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Dear Friends and Colleagues,

A few years ago, we had the privilege to spend a few hours at the Mailman Center with Eunice Kennedy Shriver and Sargeant Shriver. After a few minutes of reminiscing, Mrs. Shriver leaned over to me and asked, “What’s next”?

Over the past year, the faculty and staff of the Mailman Center have been engaged in an intensive strategic planning process to try to answer that question. The context for this strategic plan could not be more challenging. We, like every developmental disabilities center, department of pediatrics, and children’s hospital, are trying to understand how the Affordable Care Act, managed Medicaid, tough times for funding at the National Institutes of Health (NIH), and growth of new research funding from PCORI, AHRQ, and CMS Innovations will affect what we do in the future, and how we do it.

Challenges are full of opportunities. At the Mailman Center, we are considering a reorganization of how we do things, making a structural shift from organization under disciplines to organization as interdisciplinary “theme teams”. We are emphasizing training and demonstration models for care of adolescents and young adults with neurodevelopmental disabilities and other special health care needs. We are implementing and evaluating emerging leaders training programs for community professionals and self-advocates. We are exploring the role of telehealth in providing access to care, developing new ways to provide better specialized care in the communities where individuals and families live, and using assistive technology to help individuals with disabilities optimize their abilities.

The Mailman Center’s value statement is “Improving lives through innovation, impact, and connection”. That is my answer to Mrs. Shriver’s “what’s next” question. We cannot remain stagnant; our accomplishments must be transferable to the community for broad access, and while this happens, we have to be moving on with the next innovation that will have substantial impact on the lives of the community we serve. I am privileged to work with an incredible team of faculty and staff at the Mailman Center whose ability to see how things can be better, commitment, and enthusiasm will make it possible for our vision statement to be a reality.

I certainly believe Mrs. Shriver would approve.

Daniel Armstrong, Ph.D.
Director, Mailman Center for Child Development
Our Vision

IMPROVING THE LIVES OF PEOPLE WITH DISABILITIES AND THEIR FAMILIES THROUGH INNOVATION, IMPACT, AND CONNECTION

Our Mission

Within the context of interdisciplinary collaboration, cultural competence and family centered perspectives, and using the integrated mechanisms of research, training, service, and advocacy, the mission of the Mailman Center for Child Development is to:

- Address the current diverse needs of individuals with neurodevelopmental disabilities and children with special health care needs.

- Develop new models of care that improve support, independence, security, and long-term functioning for individuals with neurodevelopmental disabilities and children with special health care needs.

- Identify genetic, biologic, environmental, and interpersonal risks that contribute to neurodevelopmental disabilities and investigate ways to minimize or prevent disabilities associated with these factors.

- Integrate emerging knowledge and technology to prevent or provide primary intervention to lessen the impact of conditions or illnesses that lead to neurodevelopmental disabilities.

- Educate professionals, families, and the community about neurodevelopmental disabilities, mechanisms for prevention, and supports and services available.

Our Values

ACCESS  DIVERSITY  PARTNERSHIP
ACCOUNTABILITY  FAMILY-CENTERED  QUALITY
COMMUNITY-BASED  HOPE INCLUSION  SELF-DETERMINATION
COMPASSION  INNOVATION
Overview

The Mailman Center is a University Center of Excellence in Developmental Disabilities (UCEDD), academic Center of the University of Miami Miller School of Medicine, and the largest division of the Department of Pediatrics with:

- 39 full-time faculty
- 59 affiliated faculty from 8 Departments and 3 Schools at the University of Miami
- 69 full-time staff, 23 undergrad research assistants or volunteers

We address the concerns of individuals with developmental disabilities and special chronic health care needs through research, clinical service, training, community outreach and advocacy.

