

University of Florida (UF) Pediatric Pulmonary Center (PPC) Summary Progress Report

1. **Period Covered:** July 1, 2005 – January 1, 2010

2. **Objectives** and 3. **Results:**

Goal 1: Recruit and retain diverse graduate-level trainees and fellows who demonstrate a high potential for MCH leadership.

Objective 1.1 Recruit and retain culturally and linguistically diverse trainees with high leadership potential from underrepresented groups; **Objective 1.2** Recruit and retain 1-2 long-term trainees with high leadership potential per year in each of the following disciplines: nutrition, nursing, social work and respiratory therapy; **Objective 1.3** Recruit and retain 1-2 pulmonary fellows per year of the granting period.

Goal 1 Outcomes: See tables on pps. 5-7 for trainee statistics. Consultation and recruitment from diverse populations have been ongoing. We consult with Dr. Donna Parker, the COM Associate Dean for Minority Affairs, Dr. Rebecca Pauly, the UF VP for Health Affairs, Equity & Diversity and the Florida Alliance for Health Professions Diversity about recruitment from diverse populations. We have contacted two LEND (Learning Education in Neurodevelopmental and Related Disabilities) directors and obtained advice from additional sources on minority recruitment. Most notably, we had a two day onsite consultation from Tawara Goode, Director of the National Center for Cultural Competence (NCCC)(please see discussion under Goal 5). We have participated in several health career recruitment events for middle/high school students, including parent/student evenings, health career clubs and summer camps. We have facilitated shadowing opportunities for the UF Minority Association of Pre-Health Students (MAPS) and have given presentations about health careers and PPC training at MAPS meetings annually. Over the past granting cycle, the percentage of minority trainees increased from 18% in year one to 45% in year five. Minority recruitment brochures have been printed and distributed. A list of mentors has been developed and offered to trainees; We recruited and retained 16 long term social work trainees, three long term rehabilitation counseling trainees, five long term nutrition trainees, five long term public health trainees and two long term nursing trainees; We recruited and retained five pulmonary fellows (two Asian Indian and two Hispanic background). Over the past granting cycle, we have been particularly successful in expanding our recruitment of respiratory trainees. Recruitment outreach for Respiratory Students has been focused on Florida A&M (a HBCU), University of Central Florida (UCF) and Santa Fe (SF) college, which have a high percentage of students from underrepresented groups. The respiratory faculty has emphasized recruiting from diverse populations. Over the past granting cycle we have had 175 short/medium term respiratory trainees of whom a high percentage were from underserved backgrounds. In addition to recruiting from SF College, she is recruiting from Florida A&M University, her Alma Mater and one of the few universities in the state that offers a BS in Respiratory Care, and the University of Central Florida, which has a diverse student body.

Goal 2: Educate fellows and trainees to be leaders in the interdisciplinary care of children with chronic respiratory conditions.

Objective 2.1 Educate fellows and trainees in clinical leadership skills in the care of children with chronic respiratory conditions using an interdisciplinary, culturally competent, family-centered approach; **Objective 2.2** Educate fellows and trainees to be leaders in public health issues and population-based approaches to improving the health status of mothers and children; **Objective 2.3** Educate fellows and trainees in professional development including research, evidence-based medicine, life-long learning, professionalism and ethics, self-reflection, adult

learning theory and the use of technologic applications.

Goal 2 Outcomes: Social work, nutrition, respiratory and nursing trainees evaluated and assisted approximately 10 patients each per week and fellows evaluated and/or treated approximately 25 patients each per week, with emphasis on interdisciplinary, culturally competent, family centered care. Average trainee evaluations of overall long term traineeship were 1.1 on a scale of 1-5, where 1 is the highest score. Breakdown of individual items allowed assessment of areas that could be improved and changes were made. The percentage of medium term trainees replying “*Very or Somewhat Helpful*,” in relation to the degree to which PPC training was helpful in a particular area, when averaged over the five year granting cycle, was as follows: Children with special health care needs” – 99% (100% in 2009); Family-centered care 97% (96% in 2009); Interdisciplinary care?” 96% (100 % in 2009); Culturally competent care 75% (86% in 2009). Core Curriculum (CC) talks on pediatric sleep disorders (Sleep 101), Psychosocial Issues in CF,, Nutrition in CF, Nutrition and Asthma and Advocacy have now been placed online. Additional learning activities have been developed for in-person sessions. Non-medical trainees participated in 33 CC sessions (didactic, online and/or experiential), per year, on clinical, research, ethics and public health topics; Fellows participated in 30 pulmonary training sessions as well as select PPC core sessions. Trainee evaluations of individual CC seminars were excellent, averaging “1.2” (strongly agree) on each item on a scale of 1-5. Each trainee participated in at least two self directed learning activities (SDLAs) (e.g., advocating with legislature; interviewing agency director; home visit; research project; developing resource materials). Trainees/Fellows participated with faculty in most of the activities discussed in Collaboration with MCH/Title V and Value Added sections of this report. Former trainees practicing around the country include CF Center Directors, Directors of Lung Transplant Programs, and other leadership positions.

Goal 3: Provide interdisciplinary education programs at the local, state, regional and national levels to address key MCH issues and the Healthy People 2010 objectives.

Objective 3.1 Provide on-going statewide distance education programs to Public Health Departments (including CMS), practicing professionals and MCH trainees; **Objective 3.2** Provide on-going distance education programs to regional MCH/CYSHCN agencies in collaboration with the Institute for Child Health Policy (ICHP) and the Suwanee River Area Health Education Center (AHEC); **Objective 3.3** Provide the “Updates in Pediatric Pulmonary Care” conference annually and collaborate with other agencies/programs to meet the continuing education needs of health professionals at the local, state, regional and national levels.

