

National Alzheimer's Project Act (NAPA)

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Florida Alzheimer's Disease Initiative

Education Manual: Understanding & Dealing with Alzheimer's Disease & Related Disorders

DRAFT of Chapter on Intellectual and Developmental Disability (i.e., Down Syndrome) & Alzheimer's Disease

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Purpose

To improve specialized person/family-centered, health services and community resources to enhance the quality of life for people with lifelong intellectual and developmental disabilities (IDD), such as Down syndrome, who have Alzheimer's disease or a related dementia.

Objectives

Upon completion of this session, people will be able to:

1. Know at least five early typical signs suggesting progressive dementia that occur more commonly than memory and language problems in people with lifelong intellectual and developmental disability (IDD), such as Down syndrome.
2. Identify at least five points of a full clinical evaluation.
3. Understand at least three strategies for care management to optimize functioning of people with IDD, such as Down syndrome, who develop Alzheimer's disease or a related dementia.
4. Learn about the *Florida Model: Addressing Dementias*, a state plan with specialized, comprehensive, dementia-capable services and supports for people with IDD, such as Down syndrome, and Alzheimer's disease or a related dementia.
5. Access at least three sources of information and resources which educate caregivers and provide services to families in order to promote quality in daily life

for people with IDD, such as Down syndrome, and Alzheimer's disease or a related dementia.

KEY POINT: The key point is to understand that people with lifelong intellectual and developmental disabilities (IDD), e.g., Down syndrome, typically have different early signs of Alzheimer's disease or a related dementia (ARD), may be at greater risk, have onset at a younger age (during young or middle-age adult years), decline at a faster rate, and benefit greatly from special services and supports to the family.¹⁻⁵

Some Terms Used in this chapter:

Lifelong means throughout life.

Intellectual and developmental disabilities (IDD) refer to genetic and acquired (such as from head injuries, illness etc.) difficulties that involve memory and thinking skills as well as physical functioning and may include decreased social interactions.¹⁻⁵

Developmental Disability (DD): The U.S. Federal Developmental Disabilities Act defines DD as a lifelong condition that impairs normal development and

- A mental and/or physical impairment occurring before age 22
- Results in substantial limits to function in 3 or more major activities including:
 - ✓ self-care,
 - ✓ receptive (i.e. understanding) and expressive (i.e. speech, writing) language,
 - ✓ learning,
 - ✓ movement such as walking,
 - ✓ self-direction,
 - ✓ capacity for independent living and economic self-sufficiency
 - ✓ requires special & individualized services over the lifespan

States may vary in this definition; Florida uses categorical conditions in its definition:

Florida Statute, Chapter 393 defines developmental disabilities as a disorder or syndrome that is attributable to retardation, cerebral palsy, autism, spina bifida, or Prader-Willi syndrome and that constitutes a substantial handicap that can reasonably be expected to continue indefinitely.

Intellectual Disability (ID) may be described as having:

- Below normative intellectual functioning, due to cognitive impairment (organic or functional) present since birth or infancy that is not a mental illness or psychiatric impairment
- Varies in degree and co-impairment
- Compensated by training, education, remediation, habilitation, supports for life activities

Examples of IDD: Downs, Fetal Alcohol Syndrome, Fragile X, infection or malnutrition of the mother, environmental toxins (i.e. mercury, lead)

Down syndrome is the IDD that is the focus of this chapter. Down syndrome results during development before birth. Each person with Down syndrome is a unique individual. No matter which of three forms of Down syndrome a person has, some of the following characteristics to different degrees or none at all may occur:

- **Standard trisomy 2** - Extra copy of chromosome 21; accounts for approximately 95% of Down syndrome
- **Translocation** - Piece of chromosome 21 'trans locates' to another chromosome (usually chromosome 14); accounts for approximately 4% of Down syndrome
- **Mosaicism** - mixture of cells in that some cells contain 46 chromosomes and some contain 47; accounts for approximately 1% of Down syndrome (generally with fewer of Down syndrome traits though this varies)
 - Characteristic facial features; upward slant to the eyes
 - Low muscle tone; small stature
 - Intellectual and physical delays
 - Higher risk for heart conditions, sleep apnea, and vision problems
 - Higher risk for Alzheimer's disease, and
 - Higher risk for seizures

Of particular note are the wide range of individual differences in their abilities, learning of new skills, and challenges.¹⁻¹⁰

Alzheimer's disease is a probable diagnosis of the most commonly occurring progressive dementia given after a full medical examination. In the general population, the typical decline of Alzheimer's disease occurs first in short-term memory and recalling words, and/or difficulty completing complex tasks or making complex decisions. Other early signs include disorientation to time and place; more difficulty using both hands together to do skilled, complex tasks such as winding a clock, using a key, or buttoning a shirt; and difficulty completing daily routine tasks. Later changes may involve personality such as becoming more irritable or the opposite more withdrawn, and still later decline in movement such as walking (see more information later in this chapter and in the Chapter: *Alzheimer's Disease Overview*).

