

## A. PURPOSE/NEED

*“Children are nearly one quarter of Florida's population. They are the future workers, inventors, teachers, doctors, mothers and fathers of tomorrow and will need the health, strength and wisdom to solve the problems of a future we cannot foresee. Because health status underlies a child's basic ability to learn, grow and succeed, our stewardship of this great responsibility is one of our most important jobs in life.”* John O. Agwunobi, M.D., M.B.A., M.P.H. Former Secretary, Florida Department of Health

The University of Florida Pediatric Pulmonary Center (UF PPC) trains diverse students from a range of health-related disciplines to become leaders in maternal and child health. The PPC uses the family-centered, culturally competent, community-based care of children with chronic respiratory conditions as a model for systems-based approaches to the care of Children and Youth with Special Healthcare Needs (CYSHN). The UF PPC provides clinical and public health leadership training in a well-established environment of scholarship, leadership and partnership. The PPC provides local, state, regional and national continuing education, technical assistance and leadership in areas of clinical care, research and public health policy. The UF PPC strives to eliminate disparities in care and to achieve many of the Healthy People 2010/2020 objectives.

The UF PPC is situated in DHHS Region IV. This region comprises eight southeastern states (Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, Tennessee) with a total population of nearly 60 million, although the immediate need for health care, pediatric care and pediatric pulmonary care lies disproportionately in Florida. The Sunshine State is home over 18 million residents, or 30% of the entire region's population. Four and a quarter million children, of whom 551,263 have special healthcare needs, live in Florida. Florida ranks third in the number of children born each year. Over 14 million children, of whom two million have special healthcare needs, live in Region IV (more than in any HHS Region and two to three times the number of CSHCN in five of the Regions). Many children and families in Region IV, as in the United States overall, are affected by chronic respiratory conditions.

**Asthma:** Asthma is the most common chronic respiratory condition affecting children. Nationally, 6.5 million children have asthma, and nearly 1.5 million of these children are in Region IV. More than 9.5 million children (13%) have ever been diagnosed with asthma<sup>1</sup> Asthma prevalence, which had doubled from 1980 to the mid-1990s and continued to increase until the early 2000s, has stabilized over the past few years, possibly related to improved disease management<sup>2</sup> However, there is still immense work to be done. Asthma remains a major cause of school absences and hospitalizations for children. Asthma accounted for 12.8 million missed school days nationwide, with an average of 3.7 missed school days per child with asthma. In 2005, between 679,000 -754,000 emergency room visits were due to asthma in children under 15<sup>3</sup>. Asthma is the third leading cause of pediatric hospital admissions. In 2006 there were 335,000 pediatric hospitalizations for asthma, comprising 13.5 of all pediatric hospitalizations<sup>4</sup>. Annual direct healthcare costs related to asthma are \$14.7 billion, with indirect costs such as lost productivity included, these costs rise to \$19.7 billion<sup>5</sup>. The average family in the US spends between 5.5% and 14.5% of its total income on treating an asthmatic child.<sup>6</sup>

Striking disparities in asthma morbidity and mortality occur among racial, ethnic and socioeconomic groups<sup>7</sup> Asthma prevalence rates are twice as high in African American children

than in non-Hispanic white children<sup>8</sup>. Children of American Indians or Alaska Natives have prevalence rates 25% higher, and Puerto Rican children have prevalence rates 140% higher, than non-Hispanic white children. Compared with white children, African American children have a 260% higher use of the Emergency Room, a 250% higher hospitalization rate, and a 500% higher death rate from asthma<sup>9</sup>. Although the prevalence of asthma is lower in Hispanics, taken as a group, than in non-Hispanic Caucasians, the death rate is higher<sup>10</sup>. In 2006, the asthma prevalence rate was 1.4 times higher for poor than non-poor children<sup>11</sup> and the rate of asthma related hospitalizations was 76% higher among children living in the poorest communities than it was among children living in wealthier communities<sup>12</sup>. Asthma is also correlated with obesity, leading to multiple risk factors.

**Cystic Fibrosis:** Cystic fibrosis is the most common lethal genetic disease in Caucasians and continues to be a cause of morbidity and mortality for infants, children and young adults in the United States. Approximately one in 3000 babies are born with CF, resulting 1000 new diagnoses each year and 30,000 persons affected nationwide. The median age of survival is 37 years. Approximately 45% of all CF patients are older than 20 years of age. Insurance coverage is a challenging issue for both children and adults with CF. Nearly half of children with CF are covered by Medicaid. Of those over 18 years of age, 33% are covered by Medicaid and 5% have no coverage<sup>13</sup>. CF is most common in Caucasian children but is severely impacted by poverty. Both morbidity and mortality in CF have consistently been linked to low family income and poor insurance coverage<sup>14</sup>.

