

## **Rationale for PPC Training**

The purpose of the UF Pediatric Pulmonary Center (PPC) is to train interdisciplinary students and workforce members to be leaders in providing interdisciplinary care, increasing access to and improving systems for children with pediatric respiratory conditions and, more generally, to all children and youth with special healthcare needs (CYSHCN). Training focuses on the MCHB Competencies 3.0, especially interdisciplinary care, population based health, cultural/linguistic competence (CLC) and patient and family centered care (FCC). PPC activities address the needs of underserved individuals

The UF PPC is located in HHS Region IV, a region covering 383,000 square miles and comprising the states of Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina and Tennessee. Region IV is the largest HHS region with the greatest number of (two million) CYSHCN. Region IV is diverse in persons of color, ethnicities, culture, and public health service delivery systems. Six of the eight states rank among the lowest in median incomes and all Region IV states rank between 34th and 50th in the overall and economic wellbeing of children and have the highest poverty rates of all regions. . Region IV has a larger number of Health Professions Shortage Areas and Medically Underserved Areas than any other region . Florida is the third most populous state in the United States . With over 20 million residents, it has 30% of the population in Region IV. UF PPC patients come primarily from rural areas where workforce training, access, and resources are major challenges.

The national need for pediatric respiratory care is well documented. - Within Region IV, pediatric respiratory conditions constitute an especially critical public health issue, as evidenced by the following statistics. Asthma: In Region IV, 1,443,017 children have asthma, with an especially intense clustering of asthma severity. In Florida over 435,000 children currently have asthma (lifetime prevalence 725,000). In Florida in 2009, there were a total of 42,238 emergency department (ED) visits and 7,646 hospitalizations for asthma among Florida children.<sup>14</sup> ED visits, hospitalizations, and costs are largely avoidable when asthma is properly managed. Asthma prevalence rates are twice as high in African American children and Hispanic children than in non-Hispanic white children. African American children have 300% more hospitalizations, ED visits and mortality than white children. In 2013 households with the lowest income levels had the highest prevalence of asthma . Asthma is associated with obesity which has seen a marked rise in the southeast. Cystic Fibrosis (CF): CF is the most common lethal genetic disease in Caucasians and continues to cause morbidity and mortality for infants, children and young adults. Approximately 1 in 3700 Caucasian babies are born with CF and 30,000 persons are affected nationwide . Mortality in CF is correlated with poverty and almost half of children with CF are covered by Medicaid (a proxy for poverty). Florida has the fifth highest number of people with CF of all the states . Sleep Disorders: Sleep problems are common in childhood including insomnia, snoring, daytime sleepiness and obstructive sleep apnea (OSA) . One research group found that 41% of parents report insomnia their children and adolescents. Another survey found that 69% of parents reported that their child had one or more sleep problems a few times a week. Sleep problems are more prevalent in children with special needs and in children with psychiatric or medical diagnoses. Sleep disordered breathing has been associated with behavioral problems, poor school performance, learning deficits, autonomic dysfunction, psychiatric symptoms, hypertension, and poor quality of life.<sup>12</sup> Obesity confers a

three to four increased risk of disordered breathing in adolescents and an increased risk of residual OSA after adenotonsillectomy. OSA occurs 3.5 times more among African American children than Caucasian children. As obesity and overweight are higher in African American (36%) and Hispanic (37%) girls than Caucasian girls this group is at particular risk. The UF PPC Director, is one of the few Board Certified pediatric sleep specialists in Florida. The care of pediatric sleep disorders differs from that of adults, so pediatric specialists must be trained. Chronic Lung Disease of Infancy (CLD): CLD, including bronchopulmonary dysplasia (BPD) remains a major cause of morbidity for premature infants. 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, thus experiencing a greater burden of CLD. Tobacco use: Smoking prevalence in Florida is 17.7% but Healthy People 2020 (HP 2020) calls for reducing smoking to 12% nationally.

Region IV has an urgent need for service delivery systems to impact the multiple causes of pediatric respiratory conditions (e.g., environmental conditions, poverty, patient and provider education, health beliefs, access). Systems must include: 1) Best-practices medical care provided by well trained interdisciplinary providers from diverse backgrounds; 2)evidence-based programs that focus on the multifactoral roots of respiratory problems at the individual, community, state, regional and national levels and; 3) coordinated processes (including medical homes) which provide patient access to quality respiratory care and include medical excellence, family expertise and culturally competent, diverse interdisciplinary professionals knowledgeable about both individual and systems-level approaches to care.

