



FLORIDA CENTER FOR INCLUSIVE COMMUNITIES

University Center for Excellence in Developmental Disabilities Education, Research, and Service

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“Disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion. . .” This is the mandate of the Florida Center for Inclusive Communities (FCIC) University Center for Excellence in Developmental Disabilities (UCEDD) at the University of South Florida’s Louis de la Parte Florida Mental Health Institute and the Department of Child and Family Studies.

The FCIC was established in October 2005 through a five-year \$2.5 Million grant from the Administration on Developmental Disabilities within the U.S. Department of Health and Human Services. The FCIC works with people with disabilities, members of their families, state and local government agencies, and community providers in projects that provide training, technical assistance, service, research, and information sharing, with a focus on building the capacity of communities to sustain all their citizens. The FCIC is part of a national network of 67 UCEDDs which are located in every state and territory. UCEDDs are in a unique position to facilitate the flow of disability-related information between the community and the university. UCEDDs have played key roles in every major disability initiative over the past four decades. Many issues, such as early intervention, health care, community-based services, inclusive and meaningful education, transition from school to work, employment, housing, assistive technology, and transportation have been directly benefited by the services, research, and training provided by UCEDDs.

There are more than 240,000 Floridians with developmental disabilities whose outcomes often include low academic achievement, unemployment, underemployment, economic instability, poor healthcare, social isolation, and segregation. The FCIC is committed to improving these outcomes by developing a range of supports and services in the areas of Community Supports, Early Childhood, Transition, Education, Employment, Health, Interdisciplinary Training, Public Policy, and Cultural Competence through leadership in research and evaluation, theory, policy, capacity building, and practice.

FCIC staff is dedicated to its mission by providing technical assistance, research, systems change, and dissemination activities focused on supporting individuals with developmental disabilities to:

- Make informed choices and decisions about their lives.
- Receive support and services that are based on individual goals and outcomes.
- Achieve full inclusion and participate in society, in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of each individual.

There are currently 16 FCIC funded projects that focus on the primary goals of:

1. Improving access to effective educational supports for individuals with developmental disabilities.
2. Expanding the available and range of employment opportunities for individuals with disabilities.
3. Ensuring that individuals with developmental disabilities enjoy increased and meaningful opportunities to access and use community service.
4. Expanding access to health services for individuals with disabilities, particularly individuals from ethnic or racial minority groups.

One such project is the National Technical Assistance Center on Social Emotional Intervention for Young Children (TACSEI). TACSEI is a five-year \$3.5 Million grant from the US Office of Special Education Programs (OSEP) that establishes a national center for improving the social, emotional, and behavioral functioning of young children with or at risk for developmental delays or disabilities.

Principal Investigators Drs. Lise Fox and Glen Dunlap Both Fox and Dunlap are nationally recognized for the development of an early intervention model used for promoting social-emotional competence, known as the Pyramid Model. This model, which has been widely endorsed throughout the United States, will serve as the unifying structure for Center training, technical assistance, dissemination and evaluation activities. The framework includes four levels of practice to address the needs of all children, including children with persistent challenging behavior. TACSEI will work across service systems and age groups, to test effective models across and then replicate it in new states with a focus on supporting the social development of young children who receive early intervention services through the Individuals with Disabilities Education Act.

TACSEI will promote the social development of young children and improve early intervention results by providing training and technical assistance, guiding and evaluating model demonstrations, and disseminating information on effective practices. During the next five years, TACSEI staff will:

- Leverage resources by conducting collaborative training and technical assistance with relevant national centers and organizations.
- Develop, train and coordinate a cadre of trainers and coaches that are competent to deliver training and support on evidence-based practices and the Pyramid Model of Prevention and Intervention.
- Maintain ongoing communication with family consumers and ensure their input into all Center products and practices.
- Coordinate efforts with other federally funded TA Centers to maximize effects.
- Establish ongoing evaluation systems for all major Center functions and make course corrections as needed.
- Maintain a website that offers up-to-date information for multiple consumers: parents, providers, administrators, policy makers, and provides web-based TA and training opportunities.

In 2002, the US Surgeon General released a report¹ that drew attention to significant health disparities for individuals with developmental disabilities. Of particular concern is the community's capacity to serve these individuals who have special needs, especially in health care settings. The US Surgeon General cautioned against the seeming lack of trained primary and specialty healthcare professionals capable of working with individuals with developmental and other disabilities.

¹ *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation.*

The FCIC is partnering with the University of Florida and the USF College of Medicine on a Center for Disease Control and Prevention funded project that focuses on training medical students about the needs of individuals with disabilities and their families. The FCIC project is entitled “*Toward Healthcare Parity for Persons with Disabilities: Training Healthcare Providers*” and is a collaborative effort under the leadership of Susan M. Havercamp, Ph.D. and Laurie Woodard, M.D.