Goal 3 Outcomes: Please see Evaluation Table (p. 8) for numbers of continuing education (CE) sessions, hours and participants. The PPC Dietitian provided 3 hours of training to each of 29 WIC and Florida DOE nutrition students annually. In addition PPC faculty provided three hours of distance/live education to 40 WIC nutrition students. The AHEC has posted a series on Pediatric Sleep Disorders for CEUs on their new Continuing Education website. We are currently preparing a series of three nutrition/pulmonary lectures to go on the AHEC website. The newly developed “Asthma and Nutrition” module will be placed on the WIC intranet in spring 2010. The Dietitian coordinated downlinks of four nutrition teleconferences for a total of 60 participants. Since the beginning of the granting cycle the PPC has provided three broadcasts to all Florida CMS offices annually. The Guidelines for the Delegation of Care for Students with Asthma were developed collaboratively by the UF PPC, DOH, DOE and additional state agencies and distance presentation on the use of these guidelines provided to school personnel throughout the state in this granting cycle. Please see Title V pg xxx. This was followed by an

online survey evaluation to determine best approach for program updates. A sixth module on health disparities was added to the Cross Cultural Case Studies (please see pp 9-10 for more details). We have developed a site on Moodle that provides a forum for the interaction of PPC trainees nationally. We also have Moodle sites with curriculum materials for Sleep Fellows and educational materials for families. The PPC annual “Updates in Pediatric Pulmonary Care” conferences were provided in Years One-Four of the granting cycle, with an average of 80 nurses, RTs and dietitians attending each year. CF Education Day was held in years one-three and replaced by the more effective quarterly CF Newsletter. Faculty presented at the Family Café conference (a conference run for families of CYSHCN) in years three and four of the granting cycle. Faculty and fellows presented at numerous national conferences listed in the Value Added section (p.13) of this report. Faculty present frequently in local and University venues, as described in the Value Added Section of this report.

Goal 4: Collaborate with, and provide technical assistance to, Title V and other MCH agencies at the local, state, regional and national levels.

Objective 4.1 Provide services and technical assistance to Medicaid and the Florida DOH/CMS.

Objective 4.2. Collaborate with, and provide technical assistance to, additional agencies receiving Title V funds; **Objective 4.3** Collaborate with Region IV Asthma Coalition to enhance and improve systems of care and influence public policy for children with asthma

Goal 4 Outcomes: Please see Evaluation table p.8 for numbers of Technical Assistance (TA) activities and sessions. PPC faculty provided specialty services and care coordination to 5848 CMS, Medicaid or uninsured children and provided TA to CMS and Medicaid, as described in the Title V section of this report. PPC faculty have collaborated with Institute of Child Health Policy (IHP) on family involvement and transition programs, the residents’ self-assessment seminar, the use of the Moodle learning platform and other forms of distance learning. IHP faculty sit on the PPC CAB. The PPC provides TA to WIC several times per year. PPC faculty collaborated with the Florida Institute for Family Involvement (FIFI) on the development of our Family Involvement Program. Faculty provided requested TA to the Thomas E. Langley Medical Center. The PPC has engaged in several collaborative activities with other PPCs, UF Departments, and local and State agencies, including the newly developed Florida Office of Asthma Prevention and Control. Please see Value Added Section (p. 13) of this report for additional information.

Goal 5: Expand programs in key MCH/Healthy People 2010 areas including cultural competence/diversity, family involvement and faculty development.

Objective 5.1 Continue to develop and enhance cultural competence/diversity in all aspects of the PPC Program; **Objective 5.2** Continue to develop and enhance family centered care at all levels of the PPC; **Objective 5.3;** Maintain an emphasis on faculty leadership development in the areas of clinical, research, teaching and policy skills.

Goal 5 Outcomes: *Cultural Competence:* The average baseline self-assessment score was 1.5, on a scale of 1-3, where 1 is the highest score. Results on specific items helped highlight areas for further education which have been provided. The Systems of Care Checklist was completed and target areas for improvement were identified and addressed. A written cultural competence policy was developed at the annual UF PPC retreat in year three and is updated/re-signed each year. All faculty have studied the “Worlds Apart” videos. Several visitors and UF students from varied cultural backgrounds have presented at cultural competence in-service presentations. Three-four presentations annually on cross cultural healthcare have been provided for the division. PPC faculty now highlight cultural issues at weekly meetings. Tawara Goode, Director

of the NCCC, provided on-site TA to the PPC in the fall of 2009. In addition to providing technical assistance to the PPC on cultural competence training and recruitment from diverse backgrounds, Ms. Goode presented at Pediatric Grand Rounds, the PPC CAB meeting, met with select Health Science Center (HSC) faculty interested in minority recruitment, and conducted a divisional workshop on organizational change. Her input on training and recruitment was extremely helpful. Recruitment efforts have been successful: In 2009 45% of long term trainees were from minority backgrounds increased from 18% in Year one. The Family Advisory Board (FAB) conducted clinic follow-up calls to CF families and an email questionnaire was sent to general pulmonary families, for family feedback. Feedback has been largely positive, and several areas for improvement have been identified. Five new workshops and five new community based training exercises related to the culturally competent, family centered care of children have been developed.

Family Involvement: The PPC Family Involvement program has developed significantly over the past granting cycle: Using a family focus group meeting in 2005, the PPC first recruited family faculty in early 2006. A FAB was established to provide feedback and advice to the PPC on implementing policies that would result in more effective partnerships between healthcare providers, patients and families. In 2007 a second family faculty was recruited. Family faculty engage in four key areas: communicating with patients and families to improve the quality and safety of healthcare provided; training trainees from the core disciplines about Family Centered Care (FCC) and the benefits of partnering with patients and their families; integrating the principles of FCC into all aspects of the clinic and division; advocating for patients and their families at an institutional level, locally, regionally and nationally.