Meeting these needs is a major challenge: 1)According to the American Thoracic Society, there is a critical shortage of pediatric pulmonologists . In Region IV there are only 0.6 pulmonologists per 100,000 patients . Region IV has suffered from the national nursing shortage. Many health professionals are trained as generalists, with neither pediatric nor pulmonary specialization. Primary Care practitioners only inconsistently use the evidence- based National Asthma Education and Prevention Program (NAEPP) guidelines in treating pediatric asthma , . Pediatric sleep disorders continue to be under-diagnosed even as we increasingly discover their links to other serious health conditions. Schools and daycare programs need to better understand respiratory health . The diversity of health professionals is significantly less than that of the general population , . African Americans, Hispanics, and Native Americans make up more than 32% of the U.S. population, but account for only 10% of nurses and 9% (6.3%, 5.5% and .5% respectively) of physicians. Four percent of dietitians are African-American and 3% are Hispanic.<sup>41</sup>Continuing education (CE)for the existing workforce is also critical. 2) Programs to improve pediatric respiratory outcomes have met with limited success, often failing to address the multifactorial causes of these conditions. Evidence clearly shows that an interdisciplinary approach is associated with improved outcomes in chronic illness - on both clinical and systems levels. Policy makers are calling for interdisciplinary providers in respiratory conditions. 29- , especially in Region IV. , 3) Service delivery systems are fragmented and include disparate private insurance companies, a few integrated service delivery systems, state health insurance programs (SCHIP), state programs for CYSHCN and Medicaid. Coverage varies immensely between each product and program. Patients often have difficulty distinguishing between SCHIP, their state program for CYSHCN and Medicaid. Eligibility for these programs may shift with seasonal work. Many states (including Florida) now subcontract Medicaid coverage to private

HMOs adding to the confusion for low income families. Although HRSA , the American Academy of Pediatrics (AAP) , the Affordable Care Act (ACA) and others have highlighted the need for effective and coordinated systems of care and medical homes for CYSHN, Region IV and Florida fall woefully short in these areas. Only 43.5%, and 46.2% of families with CYSHCN, respectively, report having a Medical Home Only 67.5% of families of CYSHCN in Region IV and 63.2% in Florida have access to community services. There is a particularly great need for statewide healthcare transition services. The Florida Title V Pediatric Integrated Care System (PediCare) found that only 15 -26% of parents have discussed aspects of their child's transition to adult health care with their provider. Only 38.3% of these families in Region IV and 37% in Florida have satisfactory transition services. Overall, the data are disheartening: only 11.6% of families with CYSHCN in Region IV, and only 17.6% of such families in Florida, were satisfied on all core outcomes for CYSHCN. It is essential to train interdisciplinary health professionals who are knowledgeable about and can enhance FCC systems care for children with chronic respiratory conditions, thus leading to increased access and health equity.

In late 2014 the UF PPC conducted Community and Regional Needs' Assessments, viewed the Florida 2010 and 2013 Title V priorities , and the Florida Title V 2014 Needs Assessment Stakeholders Survey . The most frequently identified needs were access to care especially in rural areas; obtaining accurate information about and navigating CMS knowledge of community resources, shared decision making, medical home; improved healthcare transition; understanding of the lifecourse perspective, health disparities/social determinants, safe sleep, insurance coverage, parent education on health conditions, and information on the ACA.

The interdisciplinary leadership training provided by the UF PPC is uniquely qualified to meet the needs described above. For nearly 45 years, faculty and trainees have provided excellent clinical care, developed and contributed to programs addressing respiratory health, and improved systems which provide access to coordinated, equitable and quality respiratory care. Each goal in this proposal, as well as the Accomplishment Summary (AS), demonstrates specific ways in which the PPC meets the training needs of the current workforce to improve care for children with respiratory conditions through training, Technical Assistance (TA) and CE on evidence-based clinical care, quality improvement, Cultural and Linguistic Competence (CLC), social determinants, medical homes and other essential facilitators of health.