The overall goal of the Healthcare Parity Project is to increase the capacity of health care providers in Florida to provide quality healthcare to persons with disabilities. Towards this goal, this project is engaged in 2 activities:

1. Evaluate and refine the disability training offered to USF medical students (USF Disability Module).
2. Establish continuing education training on disability to medical and allied health Providers.

Anecdotally, medical students who have participated in this project have reported having found the module enlightening, having gained respect for persons with disabilities, and experienced diminished anxiety about providing caring for people with disabilities. One objective of the Healthcare Parity project is to evaluate the extent to which this training has an impact on:

- student’s attitudes toward persons with disabilities,
- student’s knowledge of disabilities, and
- student’s comfort providing care to persons with disabilities.

After visiting the homes of persons with disabilities, students are asked to write a brief summary of their thoughts and experiences. The following paper was written by a 3rd year medical student after visiting the home of a young man with a developmental disability.

This week I visited Sam, a patient with severe cerebral palsy. When he was born he was hypoglycemic and began having seizures. Ultimately, this complex problem at birth led to a more devastating condition that has affected his life permanently. Due to his condition he now suffers from seizures quite regularly, even with the medications he has been prescribed. While he is nonverbal, he communicates, and while it may seem that he is incomprehensible, if you pay close attention, you can quickly pick up on what he is “saying” through his vocalizations. His disability is severe, but he has an impressive record for health, more than I have seen with many patients without disabilities. He has not been in the hospital since he was 17 years old. He is now 33.

Sam’s mother spends most of her days caring for him. She taught us about how much of his life she was his only caregiver. Through this visit, not only did I see his physical and mental disabilities, but I learned about the amazing amount of strength that a mother has when she is caring for a child. She told us about many programs that are available for patients with disabilities. She has home health care workers who come to her house regularly and assist in the care for Sam. He not only has aids, but he has a personal physical therapist, massage therapist, and he experiences reflexology regularly. His mother spends a lot of time working with these people to make sure that she knows his progress in each area that is being worked on. This summer, Sam and his mother spent many days in the pool where he enjoyed water exercise which helped him with his flexibility to a great amount. Also, his mother was able to spend a lot of time keeping Sam’s team of helpers informed, so as to form an interdisciplinary team involved in his condition of health. When I asked her how he was doing compared to previous years, she said his health has improved. He is more stable now and has had fewer problems recently because of the integration of the team involved in his care.

This visit was truly a valuable experience. If the entire class could to a field trip to this particular home, I think it would be one of the most valuable experiences in the disabilities block. Among the values of this particular family are that Sam’s mom knows all about his condition, and she willingly told his story using

appropriate terminology. She expressed a clear understanding of his medical condition. She gave us a tour of the home so we could see all of the changes that must be made for a disabled person. She was feeding him when we arrived, and we were able to see her move him and help him change positions. The amazing amount of information that was gathered in these 2 hours was unbelievable, and the way this family has become closer through their experience was even more remarkable. This has been one of the most valuable experiences of medical school.

Another area of expertise at the FCIC is applied behavior analysis and positive behavior supports and working with individuals with challenging behaviors. Statistics show that three to eight percent of students in today's classrooms have behavioral problems severe enough to be labeled as disruptive, noncompliant, aggressive, defiant or oppositional. These students, who predictably find their way to the top of the "most troubling" list, are of greatest concern to schools.

Don Kincaid, Ed.D. is the Principal Investigator of *Evidence-based Intervention for Severe Behavior Problems: The Prevent-Teach-Reinforce (PTR) Model*. PTR will evaluate a school-based intervention model used for students who present some of the most severe problem behaviors. This four-year project is being funded by a \$4.3 Million grant from the US Department of Education's Office of Special Education Programs (OSEP). OSEP provides leadership and financial support to assist states and local districts, including institutions of higher education and other non-profit organizations to support research, demonstrations, technical assistance and dissemination.

Two hundred students from kindergarten through eighth grade will be selected from the Hillsborough County (FL), Pinellas County (FL), and the Denver (CO) Public School systems. PTR teams will be developed for each student and will include the child's teacher, a special educator or paraprofessional if the child receives part-time services in special education, and a behavior specialist. The teams will receive direct training and technical assistance from PTR project staff. Results of the project will include the development of a manual providing implementation guidelines, training materials, and assessment and tracking forms that can be used to replicate PTR in schools across the nation. One of PTR's goal is for the targeted children to successfully integrate into their communities and have positive outcomes in their lives.

For more information please visit the Florida Center for Inclusive Communities' website: www.flcic.org