Related dementia refers to other progressive conditions, such as vascular dementia, frontal-temporal dementias, or parkinsonisms (movement disorders with progressive dementia). Decline from these conditions may create different patterns of decline in:

- short-term memory
- language, such as recalling and understanding words when speaking, listening, writing, or reading
- visual spatial skills, such as identifying direction or distance to objects
- movement such as walking up stairs and skilled hand movements (i.e. using tools)

- executive functions such as planning, organizing, and problem solving
- personality (more irritable and outgoing or, the opposite, more withdrawn)

The decline in related dementias may differ from the patterns usually seen in Alzheimer's disease but also leads eventually to the point of people being unable to handle their typical daily routines, responsibilities, relationships, and eventually, personal care.¹⁻¹⁰

Brief History of Down Syndrome

Descriptions of intellectual and developmental disabilities were described as early as 1550 BC in *The Therapeutic Papyrus of Thebes*. Centuries later Jean Etienne Dominique Esquirol in 1838 and Édouard Séguin in 1844 reported similar observations.⁵ However, the English physician John Langdon Down, motivated by his grandson who had the condition, described the physical and intellectual characteristics in more detail in 1866, which led to the condition being called Down syndrome.⁶ In 1959 the French human geneticist Jérôme Jean Louis Marie Lejeune discovered the irregular triple-chromosome, an extra copy of Chromosome 21, thus the term Trisomy 21.³ Based on the observation of three people with Down syndrome (ages 37, 42, and 47) and findings from examining their brain tissue, George A. Jervis, MD published (1948) the first report in English linking Down syndrome with Alzheimer's disease.⁸⁻¹⁶

Occurrence of People with Down Syndrome and Alzheimer's Disease

More than 400,000 people in the U.S. have Down syndrome. Longevity has increased not only for the general population but also for people with Down syndrome. With changes in laws, policies, health care, and greater efforts to keep people with Down syndrome home- and community-based, about 80% of people with Down syndrome reach 60 years of age or older according to the National Down Syndrome Society (www.ndss.org/Down-Syndrome/What-Is-Down-Syndrome/). Similar to all adults, with increasing age the person with Down syndrome has a greater risk to develop Alzheimer's disease or a related dementia.

According to the National Task Group on Intellectual Disabilities and Dementia Practices (2014): "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."¹⁷

Associated with increased biological aging (accelerated epigenetic clock¹⁸), the risk to develop chronic diseases increases with Down syndrome. Research suggests that compared to the general population, people with Down syndrome have five or six times the occurrence of Alzheimer's disease, are more likely to develop younger-onset Alzheimer's disease by 35 to 40 years of age, have a different presentation of initial signs of decline, may undergo brain cell changes specific to people with Down syndrome, suffer a faster rate of decline, and are at greater risk for seizures especially in the late stage of Alzheimer's disease.^{6, 8-13}

Other research has noted in many studies of brain tissue from many people with Down syndrome tissue with brain cell disease changes (neuropathology) associated with Alzheimer's disease showed no clinical signs of Alzheimer's disease. That is, while the people were alive, they functioned as if they did not have Alzheimer's disease. In other cases where people with Down syndrome functioned as if they did have Alzheimer's disease, they did not have the expected amount of cell changes when the brain tissue was later examined.¹⁴

Importance of Good Brain Function

People with Down syndrome should lead as healthy a lifestyle as possible to keep their brain working well. The following table lists basic ways to keep the brain healthy. Regular medical check-ups of adults who have an IDD, e.g., Down syndrome, should note their usual healthy levels of function and personality, handling of responsibilities and routines, self-care, and adjustment to change.

Basics of Keeping the Brain Healthy
1. Good daily nutrition: protein, whole grains, fresh fruits and vegetables
2. 10-12 glasses of water (or similar liquids) daily unless a physician limits liquids
3. Positive interactions; enjoyable relationships; quality time with others & time alone
4. Physical exercise, especially walking or bicycling, for at least 30 minutes at a time for at least 5 days a week
5. Daily brain exercise: crossword, jigsaw, and math puzzles; reading and talking about what was read, music, handcrafts, planning and doing tasks, etc.
6. Daily purposeful (useful and meaningful) tasks whether at a job or home
7. Fun activities
8. Reduced unpleasant stress
9. <i>Following the physician's and dentist's advice for good health!</i>

For middle-age and older adults who have Down syndrome or other IDD and who have access to regular medical visits for chronic health problems (i.e. changes in vision or hearing, pain, weakness, shortness of breath, heart or blood circulation problems; muscle, joint or bone problems; diabetes, etc.), the follow-up medical exams should include and note in the medical record other changes. Other changes that occur in

relationships, mood, or personal care, or completing routine tasks may indicate the beginning of Alzheimer’s disease or a related dementia.

