

# National Alzheimer's Project Act (NAPA)

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The information that follows was included as an attachment to an email submitted by the public.

For more information about NAPA, visit the NAPA website at:

<http://aspe.hhs.gov/national-alzheimers-project-act>

# INTERPROFESSIONAL PERSON-CENTERED DEMENTIA MANAGEMENT FOR BROWARD RESIDENTS WITH ID/DD



BROWARD HEALTH  
NORTH/LUCANUS CENTER, NOVA  
SOUTHEASTERN COLLEGE OF  
OSTEOPATHIC MEDICINE  
IMPLEMENT NATIONAL PILOT

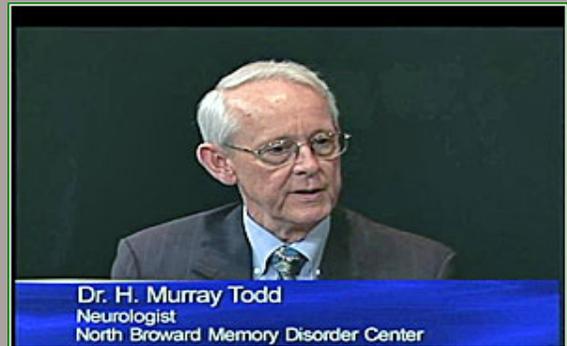


# BROWARD'S COMMITMENT TO THOSE IN NEED

**Dr. Todd:** "Every person with Down syndrome is at risk. We must provide quality interprofessional Person-Centered Dementia Management throughout the life course. Together, we can manage the Provision of Dementia Care ensuring dignity, respect, and autonomy for every person served."

## The Unintended Problem: The consequence of good care

Broward residents with intellectual/developmental disabilities today are living longer, happier and more meaningful lives. With advances in medicine, assistive technology, and public policy, most Broward residents with an intellectual disability must begin planning for their later years in life. The advancement in old age has also revealed very serious health concerns that did not present themselves in early life. These late onset conditions are known as, "Late Life Impairment".



*Laura (Mid-Stage Alzheimer's Disease) lives with her mother (Aging in Place) thanks to Community-Based Dementia Day Program Pilot (Lucanus Center) and In-Home Dementia Management Services and Supports*



## THE CHALLENGE OF AGING FOR PERSONS WITH I/DD

### Problems in Later Life

The Later Life Impairment can be the result of injury, disease, decline or other factors later in life (Cognitive Decline, injury resulting in physical or sensory impairments, mobility impairments, etc.).

The Broward Dementia Pilot Partners are proactively learning, and in return developing premier Dementia interprofessional management practices to fully support the person, family and caregiver with an intellectual disability and dementia.

### Alzheimer's Disease and Related Dementias in Persons with I/DD

Many Broward residents with an intellectual/developmental disability who are living into later life will experience Alzheimer's disease and other forms of dementia. Alzheimer's disease and other related dementias (ARD) are devastating conditions that lead to significant loss of memory, thought processes, and functioning. The Dementia will progress in a predictable course causing disorientation, insecurity, getting lost in familiar places, and total care with the activities of daily living.

Oftentimes, the person with Dementia recognizes the decline and loss of functioning and will withdraw and isolate themselves from others. The ARD dramatically increases caregiver burden and in many cases, the parent or caregiver is aging themselves with serious health issues.

*The NTG research reflects that by age 40 years, all adults with Down syndrome exhibit some criteria for Alzheimer's disease.*



*These conditions dramatically increases caregiver burden and in many cases, the parent or caregiver is aging themselves with serious health considerations.*



## Scope of Issue

Many Broward residents' with Down syndrome are now reaching old age living into their 50s, 60s, and 70s. The adults with Down syndrome and their families will face an unexpected early onset of later-life impairments. The National Down Syndrome Society indicates that, "adults with Down syndrome experience Accelerated aging," meaning that they experience certain conditions and physical features that are common to typically aging adults at an earlier age than the general population.