**Sleep Disorders:** Sleep disorders are increasingly recognized as a prevalent problem in children. Studies have reported an overall prevalence of a variety of parent-reported sleep problems ranging from 25–50% in preschool-aged samples to 37% in a community sample of 4–10 year-olds<sup>15</sup>. More than 40% of adolescents also have significant sleep complaints<sup>16</sup>. Sleep problems are even more prevalent in children with special needs, and in children with psychiatric or medical diagnoses. For example, it is estimated that the prevalence of severe sleep problems in children with autism or pervasive developmental delays is more than 40%<sup>17</sup>. Sleep disordered breathing has been associated with behavioral problems, deficits of general intelligence, learning and memory deficits, evidence of brain neuronal injury, increased cardiovascular risk and poor quality of life<sup>18</sup>. Disrupted sleep can lead to poor daytime functioning which is manifested in children as decreased attention span, poor school performance and may be a possible factor in the epidemic of attention deficit/hyperactivity disorder affecting the nation. Obstructive Sleep Apnea Syndrome (OSAS) is a major cause of sleep disruption and affects 2% of school age children and adolescents. Children with OSAS may have failure to thrive, obesity or a normal weight, but obesity is an especially grim risk factor. Obesity confers a four-fold to five fold risk of disordered breathing and the degree of OSAS is proportional to the degree of obesity. Obesity and has been demonstrated in 45-55% of children with OSAS and between 24% and 66% of obese children have some airway obstruction. OSAS may represent an important mechanism underlying the association between obesity and metabolic and cardiovascular morbidities<sup>19</sup>

OSAS is 3.5 times more prevalent among African American children than Caucasian children. As obesity and overweight continue to grow in the US, the risk of OSAS increases in the population, but particularly in African American girls. Obesity rates in African American girls are nearly twice as high as those for Caucasian children<sup>20</sup>, placing African American girls at

particular risk. It is essential that pediatric specialists in sleep medicine be involved in the evaluation, diagnosis and management of pediatric sleep disorders, as the approach with children is very different than that with adults. While there are nearly 14 million children in this region, there are only 14 physicians board certified in sleep medicine with expertise in pediatrics. In Florida, Mary Wagner, MD, the UF PPC Director, is one of only three such providers available for the 4.25 million children in this state.

**Chronic Lung Disease of Infancy:** Chronic lung disease of infancy (which includes bronchopulmonary dysplasia) remains a major cause of morbidity for the prematurely born infant. Sixty three percent of babies weighing less than 1 kilogram develop respiratory distress syndrome, and of these 43% develop bronchopulmonary dysplasia. Premature births continue to rise, contributing to the increased prevalence of chronic lung disease. African American mothers are more likely to give birth to premature babies, so they experience a greater burden of CLD.

**Additional concerns:** Interdisciplinary specialists in pediatric pulmonary care are also needed to address a range of conditions that develop respiratory complications. For example, most patients with Duchenne and Becker muscular dystrophy (affecting approximately 1 in every 3,500 to 5,000 boys in the United States) and with Spinal Muscular Atrophy (a degenerative muscle condition affecting 4 out of every 100,000 children) will require respiratory care<sup>21</sup>. Ventilator dependent children require a unique and specialized team to safely support them in their communities. In addition pediatric pulmonary teams are needed to address smoking in children and parents: despite a strong national trend towards decreased smoking between 1998-2000, smoking prevalence among adults showed no declines in six states, three of which are in region IV.<sup>22</sup> Smoking prevalence in Florida is 19.3%, although Healthy People 2010 calls for reducing smoking to 12%.

**Poverty:** 4.25 million children live in Florida – nearly a quarter of the entire state’s population – and of those, 17.9% live in poverty. Within Region IV, 22.3% of children live in poverty and poverty rates in each state in the Region have increased over the past several years. In addition, there are major disparities in poverty status when broken down by race and ethnicity. Nationally, 8% of Caucasian children live in poverty, while 32% African American children, 32% of Native American children and 26% Hispanic children live in poverty. In Region IV, the situation is even more dire. 14.4% of Caucasian children, 39.3% of African American children, 30.2% of Native American children and nearly 30% of Hispanic children live in poverty. In Florida, 17.8% of children live in poverty. Poverty rates for African American and Hispanic children 32% and 22%, respectively, as compared to 12.7% for Non-Hispanic white children<sup>23</sup>

Florida ranks second, nationwide, in the percent of uninsured children. Statewide, 15% of children have no health care coverage, either private or government-sponsored (RWJ). In Florida, 22% of African American children, 19% of Hispanic children and 8% of White Non-Hispanic children are uninsured. Even more striking is the finding that 68% of African American children and 61% of Hispanic children are either on Medicaid or uninsured, as compared to only 30% of non-Hispanic white children who are on Medicaid or uninsured (Shenkman). In Florida, 30% of households with children have a child with a chronic condition, and children with chronic conditions are more likely to have public coverage than children without chronic conditions (Shenkman).