In the next comparison table, note the differences when typical early signs of Alzheimer’s in a person with Down syndrome are compared to typical early signs of Alzheimer’s or a different dementia in the general older population.

Comparing Early Signs of Alzheimer’s Disease or Related Dementia	
People with IDD or Down Syndrome	Older General Population
<p><i>Early changes in:</i></p> <ul style="list-style-type: none"> - Personality, such as being more irritable and aggressive or more withdrawn and passive - Refusing to cooperate in activities or tasks - Mood, such as acting sad, no longer interested in previously enjoyed activities, decline in appetite, sleep, or self-care - Handling interactions - Doing (or not completing) routine tasks 	<p><i>Early changes in:</i></p> <ul style="list-style-type: none"> - Short-term memory - Recalling specific words while talking - Losing or misplacing objects; getting lost - Difficulty making decisions involving many Choices
<p><i>Later changes may appear in:</i></p> <ul style="list-style-type: none"> - short-term memory - language - decision-making and other thinking functions 	<p><i>Later changes may appear in:</i></p> <ul style="list-style-type: none"> - Not completing tasks - Doing personal care - Personality – becoming more irritable or the opposite, more passive - Movement ability

The NTG-EDSD (National Task Group-Early Detection Screen for Dementia), filled out before the annual medical exam by the caregiver or someone well-acquainted with the person who has Down syndrome, helps to identify decline in function and health in a person over age 40. The form has six-pages and is available with directions on the internet (www.aadmed.org/ntg/screening). The form is free and offered in English, Dutch, French, German, Greek, Italian, Japanese, Scottish, and Spanish.

Several key health care considerations for people with Down syndrome are:

- average age of onset of Alzheimer’s disease is 20 years earlier than the general population;
- incontinence occurs in 87% of people with Down syndrome and Alzheimer’s disease and related dementia;

- gait changes occur in 97% of people with Down syndrome and Alzheimer's disease and related dementia;
- dysphasia (difficulty swallowing) occurs in 58% of people with Down syndrome and Alzheimer's disease and related dementia;
- hypothyroidism: though the thyroid develops normally in children with Down syndrome, it stops working in 50% of adults with Down syndrome which may increase the risk for progressive dementia;
- obstructive sleep apnea is common in people with Down syndrome and may increase the risk for progressive dementia;
- late onset seizures are much more common (79%) in people with Down syndrome than for the general population (2%);
- rapid-decline forms of Alzheimer's disease can lead to death less than 2 years after onset in adults with Down syndrome

More information is available in *Health Care Guidelines for Individuals with Down Syndrome*¹⁹ and *The National Task Group on Intellectual Disabilities and Dementia Practices Consensus Recommendations for the Evaluation and Management of Dementia in Adults with Intellectual Disabilities*²⁰.

Summary: Signs of Decline

Any change from the person's own normal way of functioning should be of concern. The person undergoing the changes may or may not be aware of changes and difficulties or may deny any problems with function. Someone else such as a family member, teacher, or supervisor who knows the person well may be the first one to notice changes. The typical cooperative, competent behaviors may change to uncooperative, resistant, withdrawn, or irritable behaviors.

Later decline may occur as decreased memory, speech or word use problems, not understanding directions or explanations, or not completing tasks. Changes may occur in empathy or mood swings. A seizure may occur for the first time. If the person with Down syndrome who is typically happy, competent at their daily routine and a pleasant team member on the job or at home then becomes withdrawn, irritable during interactions, and unwilling to cooperate with team members or a supervisor, a medical exam is important.

The Medical Evaluation

A full medical exam should be done by a specialized physician who is knowledgeable in the assessment of people with progressive memory disorders such as Alzheimer's disease and related dementia. The first reason is to rule out and treat a fixable problem. Not everybody with memory problems has Alzheimer's disease. The second reason is to offer treatment, management strategies including educational materials, and links to community resources such as caregiver support groups, adult day care and other supportive services, etc.

Some people with changes in memory and thinking functions may improve with medical treatment as in cases when there is pain such as a sore tooth or joint aches, an infection such as a bladder infection, a vitamin B12 or thyroid deficiency, or a new medicine that may be having an anti-memory (anticholinergic) effect. A relationship change such as a best friend moving away, a job change, a change of caregiver, or death of a pet, friend or family member may lead to depression resulting in a person with Down syndrome experiencing problems with memory and being unable to do routine tasks.

Changes in the setting; support from loved ones; supportive resources and programs for the diagnosed person and the family; talk therapy; and mild anti-depressants may work to return the person with Down syndrome to previous healthier levels of function.