The NTG further reports, "In Down syndrome, one of the most common forms of intellectual disability, the underlying genetic link between trisomy 21 and Alzheimer's disease has been convincingly established. The NTG research reflects that by age 40 years, all adults with Down syndrome exhibit some degree of neuropathology defects postmortem that meet the criteria for Alzheimer's disease. The clinical manifestation of the Alzheimer's disease will increase with age. It is generally accepted that at least 50% of adults with Down syndrome display clinical evidence at age 60. Only 5% of the general population displays Alzheimer's disease at age 60.



## THE NATIONAL AND LOCAL LEADERS RESPOND

The drafting of this White Paper reflects the unwavering commitment Broward Leadership has pledged to persons and families aging with an intellectual/developmental disability and dementia in Broward County, Florida. The Broward Dementia Pilot is partnering with the National Task Group on Intellectual Disabilities and Dementia Practices. Senator Eleanor Sobel (Pictured Left) is our Florida Legislative Champion for the Broward Dementia Pilot.



The National Task Group (NTG) is charged with ensuring the nation will address the needs of adults with ID/DD and their families affected by dementia. The NTG has developed Dementia Practice Guidelines and Community Support, Formal Early Screening Detection for Dementia, and a Guide for families and care givers developing dementia Friendly/Capable environments. The state of Florida is represented on the NTG by Thomas Buckley (Founder-Left Painting).



*NATIONAL TASK GROUP FOR  
DEMENTIA PRACTICES  
CO-CHAIRS-DR. JANICKI, DR. KELLER AND  
(DR. BUCKLEY LUCANUS CENTER)*



## Diagnostic Indicators

Diagnosing dementia in persons with intellectual disabilities is much more difficult due to lifelong cognitive disability.

Broward health is one of the 10 largest public healthcare systems in the nation.

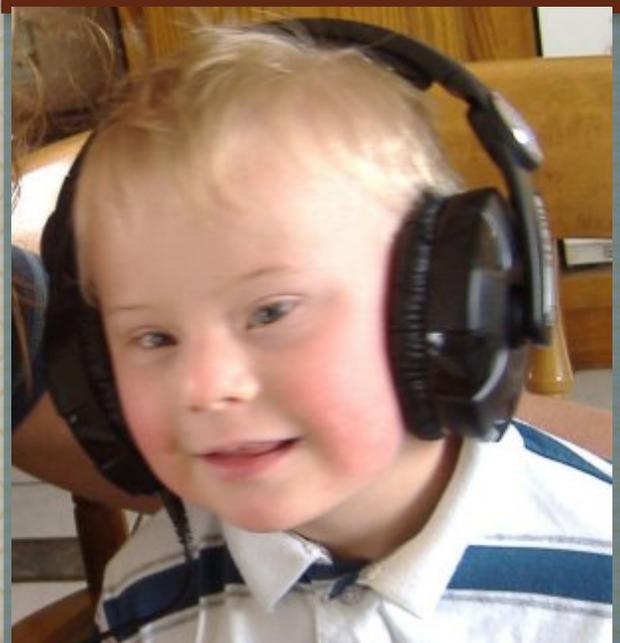
The Broward memory staff (Pictured Right) are the only JCAHO certified Alzheimer's Center in the nation. The onset of dementia related changes

typically is described by care givers as a decline in daily activities functioning. The

NTG Dementia screening instrument was administered to several participants' of the Lucanus Center in Hollywood Florida.

Dr. Janicki (NTG Co-Chair) administered the dementia screening with Lucanus staff and family members. The three persons selected have Down syndrome and recently displayed rapid loss of activities of daily living. The Support Plan did not indicate Alzheimer's disease even though the participant was in the later second stage with only 8-10 months predicted life.

Nova Southeastern College of Osteopathic Medicine will provide an interdisciplinary falls prevention and assessment team. The team will provide training to students, caregivers, policymakers and families in Broward County for prevention of falls to frail elders with ID.



Thomas Buckley (Founder/Executive Director Lucanus 40 years) hosted the NTG in Hollywood, Florida July 30, 31. Twenty Three Doctors of the NTG attended and drafted the first formal national curriculum providing Dementia Management to persons and families with I/DD and dementia. The formal curriculum will allow all family members, care givers, administrators, policy makers and the person served the opportunity to carefully structure and manage the dementia within natural community based setting.



