Many rich and unique resources are available at UF for community engagement and participatory research. Indeed, with the largest academic healthcare system in the Southeast and the largest VA healthcare system in the United States, the network of hospitals, clinics and related patient care facilities throughout north-central Florida is truly impressive. Now add the community educational outreach facilities of UF’s Institute for Food and Agricultural Science (IFAS) in each of Florida’s 67 counties and one begins to appreciate the truly statewide reach of the CTSI’s Community Engagement and Research Program (Fig. 1). These resources, together with the distributed network of the CTSI’s Clinical Research Units that support inpatient and outpatient hypothesis-driven investigations provide UF’s clinical and translational scientists and trainees with a virtual cornucopia of research opportunities!

We will have more to say in a future issue about the Clinical Research Units that are the backbone of the CTSI’s Participant and Clinical Interactions Program. Read now about how the Institute can help support multi- and interdisciplinary efforts in late-stage translational 2 (T2) research through UF’s integration with the communities it serves.

Peter W. Stacpoole, Ph.D., M.D.
Director, CTSI
The University of Florida has a long history of working and conducting research in communities throughout the state to better the health and lives of its diverse populations. Those endeavors will be expanded and strengthened under the CTSI’s Community Engagement and Research Program (CERP). The program will more actively engage members of these distinct communities as partners, not only to identify research and programs that will be most beneficial to their unique needs, but also to conduct, interpret and disseminate the outcomes of these initiatives.

Florida’s size and diversity provide unprecedented opportunity for CERP to build on community-based initiatives already being undertaken. These efforts will further encourage and support collaborative partnerships between UF clinical and translational scientists and schools, community agencies, managed care organizations, physician practices, dental practices and other community settings statewide. UF has key links in communities throughout Florida through several institutes, colleges, centers and programs that form the foundation of this expanded community-based initiative. CERP also will address several existing challenges necessary to create an integrated and functional community- and population-based research program.

**Achieving CERP goals**

**Expanding community partnerships**

CERP will encourage these dynamic partnerships through community-based participatory research (CBPR). This approach recognizes the host of social, political, economic and other complex factors involved in health, and directly and equally involves all partners who wish to improve a community’s wellbeing and eliminate inequities. CBPR is not a new concept, but until now has been limited to individual studies. UF has previously not provided internal funding earmarked for community-based research, but CERP will fund as many as two pilot studies per year through grants to CTSI researchers. In order to further enhance collaboration, a Community Advisory Council will be formed comprised of UF faculty, community healthcare providers, business leaders, school system representatives, and adult and adolescent community members, including those from minority groups.

**Aiding CTS researchers**

In addition to cultivating partnerships with communities throughout the state, CERP also will reach out to UF clinical and translational science investigators in two ways. The first is by serving as a single unified resource of expertise, support, consultation and interaction for those who conduct community- and population-based research. Currently no mechanism exists to provide this single point of reference for investigators to interact with experts regarding community engagement and CBPR methods that may be applicable for their research. But CERP will provide technical expertise on designing and conducting studies that best fit a target community, and will assist investigators in identifying strategies for participant recruitment, retention and interaction that are community specific and culturally appropriate.

An extensive set of secondary data that can be used to define populations, examine health outcomes and identify potential participants for future studies will be housed in the CTSI, which can be made available with appropriate collaborations and approvals. These include Florida birth and death certificate information, and data related to Medicaid and State Children’s Health Insurance Program (SCHIP) recipients in Texas and in Florida.

Second, CERP will provide education about community-based research and facilitate improving communication, coordination and sharing among scientists, and between scientists and community members. This will be accomplished through roundtable discussions where best practices in community research can be shared, and through forums where investigators can interact with community members. Active online databases of community, clinical and investigator partners also will also be maintained.
Improving children’s and oral health

A CTSI Pediatric Research Advisory Committee will be established to ensure that CTS research and training in child health is guided by the highest ethical and scientific principals, and that outstanding resources are available for conducting pediatric research. The committee also will facilitate and promote training in the conduct of inpatient, outpatient and community-based pediatric research.

Initially, emphasis will be placed on developing community research partnerships and practice networks aimed at promoting children’s health and proper oral health. In line with the Healthy People 2010 objectives, improving infant and child health is of critical importance not only because it reflects the current status of a large segment of the U.S. population, but also because it predicts the health of the next generation. In addition, working to eliminate disparities in access to and outcomes of healthcare among minority children may promote better health in their adult years. Dental disease is a major health-care issue for both adults and children, and CERP programs also will focus initially on pediatric and dental networks both because of their importance to population health and because UF already has well-established infrastructures in these areas for community engagement and research.