Full Medical Exam

A full medical exam for the person with Down syndrome who is having changes in personality or function should include some of the points listed in the following table. A careful exam is necessary to identify all the conditions such as diabetes or high blood pressure that may benefit from medical attention. Important also are blood tests and pictures of the actual brain [brain imaging such as an MRI (magnetic resonance imaging) or CT (computer tomography)].

A Full Medical Exam¹⁹⁻²¹

A full medical exam should consider:

- Current symptoms & changes in function: what has been the regular level of function & what changed 1st, 2nd, 3rd, etc.
- Health history including past developmental history, genetic conditions, chronic health conditions, medical & surgical treatments, trauma especially head injury, special diets, etc.
- A review of all the health & function changes, e.g., heart, vision, hearing, skin, gastrointestinal system, incontinence, sexual function, dental health, etc.
- Social history, education completed, special job training skills, employment/work/retirement history
- Health history of directly-related family, such as parents, grandparents, siblings, uncles, aunts, etc.
- History of substance abuse (tobacco, alcohol, leisure drugs, etc.)
- Physical exam including blood pressure, weight, pulse (and sometimes temperature)
- Specialty medical exams when needed, such as neurology, neuropsychology, cardiology, urology, oncology, speech/physical or occupational therapy, etc.
- Psychosocial assessment
- List of prescribed and over-the-counter medicines, vitamins, herbs, teas, etc.
- Tests of small samples of blood & urine, imaging such as MRI, or CT, etc.*
- Other tests as needed, i.e. breathing tests, stress test, EKG, EEG, EMG, chest x-ray, sleep study, spinal tap, etc.*

- * MRI – magnetic resonance imaging (brain imaging)
- CT – computer tomography imaging (brain imaging)
- EKG - electrocardiogram, a study of heart function
- EEG - electroencephalogram, a study of brain function
- EMG - electromyogram, a study of nerve function in the muscles

Medical Recommendations

A careful medical evaluation may point to the need for lifestyle changes, such as improved diet, increased physical activity, etc. (see the earlier table, *Basics of Keeping the Brain Healthy*). The doctor may recommend a change from a medicine such as an allergy medicine or incontinence medicine that blocks memory function and suggest treatment strategies or other medicine that treats the problem without weakening memory function. Based on the results of the medical evaluation, some physicians may change some medicines that could be affecting memory function, prescribe medicine, which may help memory function, and offer special care management strategies such as simplifying tasks, keeping a routine, regular physical exercise, and reducing stress.

In people with Down syndrome there seems to be a strong link between Alzheimer's disease and seizures. Researchers have noted also a steeper rate of cognitive decline.¹² Seizures occur in 90% of people with Down syndrome who are in the severe stage of Alzheimer's disease, whereas about 15-25% of others (without Down syndrome) during the severe stage of Alzheimer's disease will experience seizures.¹³ Thus, special planning should include education regarding signs of seizures, seizure management, early signs of medicine not controlling seizures, lining up backup help, and identifying other resources to help if the high likelihood of seizures becomes a reality.

The medical recommendations should include also strategies and limits to address general safety issues such as:

- ◆ Ongoing decline due to Alzheimer's disease may result in problems operating a motor vehicle such as a car, motor boat, rider mower, or golf cart; therefore, it may be time to limit or stop some or all of these activities.
- ◆ Decline in memory may result in a person losing objects, leaving doors open or unlocked, forgetting to shut off the stove or water faucet, or becoming lost on regular walks or bike rides through the neighborhood; therefore, labeling personal items such as jackets, wallets, etc., checking doors and the bathroom after use, and working together to cook and do other tasks or activities should increase safety.
- ◆ Problem with balance may result in falls or tripping on loose rugs, stairs, sidewalks or curbs; therefore, removing loose rugs, repairing stairs, applying balance bars and handrails, keeping the setting well lit, walking on even surfaces, and carefulness on stairs and at curbs should decrease or prevent falls.

- ◆ Clumsy hand skills may lead to injuries when using sharp tools (i.e. a razor, knife, scissors, needle, pin, screwdriver, etc.); therefore, it may be time to avoid sharps and use smoother tools such as an electric shaver or blunt-nose scissors.

Tips for Caregiving²⁰⁻²³

The health care team should provide tips and resources that provide good information for home-based and community-based care management. Alzheimer's and related disorders (ARD) typically progresses more quickly in people with Down syndrome, but the symptoms and decline in function are similar to the general population. Families should take advantage of the resources and educational programs available in the Alzheimer's care community. Care management at home or a community program should involve simplifying tasks and the setting to accommodate changes in function while helping the person to maintain as much independence and control as possible. Opportunities should allow the person to make choices, continue useful activity, relate easily to others, and keep up with self-care in a safe setting. A routine could include a varied schedule of activity, rest, physical exercise, tasks, crafts, time with others and time alone, mealtimes, walking the dog, and therapies such as aromatherapy, music, massage, or dance.