Communication with patients and families is achieved in face to face meetings in clinic, via email and telephone and through a quarterly education CF newsletter. In collaboration with Streetlight, an in house support program for adolescents and young adults living with chronic and critical illnesses, such as CF, the division has been able to engage teenagers more effectively in their care, specifically relating to end of life issues and transition to adult care. In relation to training, family faculty has provided training sessions to the following groups: division faculty, all trainees in the division through small group discussion, to nurses and respiratory therapists via live meeting and large group lectures and to medical students through participation in Interdisciplinary Family Health, a year long program at the University of Florida for first year medical students. Integration of FCC principles has been achieved within the division largely as a result of having family faculty physically present in the office, with office space. In relation to advocacy, family faculty actively seeks opportunities to have the Institute for Family Centered Care model of FCC adopted and integrated into all departments and divisions of Shands Hospital and the University Of Florida College Of Medicine (UF COM). The family faculty serves on the Shands Pediatric Patient and Family Advisory Board, the Shands Pediatric Family Centered Rounds Committee. She has presented to the Chairman of Pediatrics and the Dean of the College of Medicine. She is currently advising the Senior Associate Dean for Clinical Affairs of the College of Medicine on expanding family involvement to adult services. In addition, family faculty has presented at the PPC Annual Updates meeting, the AMCHP Annual meeting, the International Conference on Family Centered Care and the American Lung Association (ALA) Symposia on Health. She assists with the transition program, an essential aspect of FCC (see section on Value Added).

Faculty Development: Faculty skills are developed in discussions of challenging patients, case study presentations, teaching and attendance at local, regional and national CME seminars. PPC

faculty research skills are developed by attending and presenting at research conferences and participating in Journal Club. PPC faculty develop teaching skills by teaching in varied venues and by taking advantage of the faculty development courses offered in the COM and the Office of Instructional Technology. PPC faculty members maintain policy-related skills through their collaboration with ICHP, multiple collaborations with the Florida DOH and teaching in the Pediatric Resident Advocacy Rotation. PPC dietitian and Family Consultants assisted in developing state legislative policy for patients with cystic fibrosis. The PPC Director participates on committees on policy initiatives in the field of sleep medicine.

Summary Performance Measure Data:

PM07: The degree to which MCHB supported programs ensure family participation: score moved from an 8 to 12 (out of 15) over granting cycle.

PM08: The percent of graduates of MCHB long-term training programs who demonstrate field leadership after graduation: score moved from 80% to 100% over granting cycle

PM09: The percent of participants in MCHB long-term training programs who are from underrepresented groups: went from 29% to 45% over granting cycle.

PM11: The degree to which MCHB long-term training grantees include cultural competency in their curricula/training moved from 14 to 22 (out of 27) over granting cycle

PM58: The percentage of MCH training faculty who demonstrate field leadership in the areas of academic, clinical, public health/policy and advocacy stayed at 100% over granting cycle

PM59: The degree to which a training program collaborates with State Title V agencies or other MCH-related programs stayed at 5 (maximum score) throughout granting cycle, with 166 activities in 2008-2009

PM60: The percent of long-term trainees who, at 1, 5 and 10 years post training, work in an interdisciplinary manner to serve the MCH population went from 85% to 95% over granting cycle.

4. Evaluation

Trainees 2005-2009							
	Year	2005-2006	2006-2007	2007-2008	2008-2009	2009-2010	Total
Type							
Short term		30	54	32	47	25	188
Medium term		47	43	120	44	20	274
Long term		9	8	9	11	3	40
Total		86	105	161	102	48	502

Univers

Disciplines of Trainees 2005-2009							
Year	2005-2006	2006-2007	2007-2008	2008-2009	2009-2010	Total	
Discipline							
Respiratory Therapy (RT) (Other)	23	38	56	34	24	175	
Nursing (RN)	4	2	1	0		7	
Nutrition (RD)	9	12	10	14	6	51	
Social Work (SW/MSW)	5	2	3	4	2	16	
Public Health (MPH)	0	1	1	3		5	
Rehabilitation	0	0	0	4		4	
Pharmacy (PharmD/RPh)	25	0	0	15	8	48	
Psychology	0	6	12	0		18	
Medicine: General MD)	20	35	61	4	8	128	
Medicine: Pediatric	0	9	17	24		50	
Total	86	105	161	102	48	502	

Long Term Trainees 2005-2009

	<u>RACE/ ETHNI- CITY</u>	<u>DEGREE AT ENTRY</u>	CURRENT EMPLOY- MENT	<u>NAME</u>	<u>RACE/ ETHNICITY</u>	<u>DEGREE AT ENTRY</u>	CURRENT EMPLOYMENT
Amy Barulic	White ¹	BA	Pre-Baccalaureate U Penn	Thomas Horsman	White	MD	Our Lady of the Lake Children's Hospital, Baton Rouge
Morgan Bishop	White	BSW	DC School System	Ralph Jackson	Black	MSW	Veteran's Hospital GNV
Janet Brishke	White	MPH	AAP Chicago	Kristin Dessert	White	BS	Social worker, Mooreville, NC
Natalia Cabrero	Hispanic ²	MSW	Cuidade, Orlando	Lisa Magary	White	MSN	Craniofacial Center, UF