The Mailman Center is a:

- University Center for Excellence in Developmental Disabilities (UCEDD)
- Maternal Child Health Bureau’s Leadership in Neurodevelopmental Disabilities (LEND) training program
- Partner with the Florida Department of Health, Children’s Medical Services (CMS)
- United Way Center for Excellence
- Partner with the Member of the Association of University Centers on Disabilities (AUCD)

The combination of support from these federal and state agencies makes it possible for us to accomplish our overall mission.
The Mailman Advisory Council (MAC) is a consumer advisory committee that advises the Mailman Center for Child Development (MCCD) Director in meeting its responsibilities under the Developmental Disabilities Act of 2000.

Each UCEDD is required to have an advisory council to consult with the UCEDD Director regarding the development of the 5-year plan, to make recommendations regarding proposed revisions, and to facilitate the flow of disability-related information between community and university.

The Mailman Advisory Council (MAC) is also responsible for developing an overall understanding of the Center and its work, and advocating on its behalf. The composition of the MAC consists of self-advocates, family members of persons with disabilities, community professionals and university representatives.

The MAC discusses and advises the Director on many issues, including early intervention, health care, health promotion, family support, community-based services, inclusive and meaningful education, self-determination, transition from school to work, employment, housing, assistive technology, transportation, and training professionals in major disability initiatives.
Mailman’s History / Financials

1966
University of Miami Medical School was awarded a grant from the US Public Health Service to create a facility dedicated to helping people with developmental disabilities through treatment, research, and educational programs for professionals and parents. More funding followed to assist with the construction of the facility from the Joseph P. Kennedy Jr. Foundation.

1967
University of Miami received a gift from the Mailman brothers, Abraham and Joseph, in honor of their granddaughter Debbie Segal. Debbie who through self-determination and with the assistance of her parents, made tremendous strides in coping with her disability.

1971
Sam Giommomama-1st MCCD Director

1972
Jean Piaget is a keynote speaker for the dedication of the Mailman Center. Eunice Kennedy Shriver attends as well.

2007
Over forty years later, Mailman Center has come a long way and continues to be a leader in innovation, community connections and creating impact for children, youth, and young adults with disabilities and their families.

2008
Eunice Kennedy Shriver visits MCCD

Federal, State and Local Funding for the Mailman Center (2010-2015)

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WHAT WE DO NOW:
Innovate, Impact and Connect

The Mailman Center builds the capacity of our community to meet the needs of individuals with developmental disabilities and special chronic health care needs through education and training, research, community service and clinical programs.

Education and Training

The Mailman Center is a sought after and well-respected training program for many disciplines. More than 70 advanced (Masters, Doctoral, and Post-doctoral) trainees spend up to 2000 hours completing training related to children with developmental disabilities and special health care needs.

Leadership Training: Through our Leadership Education in Neurodevelopmental Disabilities (LEND) program, we train graduate students in various disciplines such as; pediatric medicine, social work, psychology, audiology, nursing, speech pathology, special education, occupational therapy and public health. Through LEND, the trainee receives specialized leadership development as well as their discipline specific education requirements.

Our LEND program was one of the first in the country to utilize an online learning platform to reach students anytime anywhere.
ETLP has been a life changing experience for me. I am feeling more confident in my communication skills both professionally and personally... public speaking skills have improved greatly... when conducting committee meetings, more confident working in large groups with strong-minded individuals. I am definitely a better person having experienced this program. - S. Goncz-Class II

MCCD continues to provide innovative leadership initiatives such as: The Emerging Transformational Leadership Program (ETLP), a 9 month intensive leadership training program for early-to-mid level professionals who have the passion to create systems level change for people with disabilities.

ETLP Impact-In three years, 17 ETLP Fellows have graduated and are creating systems level change. Two individuals were involved in national/policy level initiatives (Reauthorization of the Combating Autism Act, Big Cities Coalition) and four serve on non-profit boards in community.
Thank you so much for everything you did! Project SALT was a great experience. I want to thank you for the excellent night in the Graduation of the boys. Excellent work you do. - From parents

**Project Self-Advocate Leadership Skills Training (SALT):** We were a grant recipient from the Florida Developmental Disabilities Council to create a leadership skills curriculum for young adults with disabilities. The intent is to produce an ever-growing cadre of individuals with the capacity for self-determination, independence and the ability to participate in their communities in meaningful ways.