Directors and partners

The CERP endeavors will be overseen by co-directors Elizabeth Shenkman, Ph.D., and Michael Marsiske, Ph.D., on the Gainesville campus, and Mobeen Rathore, M.D., the CERP co-director and associate director of the CTSI’s Clinical Research Unit on the UF Jacksonville campus. Each is affiliated with institutes and centers that already have significant ties to Florida communities and affiliations with state and federal agencies.

Expanding established community connections

A key component of the CERP and its transformative strategies is the Institute for Food and Agricultural Sciences. With its excellent statewide infrastructure and research being conducted in all 67 Florida counties, IFAS has the potential to touch the lives of more than 18 million Floridians and will play a key role in promoting collaborative partnerships.

From its inception, IFAS has extended research knowledge and results by putting that information into the hands of the public in communities across the state to solve problems and improve the quality of life of its residents. Local needs drive programs that IFAS offers, and faculty located in each county are uniquely positioned to address community needs in collaboration with faculty throughout UF in areas such as outreach and education; promotion of healthy lifestyle choices, disease detection and screening, and immunizations; and development of strategic local partnerships and coalitions with community leaders, agencies and organi-
zations that will lower barriers and improve community healthcare.

Numerous other UF resources have established community connections. These include those that provide strong programs for children, the elderly and low-income racial and ethnic minorities through the Institute for Child Health Policy (ICHP), the UF Claude D. Pepper Center for Older Americans, and the Rainbow Center, Northeast Florida’s only comprehensive pediatric and family-focused HIV/AIDS program. Other links include those that have been launched through the colleges of Dentistry; Nursing and Medicine, not only in Gainesville but at its major urban regional medical campus in Jacksonville, as well as through the Regional Tuberculosis Training and Medical Consultation Center funded by the CDC.

CERP will build upon these connections and longstanding relationships to identify critical healthcare issues in communities throughout Florida, suggest research strategies that are feasible in their settings, and work to facilitate links between UF investigators, state agencies, and local communities.

Meet the CERP Co-Directors

Elizabeth Shenkman, Ph.D., Michael Marsiske, Ph.D., and Mobeen Rathore, M.D., will co-direct CERP.

Shenkman is a professor and chair of the Department of Epidemiology and Health Policy Research and a professor of Pediatrics in the UF College of Medicine in Gainesville. She also is the director of the Institute for Child Health Policy (ICHP), a campuswide institute that operates several community-based research programs, including a partnership with the Florida Department of Health and a novel program of funded research to prevent alcohol use among adolescents.

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Marsiske is an associate professor in the Department of Clinical and Health Psychology in the College of Public Health and Health Professions. He oversees the Participant Recruitment and Retention Core at the UF Claude D. Pepper Center for Older Americans, which is funded by the National Institute on Aging and has a rich community engagement core that supports community recruitment of participants into clinical research studies.

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Rathore directs Jacksonville’s Division of Pediatric Infectious Diseases and the Rainbow Center, which is Northeast Florida’s only comprehensive pediatric and family-focused HIV/AIDS program. The center receives federal funding from the National Institutes of Health, the Centers for Disease Control and Prevention and the Health Resources and Services Administration.

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The CTSI’s Community Engagement and Research Program (CERP) is one of the main areas in which the CTSI’s work becomes visible to the public at large. There are scores of researchers and heath-care professionals working within CERP, each conducting research and applying results for the improvement of care within various constituencies – some quite broad and others very narrowly defined. In this issue of the CTSI Newsletter, we look at a handful of people working within CERP, and the type of work they’re doing as they engage with the community at large.

Shawn Kneipp, Ph.D., ARNP

Dr. Shawn Kneipp, a faculty member in the College of Nursing, is managing a project examining women in the welfare to work program. Early results from the research indicate that there are limits to the commonly-held assumptions about the impact that returning to work has on the mental health of women who have been out of the workforce. The study, with results published in the Western Journal of Nursing Research, showed no differences on several mental health indicators between women who remained on cash assistance compared with those who had left the rolls.

“Current government policy assumes that women achieving the goal of leaving public assistance for paid employment may also have improved psychosocial health,” said Kneipp. “As a result, the federal government only requires states to measure how many welfare recipients leave the program for work, not the effect it has on their health. But this research shows that assumption may be incorrect.”