In Region IV 11.2% of children are uninsured. These children account for nearly 20% of all uninsured children nationwide. Nationwide, Hispanic children are nearly three times as likely as non-Hispanic whites to be uninsured--22% compared with 8%. Native American (27%), African-American (13%) and Asian/Pacific Islander children (13%) were also more likely than non-Hispanic whites to be uninsured. (March of Dimes/Census)

Another barrier to care is the shortage of health professionals, especially in rural areas. Major sections of Florida and the other states in Region IV have been identified as MUAs or HPSAs. (Medically Underserved Areas/Populations are areas or populations designated by HRSA as having: too few primary care providers, high infant mortality, high poverty and/or high elderly population. Health Professional Shortage Areas (HPSAs) are designated by HRSA as having shortages of primary medical care, dental or mental health providers). Additional barriers to care include great distances from rural areas to available facilities, cultural/language differences, and inadequate facilities.

**Region IV Public Health Needs:** Each of the State Needs Assessments compiled by the eight states in Region IV have identified areas in which the UF PPC can partner to achieve mutual goals, and for which training of future leaders will be critical. Three states (FL, SC and GA) specifically identify the reduction of health disparities. Five states (FL, SC, NC, MS, AB) highlight the need for increased access to care for all children and/or CSHCN. One of Mississippi's priority needs is to "Explore asthma coverage and services for children," Tennessee identifies the need to increase the number of teen with formal plans for transition, and Tennessee and Mississippi underscore the need to reduce smoking during adolescence and pregnancy. Georgia includes "Assure an adequate MCH workforce," and Florida, Alabama, South Carolina and Georgia directly address the need for systems of care and partnerships that will improve access and be consumer-friendly. These goals are based on the most critical needs in these states and make strikingly clear the need for present collaborations and future leaders to address these and related MCH challenges. The UF PPC is also well positioned to address the obesity epidemic and reduce infant and child deaths related to prematurity and respiratory conditions.

Region IV also has a need for continuing education, in order to support the public health infrastructure. Several needs assessments have been conducted related to continuing education needs in the region (Alexander, Murdock, whatever JGR did). These studies assessed both topic areas of interest for different disciplines and presentation modality. Topics related to asthma and sleep ranked highly among all states and disciplines. Respondents preferred in-state conferences, distance conferences and readings. The UF PPC has conducted a state-wide needs assessment of topics in which Children's Medical Services (state program for CYSHCN) nurses would be interested. Topics related to rarer pulmonary problems, cystic fibrosis, nutrition and advocacy were identified as holding particular appeal, although most of the 30 topics elicited interest from at least half of the respondents. Given the changing educational needs of providers and the changing technologies available for education, the PPC will be conducting a new regional needs assessment to assess content areas and preferred technologies for education, in Year One.

**Need for Diverse Health Professionals:** As a nation, state and county we are doing a woefully inadequate job of training health care providers from underserved backgrounds. While African Americans, Hispanics, and Native Americans make up more than 25 percent of the U.S. population, they account for only nine percent of nurses, six percent of physicians, and five percent of dentists nationally. Enrollment of diverse students in nursing programs has actually decreased since 2002. Faculty in health professions schools show similar disparities. Minorities comprise less than 10% of baccalaureate nursing faculties, 8.6% of dental school faculties and only 4.2% of medical school faculties. Florida's statistics are even worse: While Florida is 15.7% African American and 19.5% Hispanic, Florida currently has only 2% African American and 10% Hispanic physicians.

**Need for Health Professionals to Work with CSHCN:** Throughout Florida, regionally and nationally the need for trained health professionals to work with CYSHCN is great. Major sections of Florida and the other states in Region IV have been identified as Medically Underserved Areas/Populations (areas or populations designated by HRSA as having: too few primary care providers, high infant mortality, high poverty and/or high elderly population) or Health Professional Shortage Areas (designated by HRSA as having shortages of primary medical care, dental or mental health providers). At present, only 61% of families with asthma nationally feel that they partner in their care, and only 50% feel that they have a medical home. Nationally, only 22% of families of children with asthma under 11 and only 15% of families with children with asthma from 11-17 met all five criteria for systems of care. Nationwide, the percent of CSHCN who receive coordinated, ongoing, comprehensive care within a medical home ranges from 39%-57%, still woefully short of the goal of a medical home for all CYSHCN<sup>24</sup>. The critical need for training leaders to work with CSHCN is clear. According to the AMCHP State Title V Workforce Development regional assessment of training needs and professional development<sup>25</sup>, Region IV has particular needs for nurses, social workers and dietitians to serve MCH and CSHCN populations.