**Parent Education-Healthy Steps:** Focusing on children from birth to age 3, Healthy Steps expands pediatrician’s services by demonstrating a new, comprehensive approach to health care that helps support parents in their new role. The pediatric health care team includes a professional staff member, called a Healthy Steps Specialist, who serves as the effective link between the family, the pediatrician and the practice.
Everyone involved with the healthy steps program has always been very helpful, informative, and patient. They reassure me in what I’m doing that is best for my daughter. They alleviate my concerns when I worry about the development.

The Debbie Institute is a center for early intervention research, training and service. For more than 30 years, the Debbie Institute has conducted research on problems impacting children with special needs, provided early intervention services for children and their families and provided training for university students interested in careers in special education, speech-language pathology, physical therapy, occupational therapy, and social work. Our mission is to nurture and enrich the lives of children during the critical years of early learning to create the strong foundation they need to flourish throughout life.

The educational services of the Debbie School are delivered to children and families through three separate programs: the Early Education Program, the Auditory/Oral Education Program, and the Infant • Toddler • Preschool Education Program.

Medical Issues and the Growing Child Conferences: Since 1995, MCCD has collaborated with the Florida Diagnostic Learning System- South (FDLRS-South) and other community agencies to coordinate our Medical Issues and Growing Child conferences that address the concerns of individuals with developmental disabilities and children with special health care needs and their families. Each year we bring in distinguished speakers, many of whom are our own faculty to present on innovative and cutting-edge topics related to medical and health issues, neurodevelopmental disabilities such as autism and fragile x syndrome, social issues and assistive technology.
We have been at the forefront of innovative and translational research initiatives that provide cutting edge interventions and knowledge to lessen the impact of chronic illness or conditions that lead to neurodevelopmental disability.

**iCan Chat:** Targeted Speech/Language Interventions Using Assistive Technology: the project was a collaborative demonstration project funded by the CVS CAREMARK Charitable Trust. We worked with community agencies: the Debbie School's Inclusive Early Childhood Program, the Center for Autism and Related Disabilities and the Florida Alliance for Assistive Services and Technology (FAAST). The primary goal was to improve communication skills of children with autism and related disabilities having little or no speech by providing direct interventions using the iPad® as an assistive communication device. Parents were coached to use strategies to promote their child’s use of the device.
Parent Child Interactive Therapy Program in the psychology unit has been conducting ongoing research related to how parent perceptions of children’s emotional regulation impact the number of sessions it takes for families to graduate from treatment; children’s willingness to accept new limits; and treatment outcomes. UM PCIT has also been investing in the development of an interactive iBook for families completing treatment. The iBook includes video and text examples of how to implement PCIT skills with children. It also provides interactive games and quizzes to provide parents’ the opportunity to learn and review PCIT parenting skills in new ways.

Caregiver – Healthy Children: Targeting the Nutritional Gatekeeper to Achieve Behavior Change among Low-Income Caregivers and Children is a child care center-based obesity prevention program that includes the combination of environmental modifications and programs/curriculums that target the teachers and parents as “nutritional gatekeepers” and focus on multiethnic, low-income families are non-existent. The program proposes to address the obesity epidemic in very young multiethnic children.

Self-Management Adolescent Research Type 1 (SMART-2) is funded by NIH/NIDDK and focused on the self-management of Type 1 Diabetes during adolescence. This multi-site study follows a cohort of adolescents with type 1 diabetes over a three-year period in order to identify psychosocial predictors of self-management behaviors and glycemic control. This grant was a competitive renewal of a research project that originally enrolled 9-11 year-old children with type 1 diabetes and followed them over three years into early adolescence. The new grant continues following this cohort of adolescents into later adolescence and early adulthood in order to identify predictors of good and poor outcomes.
Community Services

Innovative new models of community based care focusing on prevention and intervention continues to be a priority.

