FIU Embrace-External Advisory Council
Meeting Minutes from April 19, 2017

FIU Embrace-External Advisory Council Members
Luis Navas, Senior Partner, Global Governance Advisors
Albert Lopez, Southeast Assurance Regional Managing Partner, BDO USA, LLP
Cynthia Gaber, Area Six Director, Division of Vocational Rehabilitation
Milton Vescovacci, Shareholder, GrayRobinson, P.A.
Yogi Hernandez Suarez, Vice President and Chief Medical Office, Care Delivery Organization of Humana

Telephonic
Ora Prilleltensky, Clinical Assistant Professor, University of Miami

Members of the Public Present
Alberto Fernandez, Principal, SPED Outreach, Miami-Dade County Public Schools
Amanda Giust, Program Manager, Project Panther LIFE
Ana Laura dos Santos Lara, Transition Manager, Parent to Parent
Andrew Bernal, Program Assistant, FIU Embrace
Belen Ortuzar, Access 4 Autism
Brenda Lampon, Department of Vocational Rehabilitation
Carlos Puentes, Department of Vocational Rehabilitation
Christine Butler, ChildNet
Daniel O Perez, Program Assistant, FIU Embrace
Deborah Dietz, Executive Director, Disability Independence Group
Diana Valle-Riestra, Director of Project Panther LIFE
Elizabeth Alvite, Administrative, FIU Embrace
Elizabeth Cramer, Professor, Florida International University
Emily Gresham, Assistant Vice President, Office of Research and Economic Development, FIU
Ernie Martinez, Center for Independent Living South Florida
Henny Cristobol, Principal, Villa Lyan Academy
Howard Holness, Chief of Academic Administration, Provost’s Office, FIU
Jaclyn Schwartz, Assistant Professor, Florida International University
James “Jim” Mueller, President, James Mueller and Associates, LLC
Janet McDaniel, Adjunct Lecturer, FIU
Jennifer Martin, Program Coordinator, Project Panther PLUS
John Ortuzar, Access 4 Autism
Maggie Marrero Neville, Transition Specialist, Miami-Dade County Public Schools
Maria Ilcheva, Research Assistant Professor, Florida International University
Mariana Barbara, Student
Marie Whitehurst, Associate, EWM
Mavara Mirza-Agrawal, Medical Director, FIU Embrace
Michelle D Mason, Senior Associate Dean for Clinical Education, Experiential Learning & Engagement, Florida International University
Nicole Attong, Director of Operations, FIU Embrace
Patricia Ramirez, Miami-Dade County Public Schools
Raquel Linares, Deputy Director, Jobs Best Buddies
Rosa Maria Barbara, Parent
Sandra Gonzalez-Levy, Senior Vice President of External Relations, Florida International University
Shanna Burke, Assistant Professor, Florida International University
Susan Lane, Assistant Vice President of Advancement, Florida International University
Susan Morantes, Director of Admissions, Dan Marino Foundation
Zoraya Ledesma, Senior Administrative Assistant, Florida International University

**Telephonic**
Michelle Palacio, Vice President or Governmental Relations, FIU
Rochelle Baer, Director Leadership Training Initiatives, University of Miami
Gilda Ferradaz, Managing Director, Florida Center for Children and Families
Call to Order
The meeting was called to order at 2:00 p.m. by the chair Yogi Hernandez Suarez. Everyone was invited to introduce themselves and identify their affiliation.

Review & Acceptance of Minutes
The chair requested a motion to accept the minutes. Milton Vescovacci put forth a motion to approve the minutes as presented. Albert Lopez seconded the motion. The motion was unanimously approved, and the minutes was accepted.

Bylaws and Committee Charter
Milton Vescovacci provided an overview of the Committee Charter and Bylaws indicating it was prepared in collaboration with Nicole Atong and Diana Firvida-Oliva, an attorney within the Office of Research and Economic Development.

Milton reviewed each section of both documents and pointed to important areas. Some sections discussed included, the role of the Council, membership, quorum and ethical standards related to conflict of interest, and the conflict of interest form was reviewed. Moreover, Milton, indicated that additional corrections to the By-Laws and Charter for Committees will be sent via email to Nicole Atong following the meeting.

