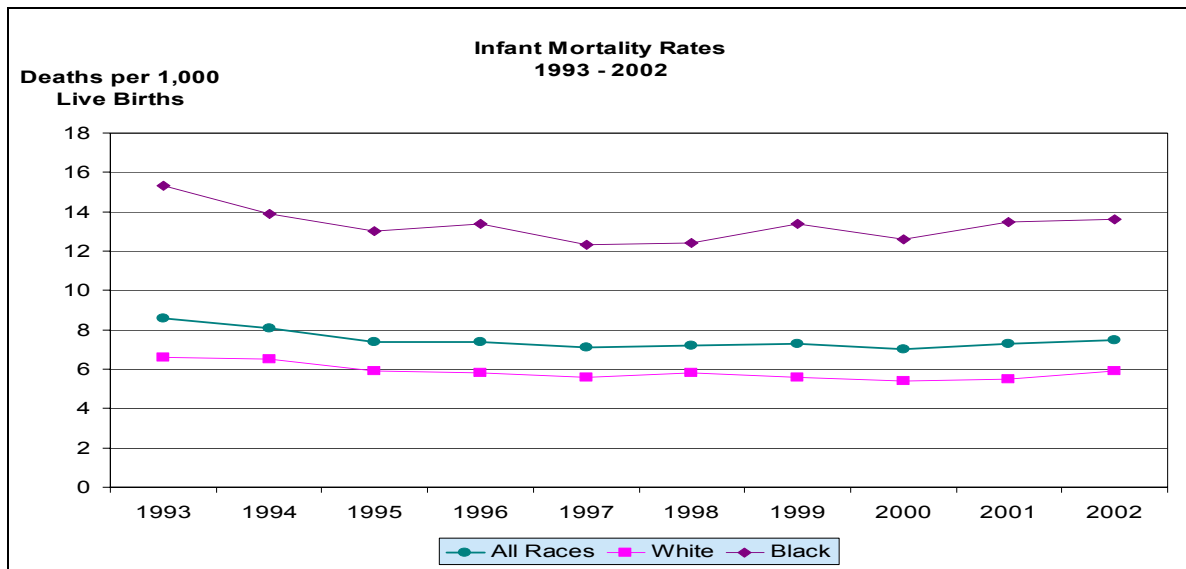


RACIAL/ETHNIC DISPARITIES
IN PERINATAL OUTCOMES
ISSUE PAPER

I. Issue Summary/Background

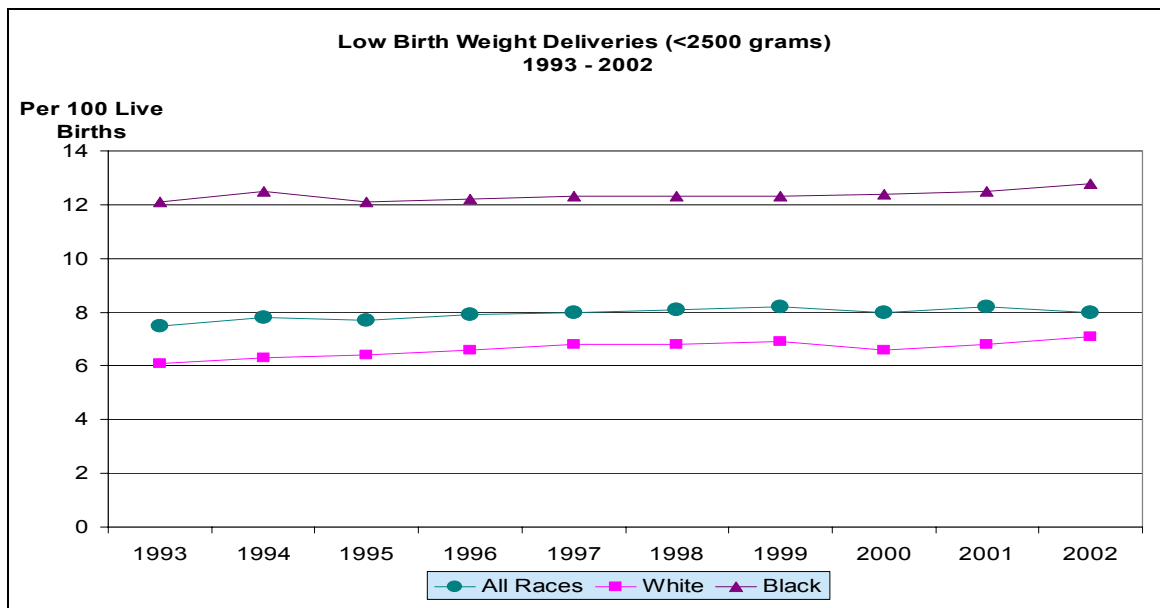
Pregnancy, birth and infant health outcomes are internationally recognized as measures of health for a community, as these outcomes are indicators of population sustenance, growth and quality of life. Infant mortality, an infant health indicator, is defined as the death that occurs within the first 364 days of life. Infant mortality is influenced by socio-economic status, education, nutrition, access to health care, quality of care and a host of other variables. Until 2001, Florida enjoyed the luxury of having a declining infant mortality rate. However, significant disparities in perinatal outcomes between the black and white populations of Florida have always been present, even during the period of declining infant mortality rates. In Florida, the rate of black infant mortality has consistently remained higher than the rate of white infant mortality. For many years, the rate of black infant mortality has been more than two times that of the white infant mortality rate. In 2002, the ratio of black infant mortality to white infant mortality was 2.3.