**Regional MCH CE Needs:** Although the CE needs reported by Region IV in the AMCHP assessment included all MCHB competencies, the needs consistently listed by at least four of the seven states included: Systems thinking; self reflection; program evaluation; strategies for incorporating family centered and medical home models; planning; funding, budgeting, staffing; grant writing; identifying leadership style; negotiation; organization and program planning and identifying an evidence base for MCH interventions. Block grant needs assessments from states in Region IV identify similar needs.

The interdisciplinary leadership training provided by the Pediatric Pulmonary Center at the University of Florida is uniquely situated to make a significant contribution in the local, state, regional and national arenas to meet these challenges and many others. This training site has a strong history of training future leaders to tackle the many issues facing children with chronic respiratory conditions and other CSHCN. The PPC provides exceptional clinical training to each health discipline. The PPC interdisciplinary team provides care to the whole child and the whole family, and coordinates the care of children with complex medical needs, exemplifying the medical home. PPC training immerses students in the team experience and provides a model for their future work. In addition, in order to ensure effective care for CSHCN and to reduce disparities in health outcomes, the PPC gives trainees the skills to conduct research, collect

secondary data, form policy, advocate, develop programs and work at a systems level to improve health and healthcare delivery.

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The UF PPC teaches trainees to respond to the unique needs of families with asthma, cystic fibrosis, CLD, OSA and a number of less common respiratory conditions. Trainees participate in a program that provide excellent medical care and responds to social, nutritional, nursing and respiratory needs as well. The assets of the UF PPC include a strong network of local, state, regional and national caregivers, policy makers and contacts in private and government agencies; cutting edge research; varied training sites/health care systems; rich educational instruction; a diverse clinical population available to trainees; and experienced interdisciplinary faculty. The faculty members are skilled in the provision of culturally appropriate and family centered care with innovative educational techniques. PPC faculty and former trainees continue their involvement in local, regional and national initiatives in public policy and public health care. The PPCs represent a source of knowledgeable professionals with enthusiasm, compassion and commitment to influence to the course of children's health care.

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<sup>1</sup> (Respiratory Health Association Fact Sheet).

<sup>2</sup> (ALA, 2009).

<sup>3</sup> (ALA 2009 vs Respiratory Fact Sheet).

<sup>4</sup> (AHRQ Healthcare Cost and Utilization Project).

<sup>5</sup> (ALA 2009)

<sup>6</sup> (Respiratory Health Association Fact Sheet).

<sup>7</sup> (HP 2010).

<sup>8</sup> (Respiratory Care Fact Sheet).

<sup>9</sup> (CDC Advance)

<sup>10</sup> (CDC Advance)

<sup>11</sup> (Pediatrics- Paying for Quality Healthcare)

<sup>12</sup> (AHRQ)

<sup>13</sup> (CFF 2007 registry report).

<sup>14</sup> Six CF/Medicaid Articles

<sup>15</sup> (Owens, Spirito, Mc-Guinn, & Nobile, 2000).

<sup>16</sup> (Ohayon, Roberts, Zulley, Smirne, & Priest, 2000)

<sup>17</sup> (Johnson, 1996). (Sleep Problems in Pediatric Practice: NAPNAP Pediatric Sleep Survey, Mindell J and Owens J- Medscape Today)

<sup>18</sup> (Halbower et al, 2008).

<sup>19</sup> (Tauman and Gozal).

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<sup>20</sup> (NHANES)

<sup>21</sup> *Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, July 27, 2005*

<sup>22</sup> CDC publication *State-Specific Prevalence and Trends In Adult Cigarette Smoking—United States, 1998–2007* March 13, 2009 / Vol. 58 / No. 9

<sup>23</sup> (Kaiser State Health Facts).

<sup>24</sup> (all from National Survey of CSHCN)

<sup>25</sup> Association of Maternal and Child Health Programs (2009) *Title V Staff Functions, Training Needs, Professional Development and Graduate Education Strategies by Region*. Washington, DC: AMCHP. Retrieved 02 06 10 from <http://www.amchp.org/mch-topics/o-z/workforcedevelopment/pages/default.aspx>