“Results demonstrate that there were no significant differences in depression, self-esteem, self-efficacy or perceived emotional support scores between the women who continued to receive Aid to Families with Dependent Children and those who left welfare for work,” Kneipp said.

Kneipp’s work has been notable for its inclusion of subjects from groups frequently represented in public assistance recipient rolls. Most prior research studies, which had demonstrated a mental health benefit to paid employment, had focused on married, middle-class, white American women, Kneipp said. Although her current research also included predominantly women who are white, Kneipp’s groups consisted mostly of single mothers with less education who were unemployed or had low-paying jobs, a group on whom little research has been done.

Kneipp said that previous studies have shown a high correlation between stress-related illnesses, such as heart disease, high blood pressure and gastrointestinal disorders, and employment that lacks authority, is not interesting, not challenging and is repetitious - characteristics frequently found in the low-wage jobs typically available to welfare recipients looking for work. When combined with the fact that such jobs often do not include benefits, such as health insurance, and can interfere with family responsibilities, including caring for a sick child, legitimate questions about the overall impact of the welfare to work program on the health of participants may legitimately be asked.
The majority of studies conducted since 1996 have focused on child health and well-being or parent-child interactions, Kneipp said. That reflects a common perception that women on welfare are not individuals, but rather only conduits to the children, who are intended to be the real beneficiaries of income support.

“Evaluating the consequences of welfare reform on children should not preclude studying the effects that these regulations will have on the mothers’ well-being,” Kneipp said. “Obviously, more research needs to be done.”

Kneipp’s research concentrates on health disparities in disadvantaged or vulnerable populations, with a focus on women. This work is guided by an ecological model, which emphasizes environmental determinants of health (social, economic, political), and how these factors contribute to health disparities in women disadvantaged by socioeconomic status. Some of the ways health disparities are currently being investigated scientifically include how disparities may be exacerbated or alleviated through welfare policy, and the pre-disease physiological mechanisms that may be contributing to disparities through chronic stress processes. Kneipp is currently involved in two funded research studies and one community health project related to these areas.

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Michael Marsiske, PhD

Dr. Michael Marsiske’s work in the College of Public Health and Health Professions (CPHHP) involves many aspects of the problems of aging, especially those aspects that have a significant impact on an individual’s ability to safely live independently. One study direction looks at cognitive aging, the changes in thought and thought processes that accompany normal aging. In this area, Marsiske’s research places special emphasis on the ways in which thinking, remembering and problem-solving changes in later life might impact everyday functioning and independence.

Marsiske is also a principal investigator on a large multi-site clinical trial aging study, which includes an examination of “Useful Field of View” (UFOV), a measure of speeded visual attention. This work has the potential for significant impact on the lives of older individuals because UFOV has been shown to be a strong predictor of behind-the-wheel driving performance.

New work under Marsiske’s direction will examine possible alternative home-based approaches, including certain kinds of video games, to improving speeded visual attention. More specifically, the research seeks answers to the question of whether these alternative approaches yield measurable improvements in driving outcomes. The goal is to find strategies that older adults can use to keep their basic driving-related mental skills sharp, and thereby remain safely mobile and independent for greater periods of time.
Marsiske’s earlier work examined areas like medication use, financial management, nutrition and transportation use are affected by age-related differences and changes in mental functioning.

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**Caprice Knapp, Ph.D.**
Dr. Caprice Knapp, Assistant Research Professor, Department of Epidemiology and Health Policy Research, is an applied economist whose areas of specialization include examining the quality of care and expenditure patterns for children and adolescents in vulnerable populations. Specifically, Knapp is investigating the association between sociodemographic factors and expenditures for children with life-limiting conditions. In addition to her research agenda, Knapp is a co-investigator on two statewide projects to evaluate Florida’s Title V programs for children with special healthcare needs and children with life-limiting conditions.

In one study Knapp and collaborators Drs. I-Chan Huang, Shenkman, and Walter Leite, looked at the issue of parent proxy ratings, which are frequently used to measure adolescent’s health outcomes (e.g., health-related quality of life or HRQOL). In the study, the researchers examined the difference between the parent’s HRQOL ratings and that of the young patients. They found that adolescents rated their HRQOL higher when compared to their parents. The discrepancy was particularly great for those adolescents with more severe health conditions. For healthcare providers, the results indicated that pediatric policy/practice standards based on ratings of children’s outcomes by parents and children should be carefully designed to take into account differential factors between parent and adolescent. Listening only to (or over-weighting) one side or the other is likely to give misleading information on patient quality of life — a critical concern, especially when dealing with adolescent patients.

