respondents (51%) reported participating in cultural competency trainings or educational opportunities within the past 12 months. Respondents reported the following benefits (Figure 4) of participating in training and professional development activities.

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**Figure 4. Benefits of Cultural Competency Training and Education**

<table>
<thead>
<tr>
<th>Benefit</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interact effectively with individuals from different cultural groups</td>
<td>83%</td>
</tr>
<tr>
<td>Confront bias, discrimination, and racism in health and social service systems</td>
<td>73%</td>
</tr>
<tr>
<td>Effectively communicate complex array of information to individuals who have low English proficiency</td>
<td>63%</td>
</tr>
<tr>
<td>Effectively communicate complex information to individuals who have low literacy or are not literate</td>
<td>60%</td>
</tr>
<tr>
<td>Work effectively with a trained/certified medical interpreter</td>
<td>46%</td>
</tr>
</tbody>
</table>

*Source: Altarum Provider Survey, 2010*
Barriers to Improving Cultural Competency

When asked about barriers to improving cultural and linguistic competence within their health care organization or practice, survey respondents identified limited linguistic capacity as their greatest obstacle (53%). This was also cited as a common barrier in the 2008 DHSS report. In that study, as in the Altarum survey, providers felt that expanded staff and staff capacity would be useful to help address patient demand and linguistic barriers. In the 2008 DHSS report, health care providers reported relying on patients’ family members or friends to interpret information in the absence of sufficient interpreter services. In the Altarum survey, inadequate staff and resources was the second most common barrier to effective cultural and linguistic competency, identified by almost half of respondents (47%).

One respondent noted “We have a functional language line 24 hours a day and 7 days a week; however, there are times when the language line is grossly inadequate and a real person is needed to help convey information.”

-Provider survey respondent

Figure 5. Barriers to Improving Cultural and Linguistic Competency

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Limited linguistic capacity (Lack of multilingual providers and or medically trained interpreters; limited ability to use translation lines; limited...)</td>
<td>53%</td>
</tr>
<tr>
<td>Inadequate staff and financial resources to meet patient needs/demand</td>
<td>47%</td>
</tr>
<tr>
<td>Limited access to training for providers to increase cultural and linguistic competency</td>
<td>39%</td>
</tr>
<tr>
<td>Insufficient time to address patient needs (Ex: Social issues that providers cannot address are affecting patient-provider interaction)</td>
<td>37%</td>
</tr>
<tr>
<td>Inadequate linkages between providers and systems (Lack of linkages between health care providers, ex. hospitals and primary care settings, for follow-up...)</td>
<td>32%</td>
</tr>
<tr>
<td>Other</td>
<td>10%</td>
</tr>
</tbody>
</table>

Source: Altarum Provider Survey, 2010
Incentives or Resources

In addition to describing barriers to access and care, survey respondents were also asked about the types of incentives or resources that would help them improve their ability to be culturally and linguistically competent. Most respondents indicated that additional information about referral resources to local social services would be the most helpful resource. This finding is consistent with the barrier of “inadequate linkages between providers and systems,” identified by almost one-third of survey respondents. More than half of respondents (58%) noted that wider availability of cultural competency training, tools, and resources would be the best incentive (e.g., part of support available to providers participating in the Community Healthcare Access Program and the Voluntary Initiative Program). This finding was consistent with one of the recommendations resulting from the 2008 DHSS report, in which providers felt that the State could play a larger role in gathering resources for providers and funding classes to train health interpreters. These providers also noted that mandates without some type of incentive—discount on malpractice insurance, translation line use—would not be well received.
Perceptions of Female Health Care Consumers in Delaware

Altarum Institute conducted focus groups with consumers and also reviewed other consumer information previously collected by the Consortium, which included a focus group study (Perceived Discrimination Study) conducted in Wilmington and a study led by the chair of the Consortium’s Health Care Disparities Committee which surveyed women who accessed prenatal care at an urban health center to determine barriers to early initiation of services.