*FLORIDA APD DIRECTOR BARBARA PALMER CELEBRATES  
FIRST NATIONAL PILOT DEMENTIA MANAGEMENT WITH  
LUCANUS FOUNDER THOMAS BUCKLEY, SR. AND APD  
QUALITY ASSURANCE LIAISON*

*"Some individuals with select  
conditions (Down syndrome, in  
particular) are more at risk for  
dementia, experience earlier age of  
onset, more rapid decline, and a  
briefer duration between diagnosis  
and death."*

*-National Task Group (NTG)*

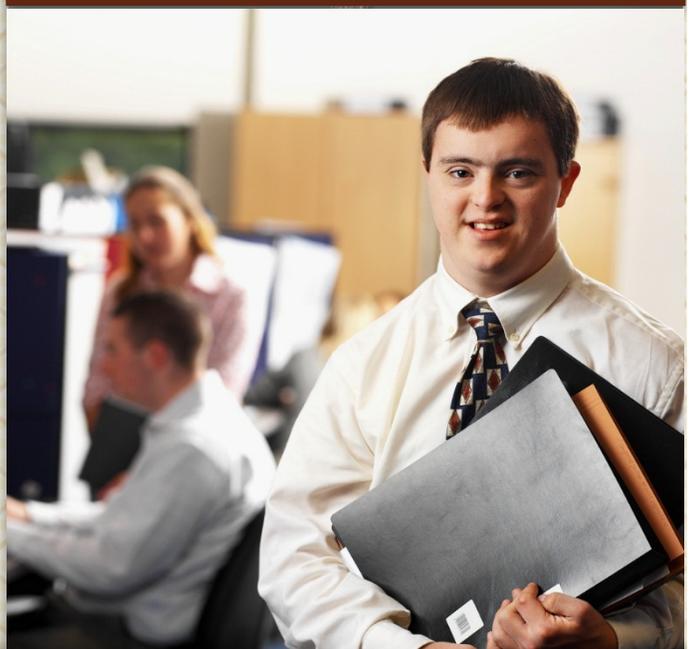
## BROWARD PERSON CENTERED DEMENTIA MANAGEMENT

### GOAL: INCREASE SELF-WORTH WHILE MAINTAINING SKILLS

The Broward Dementia Pilot is aggressively seeking input from international, national and state leaders in support of a model for dementia management that anticipates the increasing support needs as the disease progresses.

The Florida Agency for Persons with Disabilities must include "Dementia Management" for the aging person with an intellectual disability. It is estimated that 10% of the ID/DD community has Down syndrome. The Lucanus Center presently serves 315 participants. 75 participants have a diagnosis of Down syndrome. The Agency for Persons with disabilities must include resources to support the management of Alzheimer's disease for persons with Id/DD similar to the model Elder Affairs support Aging Floridians experiencing pathological aging.

*Dementia is a principle cause of disability, institutionalization, and shorter survival in older people*



## MEANINGFUL DAY SUPPORTS

As can be seen in the pictures below, it is essential for Persons with Alzheimer's disease and intellectual/developmental disabilities to be actively engaged with their world through Meaningful Day Activities.



These activities help the individual maintain an active connection with their community and help a person remain oriented with those around them. Some of these Meaningful Day activities include therapeutic gardens, nail and hair salon, exercise, behavior support plans for individuals with dementia and Alzheimer's, pharmaceutical intervention with appropriate review, and, if necessary, a fall prevention plan.



The top picture shows persons with Alzheimer's disease exercising. This is done daily for 45 minutes which helps the strengthening of the lower body to prevent falls. The increased blood flow from aerobic exercise assists in memory recall and maintains body at ideal body weights and increases the person's appetite.

The second picture shows a person participating in a nail salon appointment at the Lucanus Center, which has a dedicated beauty suite for individuals receiving services. This is instrumental in enhancing self-worth and self-esteem. Many individuals request a second hair wash just for pampering. Staff at the center provide free hair, nail, pedicure service as well as assistance with personal grooming. The main focus is making sure that the individual appears in a manner that is reflective of their worth as a person.