**Pediatric Mobile Clinic:** Established in 1992 as a response to hurricane Andrew, the UMPMC has provided medical care to uninsured children in need. Services provided include well-visits, sports physicals, and immunizations, management of chronic conditions, urgent care, mental health, and social work.

**Our Impact**

“Being served at the Pediatric Mobile Clinic was a great experience. Thanks to their social worker my child was finally enrolled in special education classes and is now receiving home based PT and case management services. I’m so happy because my child is now thriving.”

**Early Steps:** is Florida’s early intervention system that offers services to infants and toddlers (birth to thirty-six months) who are felt to be at risk for developmental delay such as:

- Delays in achieving developmental milestones
- Delayed growth
- Extreme prematurity
- Established neurologic conditions
- Severe behavior disorders
- After an initial assessment, the Early Steps team puts together a family support plan, including referrals to specialists if needed.
Early Discovery Program: provides services for children who do not qualify for Part C or Part B but who have mild but significant delays (10% to 29%) and would benefit from intervention. Intervention services for children 0-5 include care coordination, and short-term speech/language, occupational therapy, behavioral, and developmental intervention.

Our Impact

“Thanks J! So sad it’s come to an end. You were fabulous and I have truly seen a change in my son that I attribute to all of your help.” -mother

Jump Start for Child Health: is a program to help early day care and education programs to increase their internal capacity to offer better early learning experiences to children while improving program-screening efforts. This program utilizes a problem solving approach within collaborative relationship with professional consultants, family members and child care staff.

Our Impact

Children wandered away to use the cozy corner to play. It was recommended that teachers enact a play with various scenarios (e.g., feeling sad, feeling angry) of what to use it for. When teachers implemented this, they reported children were more engaged and able to be “sad” in the cozy corner. Teachers loved using acting out scenarios and will challenge the children to problem solve.
FAAST (Florida Alliance for Assistive Services and Technology)
South Florida Regional Demo Lab: is a free program dedicated to improving the quality of life for all Floridians with disabilities through advocacy and awareness activities that increase access to and acquisition of assistive services and technology. FAAST serves individuals across the lifespan. FAAST services include information and referrals, AT demonstrations and assistance through an assistive technology demonstration lab located at the MCCD, and an Assistive Device Lending Program.

Our Impact

“My child loves using the Talkable IV device. With the coaching I received I was able to choose the best device for him. Thank you for the opportunity to borrow it so we could try it at home, in school and in therapy.” - parents
University of Miami Autism Programs (UMAPS): Every child is unique and autism affects every family differently. Proper treatment of autism and related exceptionalities requires a coordinated team approach to address the often complex medical, behavioral and learning challenges. The University of Miami (UM) Autism Programs have specialists to address every aspect of autism spectrum disorders, from diagnosis and treatment to research and public policy. Working as a team, we provide integrated, family-centered care to those affected by autism spectrum disorders. Our aim is to make leading-edge research and clinical services available, through “one-stop shopping,” to all South Florida families.

Clinical Services

More than 15,000 children receive interdisciplinary clinical and educational services each year from faculty and staff of the Mailman Center through clinics, hospital services, community collaborations and mobile outreach, many supported by funding from a contract with Florida Children’s Medical Services.

Clinical Services are offered in our various units in Nutrition, Psychology, Social Work, Developmental & Behavioral Pediatrics, Physical Therapy, Occupational Therapy, Audiology, Speech and Language Pathology, Early Special Education, Medical Genetics, Neurology, Psychiatry.

Interdisciplinary Clinical Services are offered in the following clinics: IDES clinic, Fragile X Clinic, Behavioral Pediatrics Clinic, Parent-Child Interactive Therapy, Chronic Illness- Cancer, HIV, sickle cell disease, diabetes, obesity, transplant, cardiology, asthma & cystic fibrosis.
Interdisciplinary Evaluation Services (IDES): Some difficulties with learning and behavior can be diagnosed by a single professional but many children with complex situations require evaluations by more than one. The experienced IDES team, consisting of a developmental pediatrician, clinical psychologist, education specialist, speech and language pathologist, audiologist, and physical therapist – with additional members if needed, work with families and their primary care providers to diagnose and formulate a comprehensive treatment plan for each child.