It is important for the person with IDD and Alzheimer's disease to have a healthy lifestyle which includes physical exercise such as walking (outdoors or on a safe treadmill; walking with a friend-buddy walk; nature walk) or (safe) bicycling (outdoors or on an exercise bike) 5 days a week. Group activities such as bowling, folk dancing and freestyle dancing, exercise to music, and miniature golf provide great physical exercise.

Daily brain exercise should be varied, such as word games, puzzles, board and card games, doing art work (drawing or painting), playing musical instruments, singing with a group, acting out a simple play, story or song; reading with a friend (reading buddy), etc. Stimulating for the brain also are keeping up to date with family news and events and helping to plan upcoming family events such birthdays and holidays. Interesting discussions with family and friends could cover:

- special, meaningful events - local art fairs, exhibits, community programs, events at a place of worship or meditation, or outdoor events
- T.V. and radio shows – sports, music, comedy
- family activities and visitors (practice their names before they arrive)

Key tips for the person with IDD who has Alzheimer's disease are to:

- 1) keep the schedule simple, routine, and meaningful
- 2) be positive - keep activities and interactions interesting, positive, and fun

General TIPS for the Person with IDD and Alzheimer's to Use

1. Keep reminder notes and a calendar in one place.
2. Stick to routine schedules for daily, weekly, and monthly activities as well as special events such as holidays or birthdays.
3. Keep paper and pen/pencil handy (or cell phone, iPhone, or smartphone if useful) in pants pocket or purse. When you think about it, write it down. Write down: ideas, passing thoughts, tasks to do, people to call, etc.
4. Keep handy: names and phone numbers of people who can help.
5. Work at paying attention. Watch, listen; focus; keep eye contact.
6. Repeat information out loud and a few times quietly to yourself to remember.
7. Do one task at a time, one step at a time, the usual way that you know well.
8. Go the way you know. Keep handy simple directions with large print (and a small, simple map), a picture of the destination or person(s) there and the easiest way to return home.
9. Label with the first name & phone number of a contact person on/in: jacket, eyeglasses, phone, book bag, purse, wallet, etc., in case they are lost.
10. Remember to say: Please" & "Thank you" !!

Assisting People Who Have IDD and Alzheimer's Disease

The family and caregivers of the person with an IDD and Alzheimer's disease should keep the schedule simple and routine. The caregivers should plan activities ahead of time, allow extra time for tasks or appointments, make the home, work, or leisure setting easy for daily functions, and schedule for themselves as well as the care receiver down-time as rest periods in between varied activities or during a busy weekend. Creating a list of the tasks and activities should include ones that are fun and rewarding for the person with Down syndrome and Alzheimer's disease. It is important that the person continue to have activities that allow them to keep contributing to the home and family to the extent that they are able. Everyone's need to feel valued does not change once someone is diagnosed with Alzheimer's disease or a related dementia.

Tips for People Who Assist Those with IDD and Alzheimer's

1. Keep tasks and activities simple, one step at a time.
2. Keep information, directions, or requests simple (few words). Discuss details briefly and use the actual names of people, pets, places, etc. Use specifics and repeat one or two important simple details. Use statements such as "Let's eat lunch! Lunch!!" rather than asking "Are you hungry?"
3. Use a patient, pleasant voice and repeat: the question, request, or answer.
4. Keep a positive facial expression, voice, words; encourage, not nag. Avoid negative facial expressions or words, especially criticism or arguments.
5. Look for hidden meaning or feelings in words or facial expression.
6. Act as a team to: organize a drawer or bureau drawer, hang up clothes, fold laundry, do yard work, feed or care for a pet, etc.
7. Schedule time for tasks apart from each other, such as in separate rooms.
8. Allow extra time for a response, getting bathed or dressed, doing tasks, and meeting appointments.
9. Set aside or schedule regular rest times for each of you.
10. Hang a large calendar. Keep the daily schedule handy and follow it. Schedule daily tasks, activities, and exercise at routine times. Mark off what is done and past appointments. Keep that page or file for later reference.
11. Post at an assigned, regular place (i.e., bulletin board, refrigerator door, or bathroom wall, etc.) a sign, a simple, brief list, or picture to note special activities or tasks.
12. Encourage regular physical exercise such as walking 30 minutes at a time, 5 days a week.
13. Schedule daily fun brain exercise: puzzles, cards, board games, computer games, books, outdoor activities, etc.
14. For someone who loses clothes or objects, label items with a first name and contact phone number.
15. Remember to say: Please" & "Thank you" !!

Family members or significant others should try to stay as positive as possible. Maintaining a communication style that is pleasant, patient, and sensitive to preferences helps the person with Down syndrome and a progressive dementia to maintain a sense of being:

- valued
- self-sufficient
- independent or somewhat independent
- an important contributor to the activities in the work and home settings.