Figure 1 Florida's Infant Mortality Rates by Race



Low birth weight is an outcome indicator of pregnancy. A low birth weight delivery occurs when an infant is born at a weight less than 2,500 grams or 5.5 pounds. The percent of low birth weight deliveries for all races has remained relatively constant over the past five years. Although the rates for both black and white low birth weight deliveries have not fluctuated greatly, black infants consistently experience low birth weights at a greater rate than white infants. In 2002, the percent of black and white low birth weight babies was 12.8 and 7.1, respectively, which means the risk of low birth weight for black infants was 80% higher than the risk of low birth weight for white infants.

Figure 2 Florida's Low Birth Weight Delivery Rates by Race



Entry into prenatal care is important for the health of both the mother and the developing fetus. The percent of mothers who received no prenatal care or late prenatal care has been declining in Florida during the past five years for all races. The disparity between black and white women who did not receive prenatal care or received late prenatal care has existed for many years and has remained constant for the last three years. In 2002, 4.8% of black women did not receive any prenatal care. Also in 2002, 1.7% of black women reported receiving

prenatal care later than the first trimester of pregnancy. Black women were 2.1 times as likely to report not receiving any prenatal care than white women and 2.5 times as likely to report receiving late prenatal care compared to white women. Even though these percentages seem low, in absolute terms this means that 3,000 black women who gave birth either received no prenatal care or received late prenatal care, representing 6.5% of black resident live births in 2002.

While very few mothers die because of pregnancy or childbirth compared to a century ago, pregnancy associated mortality continues, although many of these current deaths are shown to be preventable. The ratio of deaths due to pregnancy, childbirth, and puerperium complications to live births illustrates the disparity between Florida's black and white populations in maternal health outcomes. In 2002, black females have a 3.3 higher ratio of deaths from pregnancy, childbirth, and puerperium (period after labor) to live births than white females.

In calendar year 2001, 45.7% of all Florida deliveries by women with a social security number were funded by Medicaid. Of these 2001 Medicaid funded deliveries, 36.5% were Black, 26.2% were Hispanic and 41.7% were White. With 30,838 pregnant women and their infants at a significantly higher risk of poor pregnancy and birth outcomes, it is of special interest to Medicaid to lessen these disparities. In an effort to address these disparities in perinatal outcomes, the Florida Department of Health Office of Infant, Maternal and Reproductive Health applied and was subsequently invited to participate in an Action Learning Lab on Racial and Ethnic Disparities in Perinatal Health Outcomes (ALL) sponsored by the Association of Maternal and Child Health Programs. As one of five states chosen to participate in this workshop, participants developed goals and strategies to reduce racial disparity in perinatal

outcomes through lasting systems change. After much deliberation, the Florida ALL workgroup (comprised of state, community and health professionals) determined that without input, buy-in and commitment by members of affected groups or populations, lasting change would be difficult to accomplish. The group, therefore, developed goals and strategies to institutionalize local community inclusion, participation and empowerment in health education, funding, promotion, prevention and care access processes. This institutionalization of community inclusion and mobilization will be achieved by the creation of community development guidelines for Florida's Healthy Start program and county health departments, and the development of community-inclusion guideline templates for non-government community-based organizations. The permanent inclusion of a community development platform is integral to the success of any efforts to reduce disparities in Florida's communities.