Nutrition Telehealth: is collaboration between the Department of Pediatrics, Family Medicine and the Miami Dade County School system. We have the technical ability to provide nutrition assessment in 9 schools; 3 high schools, 2 middle schools and 4 elementary schools. Nutrition telehealth has a weekly clinic. High and middle school students have parent approval to be seen individually and elementary students are seen with parents. The focus of telehealth nutrition counseling is to facilitate improved food choices and eating behaviors.

Our Impact

Students have reported changed eating habits; including eating more fruits and vegetables, reducing soda intake and cooking more meals. The nurse in one of the high schools reported that some students would skip school and come in only for their nutrition appointment.

The South Florida Fragile X Clinic (SFFXC): established in 2009, is one of 26 clinics located across the United States and Canada, associated with the National Fragile X Clinical and Research Consortium, a project from the National Fragile X Foundation. This state of the art clinic provides individuals and families affected by fragile X with comprehensive care and treatment supported by the latest medical, educational, and research knowledge.

Visits to the clinic typically include a comprehensive physical and developmental exam, educational, and psychological evaluations, a thorough, targeted genetic counseling session, and a review of the recommended healthcare guidelines for children with Fragile X syndrome.
Our Team
Daniel Armstrong, PhD, Mailman Center and UCEDD Director
Jeffrey P. Brosco, MD PhD, LEND Director
Michelle Schladant, PhD, Training Director
Shelly Baer, LCSW, Associate Training Director, Coordinator, ETLP/SALT
Roselyne Antao, Family and Community Education Coordinator
Ruben Garcia, Information Technology
Carmel Bronzetti, Administrative Assistant

Discipline Coordinators
Alan Delamater, PhD, Psychology
Robert Fifer, PhD, Audiology
Sheah Rarback, Nutrition
Ruby Natale, PhD, Community Based Programs
Julia Hernandez, PhD, Social Work
Claudia Coron, MS, CCC, CLP Speech & Language Pathology
Gabriel Sombario, PhD, Physical Therapy
Douglene Jackson, MOT, OTR/L, LMT, Occupational Therapy

Kathleen Vergara, Special Education, Director, Debbie School
Lynn Miskiel, Speech Pathology, Debbie School
Ana Nevares, MA, Assistive Technology, FAAST
Robert Morgan, EdD, Social Work

Charles Bauer, MD, Early Intervention
Tiffany Fields, MD, Research, Touch Institute
Veronica Accornero, PhD, Training Director, Psychology
Jason Jent, PhD, Psychology
Elizabeth Pulgaron, PhD, Health Disparities Research Coordinator, Psychology

Partners and Funders
Some Partners:
- Association of University Centers on Disabilities (AUCD)
- Children’s Medical Services (CMS)
- United Way
- Holtz Children’s Hospital/ Jackson Memorial Hospital
- American Academy of Pediatrics
- Disability Rights of Florida
- Department of Pediatrics Divisions
- Other University of Miami Miller School of Medicine Departments
- Other University of Miami Schools and Colleges
- Other University of Miami Centers and Institutes

Our Major Funders:
Federal:
- Administration on Intellectual and Developmental Disabilities (AIDD)
- Maternal Child and Health Bureau (MCHB)
- Health Resources and Services Administration (HRSA)
- National Institute of Health (NIH)
- Center for Disease Control (CDC)
- United States Department of Agriculture (USDA)

State:
- Florida Department of Health
- Department of Education
- Department of Children and Families (DCF)
- Florida Developmental Disabilities Council
- James & Ester King Biomedical Research Program

Local/Foundations:
- Children’s Trust
- United Way
- MDCPS
- Health Foundation of South Florida
- Miami Dade Health Department
- Center for Haitian Studies
- Batchelor
- Appelbaum
- Himan Brown
- Taplin
- Haiti Relief Fund
- Children’s Health Fund
- National Children’s Cancer Society