Gap Analysis & Housing Plan Summary of Initial Research Findings
Drs. Maria Ilcheva and Shanna Burke presented their initial findings of the Gap Analysis & Housing Plan. Dr. Burke discussed the literature review including services provided to individuals by type of disorder and severity. In addition, Dr. Ilcheva provided a system overview, an analysis of the overall services offered in Miami-Dade County with a focus on housing and available housing models (see attached presentation).

Charter/Strategic Plan
Mr. Muller provided an updated strategic plan that included a Vision, Mission, Strategic Imperatives and Outcomes.

Vision
We imagine a world in which all individuals, no matter their unique patterns of talents and abilities, are valued and meaningfully engaged in their communities.

Mission
Through leadership and collaboration, FIU Embrace pursues programs and activities that support neurodiverse individuals living healthy lives, maximizing their potential across their lifespans, and being meaningfully engaged in their communities. FIU Embrace will:
• **Provide educational, medical, and legal services; and support and foster a network of service providers in South Florida**

• **Conduct research that leads to evidence-based practices and solves the everyday problems of neurodiverse individuals**

• **Advocate for national policy change based upon the data and knowledge acquired through research**

There was an acknowledgment that the word neurodiverse is largely used in the Autism field. However, the Strategy Development group (SDG) redefined Neurodiverse, for the purposes of FIU Embrace. According to the SDG, this word refers to individuals with developmental disabilities including autism spectrum disorder, intellectual disabilities, and other neurodevelopmental disorders. The word was chosen by the group because it does not set people apart, and does not have a negative connotation in the community.

In addition, Ms. Atong shared that focus groups will be organized in the community and on campus through our College of Communication, Architecture + the Arts to discuss the word “neurodiverse” and explore if this is the most widely accepted unifying word. If not, an attempt will be made to identify a descriptor that the majority can identify with.

**Value Proposition**

FIU conducts solution-focused, multidisciplinary research that positively impacts daily life, offers individual and family-centric services that are available to other communities, and facilitates collaboration among diverse community stakeholders to advance solutions for the neurodiverse population.

**Strategic Imperatives to be achieved in Ten Years**

1. **Nationally recognized, individual- and family-centric model programs** for interdisciplinary care of neurodiverse individuals.
   a. Truly **integrated, comprehensive medical care** in South Florida that satisfies the needs of neurodiverse individuals and their caregivers.
   b. **Educational and independent living programs** for students, providers, and neurodiverse individuals that build skills and create meaningful opportunities for employment and community involvement.

2. **Interdisciplinary, solution-focused research** that transforms policy and results in a full complement of well-designed services for neurodiverse individuals and their caregivers.

3. **Actively engaged coalition** of South Florida community stakeholders and neurodiverse individuals that advocate to give equal voice, to change public opinion, to transform policy, and to improve access to supports and services.
Discussion

While there is a ten-year plan, will there be annual benchmarks in meeting those individual outcomes?

Ms. Attong shared that benchmarks were provided for only two years because of anticipated staff and programmatic changes. In addition, we are in an infrastructure development phase. Once all changes are complete, we will return to the strategic planning process. In the meantime, we will provide the Council with data in each of the areas outlined in the strategic plan.

A question was raised about financial sustainability particularly as it relates to services.

We are exploring all opportunities for funding. With respect to sustainability, there are multiple lines through which funds can be acquired. These include but are not limited to, state funding and Medicaid, private insurance, other state lines, grant funding etc.

Presentation - Gap Analysis & Housing Plan

Dr. Prilleltensky shared that language matters and it is used to frame attitudes from a caregiver’s perspective. Therefore, using the term “my dependent” in a survey is cringe-worthy. Also, it is important to emphasize the value that neurodiverse individuals bring to the community. We should not just highlight their needs.

Can FIU Embrace – Medical provide sedation for specific clients who need additional supports to be able to receive certain services such as ear cleaning, and dental cleaning?

American medicine does not currently allow doctors to sedate in an outpatient setting. However, we are in the process of trying to build a model of care where all people are able to receive the care they need. That will also require policy work, changes in the way the medical field delivers care, and changes to existing reimbursement for doctors.

Mr. Navas inquired if dental care is included in the scope of medical services provided for individuals with disabilities under FIU Embrace. Yogi advised that FIU Embrace has been challenged to find doctors in many specialty areas who are wailing to serve this population. While Embrace does not provide dental care, the program is charged with ensuring that FIU Embrace link its patients to doctors who will serve them so that we develop a network of specialists such as dentist, ophthalmologist, physical, occupational recreational therapist and any other areas a typical individual would seek care in.