Current Activities Addressing Racial Disparities That Involve Community Participation

The Florida Department of Health has long been connected to Florida's communities through the network of county health departments and other statewide programs such as WIC, Healthy Start and other Maternal and Child Health programs. As a means to facilitate Florida's communities in assessing and prioritizing the health issues and needs, the Department is implementing a statewide community health planning initiative called COMPASS. The product of this initiative will be the provision of access to data, technical assistance and resources that will aid Florida communities in implementing health strategies and actions that are based on a community-involved strategic planning process. To specifically address disparities, the Florida Department of Health has implemented and administers the *Reducing Racial and Ethnic Health Disparities: Closing the Gap* grant program. Due to the disparities in access to care and health outcomes, maternal and infant mortality is among the six priority health areas identified in this

grant program. Understanding the importance of community involvement, funding priority was given to grassroots, community-based programs that address problems in non-traditional ways.

Also in coordination with local communities, Florida's state and federal Healthy Start coalitions strive to ensure optimal outcomes among mothers and infants through prevention education/ promotion, care access assurance and social service coordination. Within these activities, special projects that target black citizens are administered to reduce outcome disparities. For the five federal Healthy Start projects in Florida, community development and empowerment is the foundation of program existence and continuance; each program has special projects or initiatives that target the problem of racial disparity in birth outcomes.

In 1991, Medicaid expansion allowed more women to have Medicaid coverage during pregnancy and access to prenatal care by increasing the income level for pregnant women from 150% of the Federal Poverty Level (FPL) to 185%.

Other current activities in maternal and infant health that work to eliminate perinatal disparities include:

- Providing access to prenatal care, education, advocacy, and public awareness to low-income pregnant and parenting women and teens
- Providing education in at-risk black communities in order to decrease infant deaths due to co-sleeping and suffocation
- Providing early intervention services for Hispanic and Haitian women of childbearing age
- Providing education on the effects of infections on preterm labor
- Collaborating in efforts to decrease infant mortality
- Increasing access to health care, knowledge of health issues and services
- Increasing enrollment in insurance programs
- Providing a mentoring moms program.

Special Activity: The Florida Perinatal Periods of Risk Practice Collaborative

Florida's Healthy Start Coalitions, the Department of Health and local health departments recently implemented a yearlong practice collaborative using the Centers of Disease

Control/World Health Organization (CDC/WHO) Perinatal Periods of Risk (PPOR) to examine birth outcomes in the state and in seven urban areas. This approach divides fetal and infant (feto-infant) deaths into four groups based on age at death and birthweight – *Maternal Health & Prematurity, Maternal Health, Newborn Care and Infant Health*. Rates in each group can be compared for different populations or a reference groups to pinpoint specific “periods of risk”. Periods are associated with specific interventions such as family planning and interconceptional care (*Maternal Health & Prematurity*), access to prenatal care (*Maternal Care*), neonatal intensive care (*Newborn Care*) and the prevention of SIDS and accidents (*Infant Health*).

When this approach was used for the 1998 - 2000 linked birth-fetal death-infant death files, the overall feto-infant death rate for blacks was twice as high as the rate for whites. Overall, the *Maternal Health and Prematurity* period accounted for most of the racial disparity statewide; these findings were also evident in the seven urban communities that were analyzed.

**Table 1: Perinatal Period of Risk
Feto-Infant Death Rates by Race, Florida 1998-2000**

	<i>Fetal >24 Wks.</i>	<i>Neonatal (<28 days)</i>	<i>Postneonatal (28-364 days)</i>
500 – 1499g	MATERNAL HEALTH & PREMATUREITY 3.1 (White) 7.4 (Black)		
1500g+	MATERNAL CARE 2.1 (White) 3.6 (Black)	NEWBORN CARE 1.2 (White) 1.9 (Black)	INFANT HEALTH 1.4 (White) 2.8 (Black)
	TOTAL FETO-INFANT DEATH RATE: 7.8 (White) 15.6 (Black)		

Activities of Other States Addressing Racial Disparities of Perinatal Outcomes

The following table is a summary of approaches that other ALL states are using to address disparities in perinatal outcomes. A common theme of these approaches and expected benefits is the engagement and involvement of community as part of the effort to reduce and eventually eliminate racial and ethnic disparities. As relationships have been developed between

the state teams, ongoing collaboration and sharing of best practices is expected, thus allowing Florida to learn from the other ALL participants.