Health Messages

During medical appointments, focus group participants reporting receiving information about fitness, general nutrition, smoking cessation, HIV and other sexually transmitted infections, the importance of regular medical care and infant immunizations, and post-partum depression. xxv, xxvi

When asked about their sources of health information, focus group respondents reported multiple sources:

- Television and PSAs
- Print ads and billboards
- Parents and family members
- Peers
- Doctors and health professionals (e.g. school clinics) xxvii, xxviii

A focus group of adolescent girls mentioned the Internet as an important source of information in one of the focus groups, comprised of adolescent girl. They use it to search for sensitive health information on topics such as sex or HIV. In the 2008 Wilmington study, participants emphasized the role of peers in transmitting health messages; however, this is a questionable source as other teenagers are likely to be uninformed about parenting skills. Focus group participants in several groups commented that physicians seemed most concerned about their health during pregnancy or postpartum. xxix

Consumer Focus Groups Demographics (N=21)

<table>
<thead>
<tr>
<th>Race</th>
<th>Hispanic/Latino: 50%</th>
<th>Black/African American: 28%</th>
<th>White: 11%</th>
<th>Other or Multiracial/ethnic: 11%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>18-21 years: 50%</td>
<td>22-29 years: 6%</td>
<td>30-39 years: 33%</td>
<td>40-49 years: 11%</td>
</tr>
<tr>
<td>Education</td>
<td>Some high school: 33%</td>
<td>High school/GED: 33%</td>
<td>Some college: 17%</td>
<td>Bachelor’s degree: 11%</td>
</tr>
<tr>
<td></td>
<td>Other: 6%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary language</td>
<td>English: 56%</td>
<td>Spanish: 44%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: Altarum Consumer Focus Groups, 2010
Defining Quality in Healthcare

When asked about how they defined high quality health care, similar themes emerged across multiple focus groups:

- Feeling welcomed by front office staff and providers
- Feeling that they are treated with respect
- Feeling that staff and providers take the time to provide information and answer questions

Focus group participants talked at length about the importance of a provider’s attitude and treatment on their health care experience. They were especially pleased when they felt as though the provider was concerned about their health—asked questions (both about health and about the patient’s life in general), was responsive to pain or discomfort, and explained upcoming procedures. Participants were interested in having a dialogue with their health providers. One respondent was impressed by a doctor who had already read her chart and medical history and came to the meeting with personal information: “She remembered me from the last appointment...some doctors don’t even remember who you are.” Smiling, joking, happy front office staff also put respondents at ease. Participants cited other positive factors such as having a nice waiting area with magazines and toys for children, minimal waiting time, and flexibility if an appointment has to be missed or rescheduled.

When asked to describe their negative experiences, focus group participants again focused on interactions with providers. Poor communication and listening skills were most often cited as a barrier to care. Problems included lack of follow-up from doctors regarding test results or medications, unanswered questions about billing, and especially doctors not listening to complaints or symptoms and using “medical jargon”. One respondent said, “I want to know what’s going on with my body...don’t just say ‘don’t worry about it, get out of here.’”

Poor treatment was another commonly cited barrier, with participants recounting incidents of incompetent blood draws, doctors who did not provide enough care, botched medical procedures, misdiagnoses, and hurried exams. Participants also described having to endure long wait times. The adolescent focus group participants complained about seeing patients that had arrived after them receive care first, and the African American women complained about sitting in the doctor’s office for hours.

For the focus group with primary Spanish speakers, language and immigrant status were cited as common barriers or issues during medical appointments. The women described discrepancies in the quality of interpreter services available in Sussex County. In the Wilmington Consortium study, participants identified barriers such as lack of insurance coverage.