## LLOYD'S STORY

Since graduating from high school, Lloyd was actively participating in the Lucanus Day Program and was a successful, happy, and well-adjusted person who greatly enjoyed his program. Seven months ago, at age 42, Lloyd was diagnosed with Alzheimer's disease. Since that time, he and his family's life has changed significantly.



The following plea, received by staff at the Lucanus Center, illustrates the struggle that families such as Lloyd's, go through daily.

*Hello Tom:*

*It was good to meet with you last evening to sit down and discuss Lloyd's future and the possible role Lucanus will play in his life.*

*Lucanus has been a backbone to our family for approximately 20 years, and certainly we recognize the enormous impact your organization has had on Lloyd, enabling him to fully maximize his potential.*

***As you know, the aging process is taking its toll on Lloyd's life journey so that his mental capacity has now deteriorated steadily and rapidly during the last six months.***

*After almost losing him to the gross negligence of a rehabilitative center, we have brought him home and are caring for him with the assistance of licensed aides. However, this new stage is challenging - both for us and for Lloyd, especially as he is unable to fully understand and communicate his discomforts and all that he is experiencing.*

*I am excited to hear of the new developments taking place at Lucanus for our aging Downs Syndrome people, especially in partnership with Special Olympics. Now that Lloyd's wound has healed, we feel he is ready to resume a more stimulating and enhancing lifestyle. He regularly calls out the name of Lucanus, so we know he misses his Lucanus family, and we would therefore like to see him back in the fold of Lucanus once more. For a time he was receiving physical therapy, but is no longer qualified under Medicaid.*



*This is definitely something he needs to maintain - if not improve - his muscle-building, flexibility, and coordination. He is wheelchair bound, and incontinent, and now needs help feeding himself.*



*We are anxious to slow down the progression of his dementia so that he enjoys an extended quality lifestyle. **Daily interaction once more with his peers at Lucanus would definitely be therapeutic for Lloyd's wellness plan.***

*Tom, I think Lucanus has a lot to offer Lloyd at this stage of his life, and I am eager to see him avail himself of these new opportunities. Thank you for this opportunity, and once again we cannot thank Lucanus enough for being such an integral part of Lloyd's life and wellbeing over the past years.*

*We look forward to hearing more about the extended services you have created for your clients with such intense special needs.*

*Sincerely,*

*Audrey Ebanks (Sister/Guardian)*

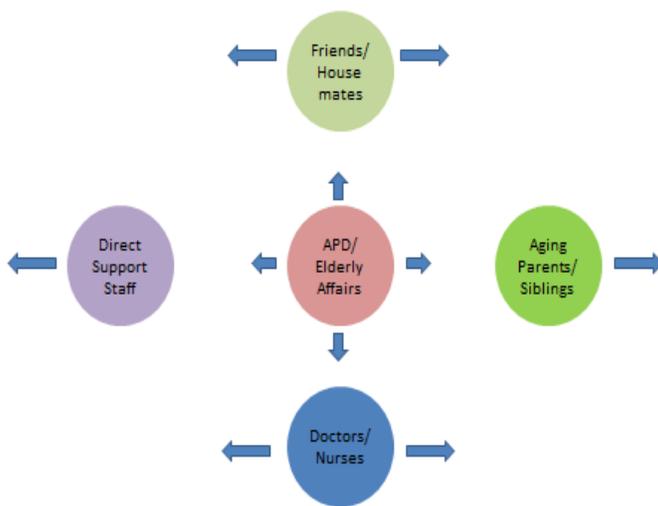
*ABOVE: SHELLY GREENBERG IS THE CATALYST BEHIND THIS BROWARD DEMENTIA PILOT. SHELLY'S DAUGHTER CHERYL IS IN HER MID-FORTIES WITH DOWN SYNDROME. SHELLY HAS PROVIDED LIFELONG DEMENTIA PREVENTIVE INTERVENTIONS AND CHERYL CONTINUES TO THRIVE IN THE COMMUNITY. SHELLY FOCUSES ON THOSE THAT ARE NOT AS FORTUNATE AND PRESENTLY SUFFER WITH ALZHEIMER'S DISEASE. THANK YOU SHELLY FOR THIS GIFT TO BROWARD COUNTY. YOUR LEGACY WILL FOREVER BE REMEMBERED FOR SUPPORTING THE MOST VULNERABLE RESIDENTS OF BROWARD COUNTY WITH DISABILITIES AND RELATED DEMENTIAS.*