Table 2: Summary of ALL States Approaches and Expected Benefits

ALL States	Approaches	Expected Benefits
Georgia	<ul style="list-style-type: none"> • Decentralized care • Pre- & interconceptual care • Perinatal surveillance • Community engagement 	<ul style="list-style-type: none"> • Reinvigorate collaborative process • Track progress through links w/ March of Dimes campaign • Enhanced statewide focus
Indiana	<ul style="list-style-type: none"> • Expanded case management • Focus groups re: racism, culture, prenatal care & outcomes • Planning w/community • ID existing community assets • Non-traditional partners for outreach • Consumer education 	<ul style="list-style-type: none"> • Pool resources • Collaboration on research & evaluation • State strategic plan • Stakeholder input & ownership
Maryland	<ul style="list-style-type: none"> • Data analysis • Assess racism/chronic stress impact 	<ul style="list-style-type: none"> • Statewide plan • Increasing awareness • Strengthen partnerships • Acquire new knowledge
Massachusetts	<ul style="list-style-type: none"> • Interconceptional care • Surveillance & reporting • Postpartum care focus 	<ul style="list-style-type: none"> • Unified statewide strategy • Strengthen collaborations & community • Evaluate outcomes • Share experience & lessons learned w/other states

II. Findings

Institutionalization of Community Development

Health outcomes are impacted by biological, environmental and social determinants. These determinants, whether positive or negative, are not distributed equally in populations due to genetics, transmission modes or socio-economic demographics. In the later part of the 20th century, the traditional medical model was successful in reducing or eliminating infectious and communicable diseases caused by sole determinants. This was accomplished by the identification, assessment and control of the biological and/or transmission aspect of the disease process through disease screening, immunization and treatment. With the successful control of sole agent infectious/communicable diseases, the current major determinants of health are multi-causal and highly influenced by health behaviors, environmental conditions and socio-economic conditions. The Health Field Model developed by Evans and Stoddart (1990) identifies factor categories that have an impact on community health: social environment, physical environment, genetic endowment, prosperity, well-being, health care, behavior. The traditional focus on only biological determinants is not effective in addressing these multi-causal determinants due to the additional presence and interaction of determinants as identified in the Health Field Model. There is still much that is unknown about how the determinants interact and the resulting perinatal outcomes that result from these interactions, but interventions have been successfully developed from what is known such as smoking cessation, early prenatal care entry and breastfeeding. The institutionalization of community involvement assures that the communities are kept at the focus of future research and interventions. The institutionalization of community

involvement also assures that other determinants that have an impact on healthy behaviors, morbidity and mortality and are unique to certain community populations, such as limited healthy food choices in neighborhoods, neighborhood violence, discrimination, stress and family structures/support, are brought to the forefront.

In a study entitled, “Racial Disparity in Infant Mortality: An Exploratory Study of Causes and Solutions”, the results of community focus groups and surveys indicated that the sources of racial disparity in Florida were stress, lack of knowledge, lack of social support and access to perinatal services. The recommendations for intervention to counteract these determinants were improved communication, cultural competency, and diversity among health care professionals, culturally sensitive education, support groups and promotion of early prenatal care. The authors’ conclusions were that programs are needed that give community members the opportunity to express feelings and concerns about the racial disparities in birth outcomes and possible solutions. The authors’ support the goal of forming community action groups that are diverse exhibit good communication skills, possess cultural competency skills and are willing to listen to the community perspective (Barber, Clark, Chu, Lee, Stabile & Thompson, 2000).

In the article entitled, “A Public Health Framework for Addressing Black and White Disparities in Preterm Delivery”, solutions are addressed for reducing infant mortality rates by incorporating the Healthy People 2010 objectives and placing an emphasis on the reduction of preterm deliveries. The article’s authors suggest that several components be addressed to address the social causes of preterm delivery. The components include improving collaboration with communities and establishing a framework that emphasizes a multilevel, multi-factorial, community-partnering approach. The authors state, “the components of this framework are meant to be used together to develop complementary and coordinated interventions that should

be pilot tested in communities with rigorous processes and outcome evaluations to assess effectiveness” (Boisseau, Ferre, Hogan & Richardson, 2001).

Benefits of Community Development

A community can be defined as *“a group of people with diverse characteristics who are linked by social ties, share common perspectives and engage in joint action in geographical locations or settings”* (MacQueen, 2001). It is widely known that community health is often disproportionately influenced by the social status and demographics of persons in the community. Persons in lower socioeconomic and/or minority racial & ethnic classifications may not experience optimal health care prevention, access, and treatment due to their socio-economic status (SES) or demographic classification.