FIU Embrace Update

Ms. Attong shared that FIU Embrace is focused around the four components of the initiative including services, research, education and coalition building.

Medical
Dr. Agrawal provided an overview of the fully integrated medical services that are provided in a sensory sensitive environment by empathetic staff who run on 'autism time'. Services include internal medicine/primary care, labs and nutritional counseling. Psychiatry, mental health/behavioral counseling, and gynecology are also provided. A specialized waiting room has been developed to support the needs of the patient and family. In addition, we will be adding vision and hearing screening.

Legal

Dean Michelle D. Mason provided an overview of the partnership between FIU Law and FIU Embrace. FIU Law has four legal clinics which requires students to complete pro bono service hours. Last year students provided 23,000 hours of free legal services for the community. In addition, the College of Law is committed to training lawyers that understand that the community is a part of their obligation.

There are a number of good organizations that work with this population however, the need is far greater than their ability to serve the community. Therefore, this project was launched through the College of Law to provide integrated wraparound legal services. The Law Clinic kicked off the services by offering a free legal needs assessment. This was done to establish the predominant needs of families. The needs identified included:

a. Guardianship  
b. Health issues  
c. Social security  
d. Landlord/tenant  
e. Immigration

All issues were handled internally, only when absolutely necessary were families linked to alumni and other attorneys outside of FIU. As a result of this work, the law school has worked with approximately 30 families, on guardianship, health directives, immigration and disabilities issues. Long term, FIU Law and Embrace will conduct outreach and workshop activities to extend our reach into the community.

Post-Secondary Education

Ms. Attong informed the Council of the partnership with the Dan Marino Foundation. The Foundation provides a 10-month post-secondary education program to students with autism or intellectual disabilities. The program terminates in a certificate and, when fully operational, will enroll up to 30 students at a time. Currently the two tracks offered at MMC are technology and hospitality.

New Business  
Research

Ms. Attong shared that FIU Embrace will be allocating resources to solution focused research and engaging faculty across the University in this area. Some Colleges/centers
that are already engaged in pilot projects include The Metro Center, Robert Stempel
College of Public Health and Social Work, College of Nursing and Health Sciences, and
College of Communication, Architecture + The Arts. Moreover, we are recruiting
faculty for a position in The Center for Child and Families with interest in conducting
research in autism in youth transition age and into adulthood. As outlined in the
strategic plan, we will be moving towards hiring more faculty with an interest in
conducting research in this area.

Funding

Nicole Attong provided the following report on behalf of Michelle Palacio,
Governmental Relations.

FIU Embrace, in conjunction with four other programs is housed under the FIUnique
line item. This line is currently funded at $3.5 million. The entire line is up for a $1.9
million cut. If we do in fact receive a cut, all programs will share the cut. We anticipate a
response by May 2nd.

Motions

Charter/Strategic Plan

The chair requested a motion to accept the amended Charter/Strategic Plan which is
the mission, vision, value statement etc. Albert Lopez put forth a motion to approve the
amended Charter as presented. Milton Vescovacci seconded the motion. The motion
was unanimously approved, and the Charter/Strategic Plan were accepted.

Bylaws

The chair requested a motion to accept the Bylaws as presented. This will be the
constitutional way that we will govern ourselves as the advisory council moving
forward. Milton Vescovacci put forth a motion to approve the Bylaws as presented.
Albert Lopez seconded the motion. The motion was unanimously approved, and the
minutes were accepted.

Vice-Chair

The chair requested nominations from the floor for a vice-chair. Milton Vescovacci
offered to be Vice-Chair. Albert Lopez second the motion. The motion was unanimously
approved, and Milton Vescovacci was unanimously approved as the vice-chair.

Finally, the Chair has asked each member of the Council to complete the Conflict of
Interest form. The form must be completed annually or upon any notable changes as
outlined in the Bylaws.

Actionable request

The Chair requested a report from each committee at the next Council meeting. The
chairs of the subcommittees can move forward with the selection of the vice-chair.
Vice-Chair for the Committees can be a non-council member. Mr. Vescovacci indicated that Rosa Maria Barbara is the Vice-Chair of the Employment Committee.