¹ Individuals listed as white are non-Hispanic unless otherwise indicated

Anita Rae Conley	White	MS, RD	Florida Hospital, Orlando, FL	Jessica McIntyre	White	MS	PA candidate, Boston
Kristin Corr	White	MSW	Social Worker	Amy McLaughlin	White	MSW	Dep't of Children and Families
Cristin Cuzzo	White	RD	Senior Dietitian, WIC	Irma McLaughlin	White	MSW	Case Mgr., The Preserve, Florida
Janai J Duncan	White	MSW	Camelot Comm. Care	Shreekala Prabakaran	Asian	MD	Sleep Fellow, UF
Russell Gibson	White	MD	U Michigan Hosp. Ann Arbor	Natalie Ricci	White	MSW	Hospice, Ocala Florida
Kim Handley	White	MSW	Daniel's Kids	Camila Irwin	White Hispanic	BA	UF Adult CF clinic
Amy Hetz	White	BSN	Pediatric Assoc. Alexandria, VA	Thalia Smith	Black	MSPH	PhD candidate in Public Health, UF
Catherine Rodgers	White	MSW	Social Worker, Gainesville FL	Emily Stapleford	White	MSW	DOD school system, Cuba
Peter Rudnytsky	White	MSW	Volunteer, UF Sleep Clinic, CAC	Claudia Tamayo	Multiracial Hispanic	MSPH	Unemployed, Gainesville
Desiree Schnoor	Multiracial	MSPH	Not currently employed	Daniel Torrez	White Hispanic	MD	Emory, Atlanta
Aaron Short	White	BA	Partnership for Strong Families	Megan Griffin	White	MS	Graduate Student, UF

² Individuals listed as Hispanic are white Hispanic unless otherwise indicated

Goal	Process Measures	Outcome Measures
<p>Goal 1: Recruit and retain diverse graduate trainees and fellows who demonstrate high potential for MCH leadership</p>	<p>Number of trainees recruited and retained: Underrepresented: 173; Non-physician: 284; Physician: 178; Fellow: 5 (MCHB funded and not)</p>	<p>Performance Measure #9: On average over the five year granting cycle, 32% of all trainees were from underrepresented groups. On average, 28% of long term trainees were from underrepresented groups (45% in 2009).</p>
<p>Goal 2: Educate fellows and trainees to be leaders in the interdisciplinary care of children with chronic respiratory conditions</p>	<p>Successful provision of clinical, public health, research training activities Number of long term trainees completing program: 40; Number of trainee products: 55</p>	<p>--Trainee General Leadership Self Assessment Scale: Trainee average went from 60% (pre) to 92.5% (post); MCH-specific Competency Assessment: Trainee average went from 35 % (pre) to 80% (post). --Core Curriculum Seminar Evaluation: Average of 1.2(on 1-5 scale) for each of 33 Core Curriculum Sessions Trainee Final Evaluation of PPC Training Program: 1.1 (all on scales of 1-5 where 1 is highest).</p>
<p>Goal 3: Provide interdisciplinary education programs at the state, local, regional and national levels to address key MCH issues and HP 2010 objectives.</p>	<p>729 statewide, regional or national CE programs provided; 11,655 participants (interdisciplinary); Developed 195 educational products</p>	<p>The evaluations on the CMS programs and the Asthma broadcast indicate that the programs were excellent. Feedback on other talks ranged from good to excellent.</p>
<p>Goal 4: Collaborate with and provide TA to Title V/MCH agencies at the local, state, regional and national levels</p>	<p>311 topics to 521 recipients of technical assistance and collaborative activities to state, regional and national organizations.</p>	<p>--Scores on Technical Assistance/Partnership evaluation forms averaged 3 on a scale of 1-3 where 3 is highest. --Please see Sections 5-7 of this report, for specific information about collaborations.</p>
<p>Goal 5: Expand programs in key MCH/Healthy People 2010 areas including cultural competence /diversity, family involvement, and faculty development</p>	<p>103 activities provided to enhance CLC, CC and Faculty development</p>	<p>--NCCC Self Assessment checklist and Checklist for Systems of Care have been completed and areas for improvement have been targeted. --TA was obtained by Tawara Goode of the NCCC 99% of families said that they would recommend the PPC to a friend. --- --Patients rated provider interactions either excellent or very good 98% of the time. Target areas for improvement have been identified. --The Family Partner has been gathering feedback from families and changes are being made in accordance with feedback. --PPC faculty have developed projects and publications</p>

5. Title V Program Collaborations:

Maternal and Child Health Bureau: Over the past five years, PPC faculty participated on the Training Program Family Centered and Family Directed Practices Workgroup and presented on Workgroup products at the AMCHP Conference. They were co-authors on several products developed by this workgroup including “A Compendium of Family Centered, Family Directed Resources” and “Developing a Family Advisory Board.” PPC faculty also provided feedback to MCHB on the Discretionary Grant Information System (DGIS) and on proposed new/revised performance measures. Medium Term Performance Measure was finalized by faculty nutritionist and has been submitted to Office of Management and Budget (OMB) for approval. Nationally, faculty provide leadership in collaborative programs that make a difference in the care of children, such as the MCHB All-Grantees Planning Committee. They have conducted several MCHB and Health Resources and Services Administration (HRSA) grant reviews, site visits and consultation to State Title V programs. PPC faculty serve on the conference planning committee and facilitated a workshop at the MCHB-funded Leadership, Legacy and Community retreat hosted by the University of Illinois at Chicago’s (UIC) School of Public Health. PPC trainees also attended this conference. The collective PPCs presented last fall to both to MCHB and AMCHP staff on PPC programs and accomplishments.

Association of Maternal and Child Health Programs (AMCHP): The seven national PPCs are AMCHP members and are kept abreast of MCH advocacy and policy issues. In September 2009 the seven national PPCs also met with AMCHP staff to discuss common interests and activities.