## THE RIPPLE EFFECT

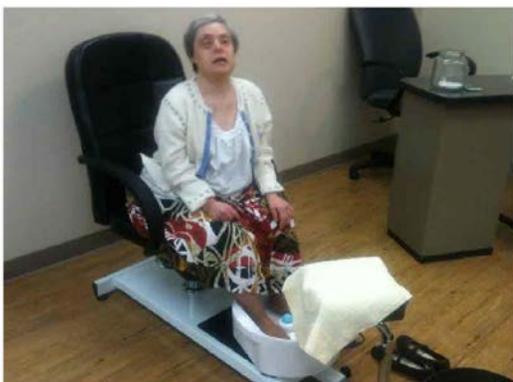
Dr. Seth Keller describes the “Ripple Effect” caused by the onset of Dementia. The myriad of issues facing the person with an intellectual disability and dementia requires collaboration and partners throughout the community.

### The Ripple Effect



The Broward Dementia Pilot will focus on the following dementia supports and services within Broward County:

- Appropriate Screenings and assessments for aging related conditions
- Supports for “Dementia Capable” care in community settings that can change as the disease progresses including education and training
- Person-Centered Health Maintenance-Nutrition and Exercise
- Engaging Activities in Community Settings to Prevent Isolation, withdrawal
- Health reviews and Surveillance
- Continued Supports and services for families to “Age in Place”
- Supporting Aging Caregiver-Recognize caregiver Challenges
- Support Sibling and Parent Caregiver
- Formal “Dementia Management Support Plans”
- Formal Education and Training for Dementia Care
- Develop and Emulate Current Models of Dementia Care that Anticipate the Increasing Support Needs as the Dementia progresses
- Support Groups for caregivers/family/Staff-Reduce Stress and Grief



Angela receiving a pedicure

## **BROWARD HEALTH AND NTG— A NATURAL PARTNERSHIP**

The Broward Memory Center will collaborate with the National Task Group for Dementia Practices and CARF International. Dr. Thomas Buckley, Ed. D. Lucanus Center serves on the NTG and CARF International Board of Trustees. The NTG partnered with CARF International to establish a set of national program standards for dementia-related services serving persons with intellectual and developmental disabilities.

As part of this process, in January 2013, CARF convened an International Standards Advisory Committee (ISAC) in collaboration with the NTG to address needs related to standards for individuals with ID/DD and co-occurring dementia. CARF International recently issued a White Paper as an interim step to the development of the formal standards for programs serving people with intellectual/developmental disabilities affected by dementia.



CARF recently completed the final field review. The final CARF standards will be disseminated in June, 2014. The Broward Memory Center, NTG, Nova College of Osteopathic Medicine and Lucanus Center developed the dementia Management pilot in close conformance to the CARF Dementia Standards.

The Broward Dementia Pilot will seek to provide, coordinate or partner services and supports commonly associated with the Florida



Long-Term Care Community Diversion Plan.

Nova Southeastern College of Osteopathic medicine will provide a comprehensive interprofessional fall prevention checklist. Disciplines involved include audiology, geriatric medicine, occupational therapy, optometry, pharmacy, physical therapy and psychology.