As symptoms progress and behavior is affected, keeping a positive attitude and communication style is not always easy. It is important to seek out caregiver education on issues such as communication and behavior management. It is highly recommended to join a local caregiver support group. In a support group or educational class, a caregiver should listen, ask questions about how to handle challenging situations, frustrations, and stress. The caregiver should ask about information on local services and resources, free online resources, and how to find them.

Caregiver Respite

Caring for a person with Down syndrome and Alzheimer's disease offers personal rewards such as a sense of accomplishment that comes from keeping someone safe and supported, an opportunity to build bonds with a loved one or other caregivers and the knowledge that you have helped someone to feel the joy of a success and doing meaningful activities. A good supply of hugs is another benefit. Over time the continuous oversight and the often unexpected challenges of caregiving may build stress in the caregiver and tax her/his health. As the person with Down syndrome and Alzheimer's disease declines, the caregiver takes on more responsibilities and tasks, often to the point of neglecting personal well-being. To continue to be effective, the caregiver must maintain physical, emotional, and spiritual health.

Respite, regular time out from care duties for the caregiver with pleasant, non-caregiving activities, is essential. (Refer to the Chapter: *Stress Management for Caregivers* for more information on this important topic.)

Planning Ahead²⁰⁻²³

Besides early interventions to stop or slow down memory and cognitive decline, another value of an early medical evaluation of the person with Down syndrome is the ability to plan ahead with the family for future lifestyle adjustments. Early on, assistance from medical, legal, financial, and social worker experts may help to identify resources and supports and to establish priorities. Early planning to fulfill the wishes and to understand clearly the preferences of the person with Down syndrome and Alzheimer's disease while function and thinking are at good levels could include:

- Listing preferred visits to or from friends, valued relatives or others
- Identifying favorite types of music, particularly those that help with calming

- Recalling memorable events that were pleasing and favorite pastimes (to use later to help with conversations and other interactions)
- Identifying preferred routines and self-initiated activities
- Discussing likes and dislikes in foods, beverages, dress, activities, tasks, movies, books, relatives, colors, music, etc.

While communication, decision-making, judgment and other executive function skills are at their strongest is the time to discuss issues and preferences of the person with Down syndrome and Alzheimer's disease. This information will become important later when the person's function depends on caregivers providing much more or full personal care. Planning ahead should consider legal, financial, and possible long-term needs, such as health care surrogates for decisions and health care preferences.

Adults with Down syndrome and early Alzheimer's disease may already have difficulty making decisions. If not, they are considered to be competent regarding health decisions unless determined and declared to be otherwise. Concerns about durable power of attorney for health, finances, and legal decisions as well as guardianship should be addressed in the early steps of planning ahead.^{18,19}

Other topics to consider include accessing resources and creating a plan of care for the family or other caregivers to provide leisure activities, emergency and medical services, life enrichment classes, and increased assistance with homemaker services or personal care over the long-term.

There are currently very limited options for specialized day programs or residential facilities with highly trained staff that specialize in care for people with Down syndrome and Alzheimer's disease. Families and other caregivers should identify what is available in their community and investigate the costs and eligibility criteria to determine the potential role in the long-term care management of the person with Down syndrome whose abilities decline Alzheimer's disease changes occur. Even if a caregiver plans to keep someone at home indefinitely, it is important to have a back-up plan (caregivers need respite, a break to visit their other family out-of-town, or may become ill). Thus, caregivers need to know and gather information about options, such as gathering brochures and visiting day programs, agencies with in-home services, day care centers, and residential facilities.

Plans for the future should consider housing alternatives as abilities change. Over time as caregivers such as elder parents change in health and the ability to oversee responsibilities including the care of their loved one with IDD and Alzheimer's disease, they should develop a backup plan for care. The backup plan should include some details that cover care for the elder parent(s) as well as the person with Down syndrome and Alzheimer's disease. Other family caregivers, e.g., siblings, other relatives, paid caregivers, or volunteers from local programs may be appropriate soon or for the future to oversee and manage care.

In some cases, the plan for future overnight care for a weekend to provide respite for the caregiver or full 24/7 care may need to rely on a facility. A dementia-friendly residence or a community-for-a-lifetime should offer a full continuum of dementia-friendly services that include independent living, limited assistance, memory care, skilled rehabilitation, and nursing care. Very few programs currently have staff who have special expertise in working with people who have Down syndrome and Alzheimer's disease.

End-of-life care and decisions should consider the preferences of the person with Down syndrome, the family culture, resource people in the community, and programs that are accessible and available to provide support.

Accessing resources for educational purposes and identifying services and programs such as specialized day care programs to help the caregiving family are important. Plans for improvements in the care system available to those with Down syndrome and Alzheimer's disease are underway in Florida. The first step has been to education for professional and non-professional caregivers and to set up a model program which are overviewed briefly in the next section.