National Pediatric Pulmonary Centers: Collaborative activities with other PPCs include participation on national PPC committees (e.g., Cultural Competence, Advocacy, PPC Orientation 101, Steering Committee). The nutrition faculty is Chair of the PPC Database Committee. The PPC Director and co-director co-chaired the national PPC Steering Committee. The UF PPC hosted the annual 2009 national PPC meeting which focused on how the PPCs can help the nation realize the new Healthy People (HP) 2020 goals. The UF PPC coordinated the collection and compilation of the Family Involvement Curricula at the seven PPCs and this compilation is now located on the MCHB PPC website. The PPCs have collaborated in the MCHB Orientation ad hoc committee to develop orientation materials for trainees. The UF PPC served as a downlink site annually for the University of Alabama at Birmingham (UAB) Department of Pediatrics MCHB funded nutrition teleconference. The collaboratively developed PPC cross cultural case studies have been marketed nationally to MCH trainees and health professionals over the past granting cycle. In 2009 The PPC Cultural Competence Task Force developed a final case “Moving Towards Health Equity”. With the completion of this case, the Cross Cultural Cases now cover all cultural competence domains identified by the Association of American Medical Colleges (AAMC) Tools for Assessing Cultural Competence Training. The cases are available at no cost (but without CEUs) on the national PPC website. There have been over 6000 users on the national website since 2005, from states throughout the country. The cases have been used in residency training programs, nursing programs, LEND programs and WIC programs and a variety of other sites. The cases were used in the Florida Initiative for Children’s Healthcare Quality and were used to inform the development of the MCHB funded “Pediatrics in Practice” courses developed by Dr. Henry Bernstein at Dartmouth. The cases were also listed as a resource for training in the newsletter of the Association of Pediatric Program Directors. The cases have been linked to the Professional Training Resource Library (PTRL), established by the International Society on Early Intervention (ISEI). The PTRL is a joint project

of ISEI and the Association of University Centers on Disabilities (AUCD), to create important, current, and easily accessible training materials for professionals in early childhood intervention worldwide. The cases are currently being used by the Diversity Health Council of Abingdon Memorial Hospital (AMH) near Philadelphia, Pennsylvania in a traveling program that will circulate among all hospital departments to increase awareness and our actions that pertains to culturally appropriate health care, and will be used to educate residents at AMH. CEUs for the cases (for a fee) have also been offered on discipline-specific websites for social workers, physicians and nurses since 2005 and for pharmacists, dietitians and respiratory therapists since 2007. The PPCs are in the process of a multi-site study to evaluate the effectiveness of the cases with pediatric residents. The PPC has collaborated with other training programs on Emergency Preparedness training. Four PPCs collaboratively conducted an online survey to assess the knowledge, availability and use of these technologies by PPC faculty, current trainees and trainees who completed PPC training in the previous 10 years. Analysis of this survey is currently in progress with full results anticipated by spring 2010. The PPC Steering Committee and other faculty representatives will use the data to launch a pilot project using social media in the fall of 2010. The UF PPC will also use these results to enhance our Distance Training and MCHB networking activities (Grant Goal 2, pp 18-20 and Goal 5, pp 25-26). The UF PPC and UAB PPC have also developed a collaborative distance education project to be implemented in 2010. (Grant Goal 1.1, p. 7))

The University of South Florida (USF) School of Public Health: We have met with, and discussed collaborative training activities with, Dr. Russell Kirby from the USF School of Public Health. These activities will initially include USF providing a lecture on MCH Systems to PPC trainees and the UF PPC Nutrition faculty providing a lecture on Nutrition and Public Health. Several additional research and training activities are being formulated.

National Center for Cultural Competence (NCCC): PPC faculty presented collaboratively with Tawara Goode of the NCCC at the 2009 AMCHP Conference. PPC faculty provided TA to the NCCC on the development of their online curriculum, on a document related to the rationale for cultural competence training in MCHB training programs and on a cultural and linguistic competence checklist for MCHB training programs.

The Florida Institute for Family Involvement (FIFI): We collaborated with FIFI in the development of our Family Involvement Program. FIFI assisted us in creating the position description and minimum qualifications for the job of Family Partner and in facilitating a focus group to identify family needs and interests. FIFI staff initially provided consultation to the PPC Family Partner, but the need for this diminished as the Family Partner became an integral part of the division.

Florida Department of Health (DOH): *Asthma:* “The Guidelines for the Delegation of Care for Students with Asthma in Florida Schools” were completed in 2005. In 2006 a two hour training program on the Guidelines was webcast to all school health personnel in Florida. In 2008, the DVDs were distributed to school and health department nurse coordinators throughout Florida followed by an evaluative survey to determine effectiveness of the presentation. This feedback was used to update content and presentation style for this asthma management enduring material. PPC faculty provided TA to the DOH in the development of the Florida State Asthma Plan and successful application for Center for Disease Control (CDC) funding for “Addressing Asthma from the Public Health Perspective” which resulted in the development of the state Office of Asthma Prevention and Control. We will continue to provide TA to this office. PPC faculty have participated in “Asthma Blowout Day,” a community-based family education fair

related to asthma and have provided TA to the Alachua County Health Department on asthma care and asthma education. *State Advisory Board*: The State Advisory Board includes the Florida State Title V Director, Director of CYSHCN and Director of Community and Family Services, as well as a number of additional DOH and other MCH professionals from around the state. The PPC provides TA and training on issues related to systems of care for children with chronic respiratory conditions to SAB members. *Tobacco Cessation*: PPC faculty members serve on several committees within the Alachua County Tobacco-Free Partnership. This partnership, funded by the Florida DOH through the local health department, comprises a county-wide coalition of healthcare providers, law enforcement, judiciary, store owners, teachers, politicians and other community members. At present, the coalition is focused on assessing the level of community interest and motivation to address the problem of tobacco use and will develop a community wide strategy to change policy to address the challenges of tobacco use. *Cystic Fibrosis*: The PPC is part of the DOH Newborn Screening Task Force. This committee implements all aspects of the State of Florida CF newborn screening program which began in September, 2007. Faculty meet with the DOH newborn screening staff, CF Foundation representatives and other CF centers in Florida to refine the newborn screening protocol. *Local Health Departments*: The UF PPC acts as a resource for the management of children with chronic respiratory conditions for health departments. Alachua, Pasco, Duval, Dade, and Broward County health departments have received presentations from PPC faculty on asthma management, evidence analysis, nutrition, and cultural competence. Advisement to Marion County on equipment and training for pulmonary function testing was provided by the Faculty Nurse. Short-term training programs on the management of children with asthma have been designed for practitioners employed in rural health departments in Florida. *Additional Title V TA*: PPC faculty members also participate on the Florida Statewide Transition Workgroup, Florida Office of Disability and Health Project, Florida Adult CF Program, the Florida Organ Transplant Advisory Council, and Consortium for Genetic and Newborn Screening Services. PPC faculty and students, in collaboration with the University of Florida Pediatric Residency Program and Dr. Nancy Hardt, the UF HSC Vice President for External Affairs, make monthly visits to Tallahassee to meet with legislators and/or DOH leadership. These trips facilitate communication regarding PPC activities and capabilities and to respond to state needs.