Adjour

The meeting was adjourned at 4:00 p.m. by the chair Yogi Hernandez Suarez.
External Advisory Council Meeting
Wednesday, April 19, 2017

WELCOME AND INTRODUCTIONS

BY LAWS & COMMITTEE CHARTER

GAP ANALYSIS & HOUSING PLAN
A SUMMARY OF INITIAL RESEARCH FINDINGS

Assessment of the Needs of Services to Individuals With Neurodevelopmental Disorders

Research Scope

Research Purpose:
Define the current state of service delivery as well as identify any service gaps

- Comprehensive review of existing research relevant to the needs of people with developmental disabilities and their families.
- Interviews with experts and practitioners in the area of service delivery to disabled persons.
- Caregiver survey
- Research on service models for individuals with disabilities, with a particular focus on housing
- Review of Miami-Dade’s Housing Plan for people with disabilities
- Asset mapping – an environmental scan of services available to disabled individuals
**Summary**

- The study found that sexual health education, socialization, and adult-focused medical care are universal needs among the six conditions.

  - Adult-focused medical care
    - Requires the successful transition from adolescent care to adult care.
    - Items to consider: Independent living, the evolution of personal financial responsibilities, arranging independent transportation, developing a sexual identity, and establishing intimate and social relationships.

  - Sexual health education
    - Some individuals may be vulnerable, and easily taken advantage of.
    - Still, most have the ability and desire for healthy intimate relationships.

**System Overview**

- Fragmented service delivery to clients along the IDD spectrum
- Mental and physical conditions not comprehensively aligned with quality of life considerations
- Critical gaps in medical training, housing choices and economic opportunity
- Housing in Miami-Dade:
  - Pervasive lack of affordable housing
  - Public housing agencies lack capacity to address needs of IDD community
  - Nonprofit sector attempting to fill the gaps

**Housing Models**

Focus on CHOICE and the creation of community-based, cost-effective housing models

- Over 80% decline of IDD in state-run institutions.
- Only 24% of Florida’s IDD community lives outside of a family member’s home.
- A spectrum of residential settings that may provide a variety of experiences to the growing IDD adult population along an integration/congregation continuum.
- Integration is an individual-driven approach, with no more than four IDD adults living together within a standard American neighborhood.
- Congregation includes residential settings ranging in size from single to multi-stratum communities with on-site affiliate antenatal.

**Spectrum of IDD Housing by Service & Design**

- Includes various types of housing services and designs for IDD individuals.
- Focuses on providing a range of options to meet the diverse needs of the IDD population.
Public Housing in Miami-Dade

- Lack of affordable housing influenced by low wages creates high demand for public housing and housing vouchers.
- Long waiting periods for waiting lists, closed since 2014.
- Miami-Dade Housing plans affirm compliance with the federal requirements for consideration of individuals with disabilities.
- When disability accommodations are mentioned, there is no differentiation between physical and developmental needs.
- Overall shortage of affordable housing makes prioritization in fund allocation difficult.

Housing Assistance Through Non-Public Agencies

- Nonprofit sector attempting to address some of the unmet housing and other needs.
- Center for Independent Living of South Florida helps IDD individuals develop an Independent Living Plan.
- WVRI Center offers vocational training, job coaching and placement.
- SCLAD (Spinal Cord Living Assistance Development) is a Community Housing Development Organization which developed 76 barrier-free units, sold twenty-four condominiums and is managing fifty-two rental units for disabled individuals.
- Carefour Supportive Housing developed Riverton House (789 NW 13th Avenue in Miami), consisting of 76 affordable housing units for former homeless individuals, with 36 units serving disabled persons and 15 units serving elderly residents.

The Caregiver Perspective

- The majority of caregivers (75%) reported their family covers more than 50% of the disabled individual's expenses.
- A small majority (52%) indicated that the ideal arrangement for their dependent as an adult would be their current home.
- Only 2% chose "where my dependent chooses" as an answer.

Other Challenges

The biggest challenge: economic self-reliance

- Only 17.5% of persons with a disability are employed.
- Unemployment rates are higher for persons with a disability than for those with no disability among all educational attainment groups.
- In 2013, 32% of workers with a disability were employed part time, compared with 18 percent for those with no disability.
- Workers with a disability are more likely to be self-employed than those with no disability.