Many participants noted that these experiences have affected where they seek medical care; they are willing to travel farther to avoid hospitals or doctors where they have received poor care.
Perceived Differences in Treatment

Consumers identified situations in which they perceived differences in treatment for which they cited different reasons. All groups mentioned that having public insurance could cause differences in treatment, with doctors not accepting public insurance, delaying appointments, and in general being less receptive to patients who have public insurance. The 2008 Wilmington Consortium study confirms this concern, with respondents believing that people are treated differently based on the type of insurance they have or their social class, and that those who have Medicaid are treated less favorably. xxxv

In the adolescent female group, participants discussed their perception that physicians are more dismissive of younger patients and less likely to take them seriously. The women in the Spanish-language group felt they were treated differently by front-line staff and providers because they could not communicate in English. Women who were not legal immigrants or whose children were not legal immigrants described receiving a different level of care compared to other patients. xxxvi African American women who participated in the Wilmington Consortium study felt that their race was a factor in treatment and felt that providers view them negatively when they have multiple children or when they are single mothers. xxxvii This is consistent with the findings from the Perceived Discrimination Study, which also suggested a connection between racial bias and seeking care. The study found that prenatal care was initiated later among racial and ethnic minority patients who thought doctors and nurses were biased against minorities or felt they discriminated based on race. Participants who perceived that they were treated unfairly because of their race delayed prenatal care 4.2 weeks on average compared to participants who did not have that perception. The perception of bias also can affect non-minority patients. Study participants who perceived that doctors and nurses treated others unfairly due to race delayed prenatal care 2.4 weeks on average compared to their counterparts. xxxviii

Consumer Empowerment

Several themes emerged regarding ways in which consumers feel empowered in their health care experiences. First, focus group participants felt empowered when they could make informed choices about their health care—able to understand the benefits they could access through insurance, able to make healthy food choices and exercise, and able keep track of their appointments and checkups. They felt it was important to not “play the blame game” and to take care of themselves. The African-American women in particular felt that taking control of their diets and taking steps to end bad habits such as smoking helped them to feel empowered. Conversely, the Spanish-language participants generally felt disempowered about improving their health. They described knowing what to do—to maintain a healthy weight and reduce their risk of diabetes—but struggled with incorporating these practices into their lives. They also mentioned that stress is a major contributor to feeling a loss of control and a challenge to making healthy choices. The adolescent group emphasized research and education as a form of empowerment, including double-checking information from the Internet because it might not be valid, and making phone calls to find out about needed services.

The second major theme to consumer empowerment was the ability to partner with their providers in navigating their health care, which was contingent on open communication. Respondents felt more comfortable with doctors who were willing to answer patient
questions and engage in a dialogue with patients. In contrast, poor communication discouraged consumers from pursuing their own care. Respondents felt that they did not have control over their health when they could not afford doctor’s visits, when they did not know how to fix a health problem, and when they could not get answers to their health questions from doctors. One participant noted, “If they [healthcare providers] don’t have the answer where they can fix it or anything they can do about it...that really puts a damper on me. That makes me feel like oh, what I’m going to do now? There’s no control.”

**Recommendations**

Consumers and providers shared their recommendations for improving the quality and provision of culturally and linguistically competent health care.

**Recommendations from Consumers:**
- Provide training to providers to improve their ability to explain medical information using terms that are clear and easy to understand
- Provide training on good customer service to all staff in health care facilities—be friendly, treat patients respectfully, take time to answer questions and explain procedures, maintain confidentiality
- Expand services that will increase access to patients (e.g. interpreter services, office hours)

**Recommendations from Providers:**
- Develop a resource guide for providers that describes available local referral resources for patients
- Develop educational materials and strategies (e.g. health navigator) to help patients navigate the health care system
- Offer incentives and training (for providers and interpreters) to support the implementation of cultural and linguistic policies and practices
- Support the implementation of innovative strategies (e.g. interpreter cost-sharing) to address needs of the most vulnerable populations
Endnotes


2 Ibid.

3 Ibid.

4 Ibid.

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9 Ibid.

10 Ibid.


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