Children's Medical Services/Medicaid: Collaboration with Children's Medical Services (CMS) includes direct services to and care coordination for CYSHCN, expanding distance education programs, setting standards, evaluation of client satisfaction and patient advocacy. PPC faculty and staff serve as consultants to CMS (as well as Medicaid and home care providers) to set policy for home care of children with complex care needs. They also give TA to local providers regarding sleep and home technology issues. PPC faculty members provide clinical service and TA to CMS outreach clinics in Panama City and Tallahassee three times/year. PPC members attend quarterly CMS/Medicaid meetings designed to influence policy around reimbursement and access issues. Through these meetings, standards for appropriate use of Continuous Positive Airway Pressure (CPAP) and Bilevel Pressure Support have been developed. PPC nutrition and nursing faculty participated in the revision of performance standards for CMS State Contract. The team has also collaborated with CMS to expand pediatric DME services to outlying areas of the state. CMS staff also teach in the PPC Core Curriculum. **WIC**: The PPC faculty provide TA and CE to Florida WIC nutritionists on nutritional care of children with chronic respiratory conditions. The PPC collaboration with WIC includes the provision of an internship site for public health nutritionists enrolled in the Pasco and Duval

County Public Health Dietetic Internship Programs (42 WIC trainees over past granting cycle), and clinical care of WIC clients. WIC nutrition trainees participated in the development and revision of the cross cultural case studies. The North Central Florida (NCF) WIC director serves as a member of the PPC CAB. The PPC Faculty Nutritionist serves as a member of the Pasco County WIC preceptor advisory boards. Two former long term nutrition trainees are now employed by WIC. Two long term trainees conducted a state-wide assessment of WIC Directors' and local WIC staff's learning needs. As a result of this the PPC has developed an online CE module for WIC nutritionists on asthma and nutrition. This program has been presented locally and nationally. The faculty dietitian provided TA on program analysis to the Pasco County Dietetic Internship Program. The PPC Nutrition Faculty received the Mildred Kaufman Public Health Nutrition Award for excellence in dietetic education from the Pasco County Health Department WIC dietetic internship. PPC faculty participated in a WIC-based simulated learning experience related to disparities in care at the Alachua County.

Institute for Child Health Policy (ICHP): There are several PPC-ICHP collaborations. ICHP has a contract with MCHB for website development and distance training. PPC faculty pilot and provide feedback on ICHP's distance technology tools. PPC served as a pilot site for the development of a Digital Storytelling methodology. PPC and ICHP faculty co-teach pediatric residents on self awareness, physician-patient communication and recently participated in the development of a module on "Working with People with Disabilities" for medical students. They have collaborated on the development of a course in Health Care Transition to be offered to students in various graduate programs through the UF College of Education as part of the Interdisciplinary Collaborative on Healthcare and Education Transition (ICHET) (see Value Added, University, p.15). Development of transition programs in collaboration with ICHP is progressing as the program is field tested in UF clinics. Original tools are being modified and streamlined as a result of feedback from families and staff. Faculty trainees and Family Partners attended the Transition Conference hosted by CMS and ICHP.

Florida Office for Disability and Health (FODH): This CDC-funded Center is housed at the University of Florida College of Public Health and Health Professions and is Florida's first centralized program to coordinate Florida's disability programs and services. PPC faculty serve on the advisory board of FODH.

PPC Community Advisory Board (CAB): The PPC CAB comprises representatives of community organizations, many of which are funded through Title V. CAB members include individuals from Medicaid, Children's Medical Services, WIC of North Central Florida, UF College of Education, American Lung Association, ICHP, Child Abuse Prevention Project, the Florida Department of Children and Families and Alachua County Health. The PPC solicits feedback from CAB on our training program and the group discusses mutually beneficial training opportunities and collaborations. Thus far, numerous collaborations have developed, including a post-transition survey, a health careers camp, a collaboratively developed graduate level course and the early stages of a sleep-autism project.

6. Regional and National Significance

Cystic Fibrosis Foundation: The PPC faculty nutritionist and social worker have served as mentors for the newly developed Nutrition and Social Work Mentoring Programs developed by the Cystic Fibrosis Foundation (CFF). They have mentored four apprentices through this program. The PPC faculty social worker chairs the CFF Education committee and the nurse is serving a second term on this committee. PPC faculty have presented annually at the North

American CFF Conference. PPC faculty are also members of the CF Screening Consortium.

American Academy of Pediatrics (AAP): Two PPC faculty members have co-authored a chapter on Nutrition for Children and Adolescents with Pulmonary Conditions for the AAP's "Blue Book of Pulmonology."

American Dietetic Association(ADA): The faculty nutritionist serves as an evidence analyst for the ADA Foundation's Evidence Analysis Library (EAL). She has reviewed over 105 articles and contributed to the recommendations and guidelines for practice for Gestational Diabetes, COPD, HIV/Aids, and unexpected weight loss. She is also reviewing articles for the revision of the US Dietary Guidelines that is currently being conducted by The Center for Nutrition and Public Policy (CNPP). She serves as an abstract reviewer for the ADA annual meeting, attended the ADA Leadership Institute Certificate Program in 2008 and reviewed grant applications for the "Champions in Fitness" grant funded through the ADA Foundation. She is co-authoring the Pulmonary Nutrition chapter for the ADA's online Pediatric Nutrition Care manual to be published in 2010.