## THE HEALTHY COMMUNITY

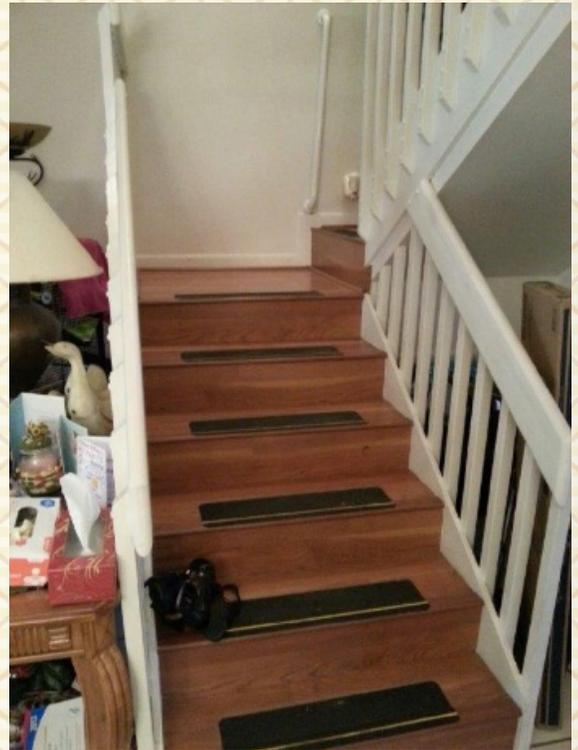
As a result of this intense focus on individuals with intellectual/developmental disabilities and dementia, a partnership is forming between Broward Health, CARF, NTG, and several recognized leaders: Dr. Todd, Shelly Greenberg (Supervisor Broward Memory Center), Dr. Matthew Janicki, Buckley Family (Lucanus Center), Dr. Seth Keller, and Sherry Wheelock (CEO Special Olympics Florida). The focus of this initiative would be to foster the development of paradigm to allow the South Florida Healthy Community to become an international model for the provision of quality congregate care to individuals in this group of individuals. This would be done through intense formal staff training, physical plant review, development of highly individualized dementia programs, collaboration with professional staff, and other innovative interventions.



*Engaged/Meaningful Dementia Services  
(Lucanus Center Pilot)  
Laura was withdrawn, isolated-Wakes  
Everyday Anticipating Nails, Brush/Cut Hair*



Jean receiving a manicure



*Textured Stairs (right), Hospital Bed (below)  
lower to ground— Dementia Friendly  
Modifications allow supported Lucanus  
Participant continue living at home*



*We want a society where older adults can live safe, healthy and independent lives. While falls are a threat to the health and independence of older adults and can significantly limit their ability to remain self-sufficient, the opportunity to reduce falls among older adults has never been better.  
(CDC, 2013)*

# RESOURCES FOR DEMENTIA CARE FOR INDIVIDUALS WITH ID/DD

ALZHEIMER'S ASSOCIATION® [WWW.ALZ.ORG](http://WWW.ALZ.ORG)

ALZHEIMER'S FOUNDATION OF AMERICA [www.alzfdn.org](http://www.alzfdn.org)

AMDA™ [www.amda.com](http://www.amda.com)

CARF International [www.carf.org](http://www.carf.org)

*Guidelines for Structuring Community Care and Support for People with Intellectual Disabilities Affected by Dementia*  
<http://aadmd.org/sites/default/files/NTG-communitycareguidelines-Final.pdf>

*'My Thinker's Not Working': A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports*  
[http://aadmd.org/sites/default/files/NTG\\_Thinker\\_Reportv6-edit%20version-e.pdf](http://aadmd.org/sites/default/files/NTG_Thinker_Reportv6-edit%20version-e.pdf)

LEAD [www.leadcoalition.org](http://www.leadcoalition.org)

NAPA <http://aspe.hhs.gov/daltcp/napa>

NTG, hosted by the American Academy of Developmental Medicine and Dentistry (AADMD) <http://aadmd.org/ntg> **3**

Working Resources List on Dementia Care Management and Intellectual Disabilities, University Of Illinois in Chicago:  
Dr. Matthew Janicki: Alzheimer's Disease ID/DD:  
<http://www.rrtcadd.org/TA/DementiaCare/Resources/Info.html>

Broward Health North Memory Disorder Center is the first and only in the Nation to receive Joint Commission Certification for Alzheimer's Disease. The MDC team of neurologist, neuropsychologists, psychiatrists, social workers and nurses provide a comprehensive diagnosis. Upon the completion of the diagnostic process, the patient and caregivers meet with the neurologist and members of the multidisciplinary team to discuss diagnosis, planning for the future and available resources  
<http://www.browardhealth.org/memory>

**Nova Southeastern University College of  
Osteopathic Medicine**