The Florida Model: Addressing Dementias

Addressing the Challenge for Floridians including people with IDD, especially Down Syndrome, and Alzheimer's Disease or a Related Dementia

Many Floridians with IDD will experience Alzheimer's disease or related dementias in middle or later adult life. As mentioned before, people with IDD such as Down syndrome typically have different early signs of Alzheimer's disease or a related dementia. Often they display initial changes in behavior, mood, or personality, relationship difficulties, having difficulty or being unwilling to follow directions, difficulty doing routine tasks at work or home, and decreased self-care. After a while decline affects short-term memory, disorientation to time and place, getting lost in familiar places or losing items, and eventually, needing total, daily personal care.

Alzheimer's disease and related dementias are devastating conditions that dramatically increase caregiver burden. Families involved in the daily care management of someone with Down syndrome may become overwhelmed with the growing demands. The additional, increasing responsibilities and challenges may overwhelm and exhaust many aging parents or caregivers who are developing their own serious health issues.

The National Alzheimer's Project Act includes People with Intellectual Disabilities, especially Down syndrome, a targeted group protected and considered "specialized". (<http://aspe.hhs.gov/daltcp/napa/>)

The **National Alzheimer's Project Act (NAPA)**, which the U.S. Congress passed unanimously in 2010, called for a national action plan to address issues related to Alzheimer's disease and related dementias in 2014. The NAPA also created a federal advisory council for overseeing NAPA activities including a special focus on persons with IDD, especially Down syndrome, and Alzheimer's disease or related dementias:

"Some populations are unequally burdened by Alzheimer's disease. People with Down syndrome almost always develop Alzheimer's disease as they age. In addition, because Alzheimer's disease primarily affects older adults, the population with younger-onset Alzheimer's disease faces unique challenges with diagnosis, care and stigma." (National Plan to Address Alzheimer's Disease: 2013 Update; Appendix 3; aspe.hhs.gov/daltcp/napa/NatlPlan2013.shtml)

Along with the federal effort was the creation of the **National Task Group on Intellectual Disabilities and Dementia Practices** to ensure a lifelong approach to address the dementia-related needs of adults with IDD and their families. The National Task Group on Intellectual Disabilities and Dementia Practices Co-Chairs, Matthew P. Janicki, PhD,²⁴ and Seth M. Keller, MD,²⁵ joined Thomas J. Buckley, EdD,²⁶ in partnership with the Florida Department of Elder Affairs to propose the formal designation of Down syndrome and intellectual disabilities as *specialized*. In addition, they created a national pilot program in Florida at the Lucanus Developmental Center in Hollywood, Florida.

The Florida Plan: Florida Leadership in Specialized Alzheimer's Care

A team from the Florida Department of Elder Affairs in collaboration with the Lucanus Developmental Center developed a Florida Plan, to model the first U.S. specialized, comprehensive dementia-capable system of services with a network of supports. The initiative ends marginalization and eliminates institutions as the only option for people with IDD and a diagnosis of Alzheimer's disease or a related dementia.

The Florida Model: Addressing Dementias calls for the creation of:

- specialized dementia-capable services and supports,
- formal, specialized, evidenced-based curriculum for aging caregivers and workforce, and the
- first formal, specialized caregiver support groups created to support the aging caregiver suffering from the death of their child while they provided total care with no dementia supports.

In 2013 staff at the Broward Health North Memory Disorder Center, the National Task Group on Intellectual Disabilities and Dementia Practices, the Florida Department of Elder Affairs and the Agency for Persons with Disabilities had developed the Florida Model: Addressing Dementias curriculum, a formal, specialized person-centered curriculum to educate the workforce. The curriculum addresses respite, day services, meals, transportation and early diagnostic protocols implemented through Florida's hallmark 15 Alzheimer's Disease Initiative Memory Disorder Clinics/Centers, which includes the Broward Health North Memory Disorder Center.

The unveiling of the nation's first formal, evidence-based, Florida Model: Addressing Dementias curriculum was honored with the participation of Erin G. Long, the Social Science Analyst responsible for creating specialized dementia services and supports in the U.S. Health and Human Services, Administration for Community Living (ACL), Center for Program Operations (<http://www.hhs.gov/ogc/contact/contacts.html>).

On July 6, 2014, the U.S. Department of Health and Human Services received a grant application from the Florida Department of Elder Affairs, the Florida Agency for Persons with Disabilities, the Lucanus Developmental Center, and several other collaborators [i.e., Broward Health North Memory Disorder Center, Nova Southeastern University College of Medicine GEC (Geriatrics Education Center), CARES (Comprehensive Assessment and Review for Long-Term Care Services) Tampa Bay, the Alzheimer's Association-Florida Gulf Coast Chapter; Easter Seals]. Valuable assistance came from Drs. Janicki and Keller, Co-Chairs of the National Task Group on Intellectual Disabilities and Dementia Practices. The purpose of the grant was to create the nation's first formal specialized, dementia-capable system providing services and supports for Americans with IDD, especially Down syndrome, and Alzheimer's disease or a related dementia. The National Task Group on Intellectual Disabilities and Dementia Practices support letter to the U.S. Health and Human Services stressed that, "The national specialized ADRD model created in Florida will be emulated across the nation enabling all Americans living with an intellectual disability, especially those with Down syndrome and Alzheimer's disease and their aging caregiver the opportunity to access quality person/family-centered dementia-capable services and supports while aging in place."