Conclusion

- Medical care provision through Medicaid is fragmented and remains anchored to pediatricians well into adulthood.
- Housing alternatives in Miami-Dade that relieve caregiver burdens while maximizing client choice and individual growth remain limited.
- Provision of housing and medical services to IDD clients must be tailored to meet the caregiver's social ecology relative to transit availability, financial capacity, and health status.
- Navigating this ecology without a "systems integrator" is likely to result in less-than-optimal health and housing status for clients.

Questions

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Vision Statement

- FIU Embrace Vision:
  - We imagine a world in which all individuals, no matter their unique patterns of talents and abilities, are valued and meaningfully engaged in their communities.

Mission Statement

- FIU Embrace Mission:
  - Through leadership and collaboration, FIU Embrace pursues programs and activities that support neurodiverse individuals living healthy lives, maximizing their potential across their lifespans, and being meaningfully engaged in their communities.

FIU's Definition of Neurodiverse

- Neurodiverse, for purposes of FIU Embrace, refers to individuals with developmental conditions including autism spectrum disorder, intellectual disabilities, and other neurodevelopmental disorders.

Value Proposition

- Purpose of a Value Proposition Statement:
  - Component of the case for financial support
  - Succinctly defines areas of impact
  - Serves as a statement of core strategy

- FIU Embrace Value Proposition:
  - FIU conducts solution-focused, multidisciplinary research that positively impacts daily life, offers individual and family-centric services that are available to other communities, and facilitates collaboration among diverse community stakeholders to advance solutions for the neurodiverse population.
Value Proposition

- Definition of Value Proposition:
  - What FIU Embrace does is different or better than anyone else to provide value to those we serve while securing philanthropic support.

- Purpose of a Value Proposition Statement:
  - Component of the case for financial support
  - Serves a statement of core strategy

The Means to Deliver the Value Proposition

- Unique Attributes of FIU That Are the Means to Success:
  - As a prominent, urban, research university with deep ties to its community and a committed leadership team, FIU is uniquely positioned:
    - To foster cultural and community transformation that results in all individuals being valued by and integrated into their communities.
    - Its multidisciplinary, collaborative research, conducted by faculty experienced with issues related to neurodiverse individuals, is vital to the development of holistic solutions.

Strategic Imperatives to be Achieved in Ten Years

- Nationally recognized, individual- and family-centric model programs for interdisciplinary care of neurodiverse individuals.
  - Truly integrated, comprehensive medical care in South Florida that satisfies the needs of neurodiverse individuals and their caregivers.
  - Educational and independent living programs for students, providers, and neurodiverse individuals that build skills and create meaningful opportunities for employment and community involvement.

- Interdisciplinary, solution-focused research that transforms policy and results in a full complement of well-designed services for neurodiverse individuals and their caregivers.

- Actively engaged coalition of South Florida community stakeholders and neurodiverse individuals that advocate to give equal voice, to change public opinion, to transform policy, and to improve access to supports and services.
FIU Embrace - Initiative Components

- Model Programs
  - Medical services
  - Educational services
    - Post-secondary educational opportunities for neurodiverse students
    - Professional development, parent/caretaker education
    - Student development
  - Legal Services
  - Research
  - Coalition Development

Medical Services

- Fully integrated medical care where services are provided in a sensory sensitive environment by patient, empathetic staff who run on 'autism time'
- Services include:
  - Internal medicine including primary care, lab, nutritional counseling
  - Psychiatry services and mental health/behavioral counseling
  - Gynecology
  - Specialized waiting room and supports as needed to accommodate the needs of the patient and family.

Legal Services

- The purpose of FIU Embrace Legal Project will be to promote the self-determination and independence of low-income adults with intellectual and developmental disabilities by providing direct legal services that protect individual autonomy and access to services.
- Services include:
  - Workshops, events, and community training to education and encourage these adults, their families, service providers (doctors, nurses, social workers, other health care staff, and community-at-large) regarding issues impacting the disabled.
  - Legal services
  - Other projects

Post-Secondary Educational Services

- FIU Embrace students
  - Expand and strengthen existing education opportunities to build skills and create meaningful opportunities for employment and community involvement.
  - Expand on campus residential opportunities.

Research

- Interdisciplinary, solution-focused research that transforms policy and results in a full complement of well-designed services for neurodiverse individuals and their caregivers.
Coalition Building

- Actively engaged coalition of South Florida community stakeholders and neurodiverse individuals that advocate to give equal voice, to change public opinion, to transform policy, and to improve access to supports and services.

“Do one thing every day that scares you”
Eleanor Roosevelt