In another study, Knapp and collaborators Drs. Lindsay Thompson, and Shenkman looked at the relationship between predisposing (age, race/ethnicity) and need (diagnostic) factors and healthcare spending patterns for inpatient, outpatient, emergency department (ED) and support services (i.e., home nursing, counseling, various therapies) among Medicaid eligible children with life-limiting conditions during the last 12 months of life. This study is critical because over 500,000 children each year fall into this category. Examining healthcare use patterns provides valuable information about the types of services used by different groups of children that can be used to identify potential gaps or disparities in care.

Knapp and her colleagues examined variations in healthcare expenditure patterns based on diagnostic categories, age, and race/ethnicity. Infants and children had similar mean annual total expenditures ($75,000). Ninety-six percent of total expenditures for infants were inpatient; they represented only 63% for children. Knapp also found that expenditures decreased in the last six months of life for children overall. However, racial/ethnic variations were found. Inpatient expenditures decreased for White and Hispanic children in the last six months of life; whereas Black non-Hispanic children had a 32% increase in inpatient expenditures. While Hispanic children experienced de-
clines in inpatient expenditures in the last six months of life, their inpatient expenditures during the last 12 months of life were double those of White non-Hispanic children. Unexpectedly, Hispanic children’s expenditures for support services were 10 times higher than White non-Hispanics while Black non-Hispanic children had support service expenditures that were about 80% relative to White non-Hispanic children.

There is an increasing emphasis on implementing comprehensive care programs for children with life-limiting conditions that would provide supportive therapies from the time of diagnosis to the time of death with an emphasis on care in the home and community. Knapp and her colleagues found that children with life-limiting conditions would likely benefit from placement in these programs, which are designed to improve children’s quality of life through pain and symptom management, therapy, counseling, and general support for the families. This type of result, with clear implications for the treatment and management of the youngest patients, is an example of research translating rapidly from academic settings to the “real world” of patient care.

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David L. Wood, M.D.

Dr. David Wood is involved in several significant projects that focus on the special needs of children and adolescents. Two projects in particular are producing positive results for young healthcare patients, especially those in various stages of transition.

UF’s Jacksonville Health and Transition Services program, known as JaxHATS, targets a very special sort of “tween” - teens and young adults with disabilities and special healthcare needs caught between pediatric and adult-oriented health systems. The only test pilot program of its type in the state, JaxHATS - a collaboration between Children’s Medical Services and the departments of Pediatrics and Medicine in the College of Medicine-Jacksonville - helps 16- to 26-year-olds with special healthcare needs in the five northeast Florida counties it serves - Duval, Clay, Baker, St. Johns and Nassau - make that transition.

Ironically, the reason this group needs help is because of medical advances in pediatrics. “Children with congenital health problems or chronic health conditions originating in childhood are living longer and longer,” said Wood. “In the 1960s and 1970s, children with Down syndrome or cystic fibrosis rarely made it into adulthood, but now, due to advances in medical science and treatment, their life expectancy is almost normal - into their 50s and 60s,” he said. “The healthcare and insurance system is not prepared to incorporate these chronically ill young adults into the adult care system.”
The JaxHATS multidisciplinary team includes Drs. Wood; Linda Edwards, an associate professor and division chief of general internal medicine; Deborah Ducett, the program director who also serves as social worker; nurse care coordinator Paulette Daniel; and UF medical residents and medical students.

The program provides a safety net for the tweens, their parents and guardians. It serves as a support group and vital information source for patients and families that can all too easily fall through the cracks of the healthcare system.

Drs. Wood and William Livingood, developed the TRAQ based on a review of the existing literature and on a theoretical framework of skills needed to navigate healthcare transition successfully. For each identified area or skill they have applied as a measurement scale the five-stage Stages of Change model. The instrument was sent to experts in the field of healthcare transition and they were asked to prioritize items and provide feedback on item content. A revised version was administered to 15 youths and tested for readability and clarity. The resultant questionnaire has 11 subscale scores and is organized in the following three domains: managing your own healthcare, interacting with healthcare providers, and other translation activities.

Wood is collaborating with a number of other investigators to field and test the TRAQ 3.0, including Dr. Gregory Sawicki, instructor in pediatrics at Harvard Medical School and associate director of the Pediatric CF Center Division of Respiratory Diseases at Children’s Hospital Boston, as well as Dr. Patricia Shearer, an associate professor of pediatrics and director of the Cancer Survivor Program at the University of Florida in Gainesville.

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