Florida Department of Education: Over the granting period, six interns from Florida Department of Education (DOE) School Food Service Dietetic Internship completed medium term nutrition traineeships with the PPC. The PPC has consulted with DOE to conduct the Youth Behavior Risk Surveillance Survey (YBRSS) in the Alachua County Public Schools.

American Academy of Sleep Medicine Fellowship Training Committee: Dr. Wagner is a member of this committee which is in the process of recruiting sleep medicine programs to match potential fellows with training programs. This committee has facilitated in-service training exams and reviewed behavioral sleep medicine programs for certification.

Myopathy Standards of Care Development Committee and the Workgroup on International Standards of Care for Congenital Muscular Dystrophy Dr. Pam Schuler participates on these committees which develop guidelines and policies, and is the United States Pulmonary Group leader for the MD Workgroup.

Florida Organ Transplant Advisory Committee: Dr. Schuler participates on this committee which accredit programs for Medicaid sponsored transplants as well as approving any out of state lung transplants.

7. Value Added:

College of Medicine(COM)/Health Science Center(HSC): The PPC grant allows PPC faculty to provide a wide range of teaching, continuing education, and technical assistance that they would not otherwise be able to provide at UF and in the community. These offerings, on such topics as care of CYSHCN, interdisciplinary care, medical home, disparities in care, help PPC faculty integrate MCHB core values within the institution and community. Within the COM, faculty and trainees participate in pediatric house staff education, PA student education, Pediatric Grand Rounds, medical student lectures/seminars, the pediatric residents' self-assessment seminar, and mentoring of graduate and undergraduate students. PPC faculty members teach modules on disability in the COM "Essentials of Patient Care" course and guest lecture in the Narrative Medicine course. The PPC Social Worker, Nutritionist and Family Faculty teach in "Interdisciplinary Family Health,"(IFH) an innovative program developed in the UF HSC in which interdisciplinary groups of three or four first year health science students participate in five home visits over the course of the year.

The Family Faculty member has taught about family involvement to a variety of groups within the HSC including medical, public health and nutrition students, UF COM faculty and

Dean, patients and families. The PPC Nurse serves on the COM Committee on Medical Education (CME). The PPC social worker is a preceptor for the pediatric residents' advocacy rotation (primarily community pediatrics) and co-lead the revision of this rotation with the pediatrician who coordinates this rotation. As part of this effort, she also precepts in the School Health Interdisciplinary Program through which teams of interdisciplinary health students engage elementary school students in health promotion activities. PPC faculty members serve as mentors for HSC students and provide TA to pediatric residents and faculty in grant writing.

The PPC Director has provided TA to UF COM and Shands Hospital in the development of a comprehensive sleep program, including a Sleep Disorders clinic, Sleep Fellowship and the new Shands Sleep Disorder Center. She also consults on Sleep Medicine and provided a lecture on sleep apnea in athletes to the UF Sport Medicine Advisory Board. She is working with this group to create a screening tool for Obstructive Sleep Apnea (OSA) in athletes. She and the Sleep Center Program Manager host a half-day Sleep Conference for polysomnography technicians and respiratory therapists once or twice each year. PPC faculty have provided TA to the Shands Respiratory Therapy Department.

In 2007, the PPC collaborated with the Department of Clinical and Health Psychology in writing and implementing a grant from the Blue Foundation to provide psychological screening and treatment of uninsured or underinsured Pediatric Pulmonary Patients. PPC faculty have been involved in student training and professional development related to this grant. The PPC has also participated in several research projects conducted by Clinical and Health Psychology graduate students. PPC faculty have also presented to this department several times over the granting period.

The PPC collaborates in several ways with the College of Pharmacy (COP). Dr. Hendeles, a COP faculty member, is active in the PPC. He participates in journal club and other educational meetings, assists with clinical training of interdisciplinary students and supervises PPC fellows and trainees on their research. Dr. Hendeles is involved in a number of program and policy activities. He has served on the Food and Drug Administration (FDA) panel examining drugs used in asthma and allergy and collaborates with Medicaid officials to improve access to state of the art asthma medications. He also developed a program to treat severe allergic asthma within local communities. Dr. Hendeles talks with trainees about these activities, putting a human face on policy and advocacy. PharmD interns serve as medium term trainees in the PPC, assisting with clinical management of and advocacy for PPC patients.

In addition to training students from the UF College of Public Health and Health Professions (PHHP), the PPC is collaborating with the PHHP in the development of a module on disability for medical students. The PPC social worker, nutritionist and family partner teach on the topic of Children with Special Healthcare Needs to a graduate course in Maternal and Child Health in the UF College of Public Health.

The PPC continues to work on the development of transition programs in collaboration with the Shands Hospital Adult CF Clinic and ICHP. The modified ICHP transition tool is given to adolescents and used as a guide to transition discussions. Based on suggestions by the PPC CAB, a PPC trainee conducted a survey of patients who had already transitioned to the adult clinic to assess the strengths and weaknesses of the transition program. The results of this survey were presented by the trainee in a poster at the American Public Health Association Meeting in October 2008, and have been incorporated into the transition process. The PPC meets monthly with the adult CF Center to coordinate and facilitate transition efforts. The PPC has also been fortunate to be a consultant to, and a beneficiary of, Streetlight, an inpatient palliative

care/support program for youth with chronic illness. Streetlight received private funding to create transition activities for youth with CF while they are hospitalized. PPC input has been solicited regarding types of activities to use, how best to engage families and contacting specific families. Streetlight's work will greatly enhance the PPC outpatient transition efforts.