Before the 1970s, the community was viewed as something to be acted on or reacted to. Community members were rarely involved with the planning, funding, and implementation of health assessment, education, strategic planning or prevention efforts. The results of these omissions were the implementation of strategies and programs that were not connected to communities. In turn, community members did not feel inclined to support or to participate in these programs, which led to many program failures and wasted resources. In the past twenty years, the dynamics of the patient-doctor relationship changed. Patients demanded a more participatory role in the health of themselves and their communities (Emmel & Conn, 2004). This participatory role included involvement of the community in all aspects of the health care spectrum. Research has also found that communities empowered by the knowledge that they have control over their environments and activities pertaining to their environments are found to be healthier (Emmel & Conn, 2004).

The ideation of community inclusion is widespread and few would argue that this mantra is not gallant in its intention to include community members. However, this ideation has no

value if not put into practice. To ensure the implementation and adherence to the practice of community involvement, the methods to perform community involvement must be included in the policy and procedures of an organization.

In 1999, nine Federal Healthy Start programs were involved in a Policy Link study to assess the impact of community involvement (PolicyLink, 2000). The study found that community involvement led to increased community knowledge of infant mortality, effective outreach to at-risk families, positive behavioral changes, identification of factors that influences outcomes, programs that addressed community needs, institutionalized programs, policies and practices that linked health intervention with achievement of improved health outcomes. The overall finding of the study is that community involvement is necessary for the success of the Healthy Start Program. To support community involvement, program mandates and policy should be directed towards the development and support of community involvement activities, analysis, linkage and training.

III. Policy Implications

As exemplified in the description of current activities, the concept of community inclusion is not new in the implementation of DOH maternal and child health care planning and coordination. However, a foundation has not been available that will ensure the concept of community involvement will be put into action with all aspects of care provision and coordination. The Florida ALL team has determined that a focus of the activities for the ALL workgroup will be to develop this foundation by the inclusion of community development in the Healthy Start Standards and Guidelines, county health department Technical Assistance Guidelines and other documents for community leaders.

The Healthy Start Standards and Guidelines (HSSG) is a document that provides guidance in the implementation of Healthy Start program services. Florida Administrative Code mandates that Healthy Start coalitions and providers comply with the policies and procedures set forth in the HSSG. The inclusion of community development guidelines in this document provides the assurance of compliance which can be assessed as a Healthy Start Coalition contract performance indicator for the coalition catchment area. The county health department monitoring process will be revised to incorporate a discussion of community development activities in the county area.

Affected Agencies/Groups

Agencies affected by the implementation of community development guidelines will be state Healthy Start Coalitions, county health departments and the Florida Department of Health. These groups will be required to conduct activities that involve community input for their health care provision, planning and funding efforts.

Groups that will benefit from this infrastructure of community development and involvement are all of Florida's citizens who comprise our state's communities. These persons will now be a permanent part of the health care process that affects each of them so much in their daily lives. These guidelines will aid in the production of healthy messages and practices that are necessary and relevant to communities and, therefore, will increase chances of public improvement.

Of women with a valid social security number, the Medicaid program served 64 percent of those who were provided a prenatal risk screening. Medicaid covered 45.7 percent of the Florida deliveries by women with a valid social security number in 2001 and 78.0 percent of their infants who were screened for risk of postneonatal death. (Maternal Child Health and

Education Research and Data Center, 2003) Unfortunately, persons covered by Medicaid often are at a higher risk for adverse pregnancy and birth outcomes. It is vital that persons of this population be part of the community development process, because although they are the most at need, often times their input is not sought or, when given, not adhered to (Oakley & Kahssay, 1999). Activities that work to promote the inclusion of community mobilization for all communities will definitely affect persons who are covered under the Medicaid insurance program. Since community inclusion is vital for most strategies to work, once the guidelines are implemented and outcomes are assessed, these same strategies can be used with other areas of racial and ethnic disparities in health.

IV. Next Steps/Follow-up Activities

Community Development Guidelines

To create community development guidelines, the Office of Infant, Maternal and Reproductive Health (IMRH) will form workgroups from the ALL Home Team members. These group members are maternal and child care systems experts from the DOH, federal and state Healthy Start Coalitions, medical professionals and health consumers. Invitations to other MCH and community experts will also be sent to include those who wish to have input into the development of these guidelines. The goal is to develop these guidelines by June 2005.

The development or revision of HSSG chapters and guidelines is an established process that IRMH follows for all HSSG chapter/guideline additions and revisions. The workgroups will communicate by conference calls in this process. Transmitted PowerPoint presentations will be provided for viewing during the conference calls and will provide helpful cost-effective visual references during the development process. Upon finalization, the new HSSG chapter will be

posted to the MCH Internet site along with an accompanying PowerPoint training module on the new chapter. The end result of the training and document posting, the learner will be able to:

- Discuss the importance of community involvement in eliminating racial disparities in birth outcomes
- Identify initial steps for community mobilization
- Discuss effective strategies to assist in motivating community involvement
- Identify barriers to community mobilization
- Identify community member recruitment focus areas
- Discuss strategies to sustain community involvement
- Discuss the importance of quality assurance and evaluation in the formation of community action groups

The community guidelines for non-Healthy Start programs will be developed in parallel with the HSSG chapter and guidelines. A training module will be created and made available to accompany these guidelines for use by local providers and community organizations.

DOH will host community development website that will contain the community development guidelines and also provide links to other resources on community partnering and development.

Community Development/Mobilization Pilot Projects

Once the guidelines have been developed, DOH will recruit at least one Healthy Start Coalition and at least one county health department to pilot community development/mobilization projects. Memoranda of agreement between DOH and the selected entities will outline the implementation steps following the newly developed community guidelines. The pilot sites will be provided with curriculum, training materials and technical assistance for this implementation.

An evaluation of these pilot projects will take place to assess if the projects were able to succeed in the goal of community involvement/mobilization and provide information on best practices that can be incorporated into refinement of the community development guidelines and processes. The evaluation will encompass project goals and activities, an analysis of perinatal outcomes in the pilot service areas and an analysis of qualitative data from our key community partners. The key community partners for these projects will include: federal Healthy Start projects, Florida A & M University, local Healthy Start coalitions, county health departments, the Lawton and Rhea Chiles Center for Healthy Mothers and Babies, the FSU Center for Health Equity, the Agency for Health Care Administration, prenatal care providers and most importantly, consumers.

V. Conclusions/Recommendations

Conclusions

Based on literature review, participation in the ALL process and the input of our community partners, the following conclusions can be made:

- Community confidence, cohesion and holistic health are enhanced by involving its members in all aspects of the health care planning and delivery process.
- Community involvement and mobilization must be institutionalized as part of the platform of health care strategies and interventions to affect lasting health outcome change.
- Communities are multi-layered entities; many of its components (social, environmental, economic) that affect health must be addressed to decrease the risk of adverse health events.
- The manner of service organization and delivery not just the provision of services is important for communities. (i.e. neighborhood-based, tailored to community needs and risks, indigenous providers)
- The planning, implementation and outcome of any intervention or project must be evaluated to provide evidence of success, suggestions for improvement and determination of application to other health areas.

Recommendations

In light of the above conclusions, the following recommendations are made to the Medicaid Program:

1. Support implementation of strategies identified through the ALL.
2. Monitor and evaluate the impact of community development in perinatal racial disparity. If found effective, this approach should be required in other programs targeting where racial disparity exists, such as cardiovascular disease, diabetes, hypertension and HIV/AIDS,
3. Create community development/mobilization tools targeted to other areas of health where racial and ethnic disparities exist.

VI. Definition of Terms/Acronyms

County Health Department – Florida Department of Health entity responsible for the promotion of the public's health, the control and eradication of preventable diseases, and the provision of primary health care for special populations.

Disparity – the condition or fact of being unequal, as in age, rank, or degree.

Federal Healthy Start – federally-funded programs designed to reduce maternal and infant morbidity, in communities experiencing the most adverse perinatal health outcomes in the nation. There are five Federal Healthy Start Projects in Florida.

Fetal – of, relating to, characteristic of, or being a fetus.

Healthy Start Coalition – community-based nonprofit agencies located throughout the state whose purpose is to address the diverse needs of pregnant women and infants up to age 3.

Institutionalization – to make into an institution; give character of an institution to; to incorporate into a structured and often highly formalized system.

Interconceptional – period of time between one pregnancy and before another pregnancy begins.

Pregnancy Associated Mortality – the death of a woman, from any cause, while she is pregnant or within one year of termination of pregnancy, regardless of duration and site of pregnancy.

Ratio - the relationship in quantity, amount, or size between two or more things.

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