The PPC social worker is on the Advisory Board of the Office of Equity and Diversity and the Community Subcommittee of this board. In early 2008, the PPC Social Worker and the VPHA-OED collaboratively wrote a HRSA Health Careers Opportunity Grant. This grant application proposed collaboration with Santa Fe College, the Suwannee River AHEC, The Gainesville High School Academy of Health Professions and the African American Accountability Alliance geared towards developing awareness of health careers among educationally and economically underserved middle school students. The grant proposed the use of a traveling (InvestiGator) van with youth-friendly, engaging activities educating students about the various health careers and building the skills necessary for these careers. This grant was recommended for funding, but not funded. The PPC and OED nonetheless implemented one aspect of the grant, a week long summer Health Careers camp for middle school students at the PK Yonge School. They continue to actively search for additional private or federal funds in order to realize the remainder of this project. A pamphlet and one-page flier describing the project have been developed in order to educate potential supporters.

The PPC assisted the UF Maternal and Child Health Education and Research Data Center (MCHERDC) in submitting an National Institute for Health (NIH) grant to address childhood obesity in Alachua County. If this grant is approved, the PPC will participate in the various data collection, mapping and intervention activities of this grant.

University: The PPC Nutritionist, Social Worker and Family Partner teach on Professionalism to several classes within the Food Science and Human Nutrition(FSHN) Department. The PPC social worker and dietitian serve on the FSHN Dietetics Program Advisory Board and have provided guest lectures in the graduate and undergraduate programs annually. The faculty dietitian also spoke on Evidence Analysis at the Masters of Science and Dietetic Internship (MSDI) students' summer continuing education program. The PPC dietitian collaborated with FSHN faculty on annual downlink of the Pediatric Nutrition Teleconference sponsored by the UAB PPC. The MSDI program director serves as a member of the CAB..

Several PPC faculty are currently collaborating with the Interdisciplinary Collaborative on Healthcare and Education Transition (ICHET), an interdisciplinary group of faculty from the College of Education, Department of Pediatrics, Department of Medicine and ICHP to increase collaboration between the worlds of healthcare transition and education transition. ICHET developed an online graduate level course on Health Care transition for various disciplines. Ideas for this course emerged from the CAB. We became aware of the potential value of such a course as we began to realize that different professions held remarkably differing views on the meaning of "transition" and that improved communication between health and educational professionals would greatly enhance the transition process for CYSHCN. The course was offered online through the UF College of Education in the winter/spring 2010 semester and will be repeated in fall 2010. ICHET will develop two more courses related to transition and to offer a certificate program in healthcare transition. ICHET will also develop a research proposal to compare two online models for education healthcare providers, educators and families about Healthcare Transition.

Local: The UF PPC provides technical assistance to a number of local agencies and educational groups serving children and families. The faculty social worker serves on the Board of Directors

of the Gainesville Child Advocacy Center (CAC). She also co-chairs the CAC Conference committee which develops and conducts an annual conference to train local care providers in topics related to prevention and treatment of child abuse and neglect. The PPC Director participates on the Board of the Girls Place, an organization providing afterschool and athletic programs for girls from diverse backgrounds, emphasizing service to girls from underserved backgrounds. She also serves as Advisor to the National Junior Honor Society Chapter and the Organizer for the Volleyball Team at a local middle school in a low income neighborhood. She volunteers for several activities in both a high school and middle school in low income neighborhoods and assists with a youth choir.

The PPC has also collaborated with a community psychiatrist who is an expert on Attention Deficit/Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder(ASD). He has an appointment as an Affiliate Associate Professor at UF and we are exploring research/clinical collaborations related to the high prevalence of sleep disorders in children ASD and the relationship between ADHD and sleep problems. He currently lectures to PPC trainees.

The PPC has collaborated with the regional AHEC on providing the annual Updates Conference and additional educational programs for a variety of health care professionals including those in rural settings where training is less available. This effort has gained importance with the recent economic downturn making travel funds unavailable for many caregivers. Additional PPC-AHEC collaborations include the online hosting of CEU offerings, minority recruitment efforts, smoking cessation activities, and training. Most recently the PPC and AHEC have collaborated in the training of three AHEC Public Health Scholars. In addition to the project described above (WIC) one of the students developed a project investigating the prevalence of smoking, and readiness-to-change of the parents of pulmonary patients. She will also collaborate with an intern at the Alachua County Health Department to provide smoking cessation materials once the preliminary needs assessment has been completed

Statewide: In addition to state Title V organizations, the PPC provides technical assistance to such state organizations as the Florida Lung Association, the Florida State University (FSU) School of Social Work and the Florida Dietetics Association. The Faculty Nutritionist reviews abstracts and is a planning member for the Florida Dietetic Association's annual meeting. She also developed a curriculum and mentored a dietetic intern from the FSU dietetics program.

National: PPC faculty members provide leadership in collaborative programs that make a difference in the care of children. The PPC director was a member of the American Academy of Sleep Medicine's (AASM) the National Sleep Fellowship Policy Development Program and is now a member of the AASM Sleep Fellowship Training Advisory Committee. Faculty members provide peer reviews for submitted journal articles and grants (e.g. New Zealand Institute). A PPC faculty member participated as a site reviewer for the Oregon Health Sciences Center CYSHCN data center and another is an ALA grant reviewer. Faculty also participate in national collaborative research efforts and recently completed the CF Twin and Sibling Study. Faculty and fellow present at national conferences such as the North American CF Conference, AMCHP, IFCC, American Thoracic Society and the American Academy of Allergy and Immunology. the American Society of Transplantation, the National Association of Social Workers, and the Collaborative Family Healthcare Association. PPC faculty will also continue to write and review articles for such journals as Pediatrics, Academic Pediatrics, Journal of Clinical Sleep Medicine, New England Journal of Medicine, the Journal of Allergy and Clinical Immunology.