Initiating the plan for the Florida Model: Addressing Dementias, specialized pilot training program related to Alzheimer's disease or a related dementia on the west coast of Florida were:

1) Christine Powers is the Director of Community and Aging Retirement Services and Adult Day Services, Tampa, Florida, and Chair of the Florida Alzheimer's Disease Advisory Committee. Ms. Powers provides specialized day, respite, homemakers, and geriatric counseling through Community and Aging Retirement Services (CARES) and work with the Alzheimer's Association-Florida Gulf Coast Chapter.

2) Kathleen J. Houseweart, MBA, is the Manager of Geriatric Services, Coordinator of the Memory Disorder Clinic at the Sarasota Memorial Health Care System. Ms. Houseweart through her Alzheimer's Disease Initiative Memory Disorder Clinic at the Sarasota Memorial Health Care System developed the initial in-service presentation for the State Memory Disorder Clinic Coordinators presented at the October 2015 meeting in Orlando. Kathleen Houseweart is also a partner in the Alzheimer's Support and Education Network in Sarasota, Florida, a partnership with Jewish Family & Children's Services (Sarasota) that targets the ID/DD population with dementia.

Florida Model: Addressing Dementias - Emphasis on Higher Quality (*Note: High quality* refers to the Advisory Council on Alzheimer's Research, Care, and Services

meeting in 2014 addressing the national concern for high quality dementia services and supports. aspe.hhs.gov/advisory-council-alzheimer%E2%80%99s-research-care-and-services-2)

In December 2014, the Florida Agency for Persons with Disabilities under Director Barbara Palmer, MA, sought information regarding comprehensive specialized person/family-centered community-based services and supports for Floridians with Alzheimer's disease or a related dementia and their aging caregivers. Director Palmer joined forces with Samuel P. Verghese, Secretary of the Florida Department of Elder Affairs, to create the nation's first, "**High Quality-Specialized, Person/Family-centered Dementia-Capable Services and Supports Model.**"

Some components of this Agency for Persons with Disabilities-Department of Elder Affairs joint planning highlighted important services include:

- Access to 24-hour, in-home supports for caregivers with:
 - Home health services
 - Meals preparation
 - Housekeeping services
 - Companion services
 - Respite care
 - Adult day services
 - Transportation
 - Memory Disorder Clinic/Center services
 - Abuse/Neglect/Exploitation Protection Services
- Development of alternative living
- Access to training/education and resource information
- Targeted screenings and assessments

Florida Commitment to Dementia-Friendly Communities

A multitude of Floridians living with IDD, especially Down syndrome, will experience the debilitating effects of Alzheimer's disease and related dementias, because though treatment is available, no cure exists at this time.

The Florida Governmental leadership; the Florida-wide 15 Alzheimer's Disease Initiative Memory Disorder Clinics/Centers and 3 associated adult day care programs; the Florida Governor's Committee on Alzheimer's disease (the Purple Ribbon Task Force), the National Task Group on Intellectual Disabilities and Dementia Practices; and the Lucanus Developmental Center continue tirelessly to create the specialized person/family-centered dementia-capable services and supports which Florida families need desperately. The goal of Florida is to serve its families as the paragon leader of Dementia-Friendly Communities which are:

- informed, safe, and easy to navigate,

- technologically advanced with high quality, meaningful dementia-capable services and support options,
- respectful of all Floridians suffering with Alzheimer’s disease, and
- provide quality in life to families and aging caregivers while they age in place.

Several national and Florida groups have collaborated to develop a statewide plan and have launched the pilot, a model of “*Florida High-Quality Specialized Dementia-Friendly Communities*” including but not limited to the following:

- Public awareness, information
- Accurate and timely diagnosis, medical management and treatment
- High quality dementia care coordination
- Future Planning
- Meaningful day activities
- Specialized dementia-friendly transportation
- Specialized dementia-capable settings for young onset, IDD (Down syndrome) Alzheimer’s disease or related dementias

Summary

People with lifelong intellectual and developmental disabilities (IDD), such as Down syndrome, have a wide range of individual differences in their abilities and learning of new skills. Down syndrome is associated with intellectual and physical delays, a higher risk for heart conditions, sleep apnea, and accelerated aging. Compared to the general population, people with Down syndrome appear to be at greater risk to develop Alzheimer’s disease, have onset at a younger age (during young or middle-age adult years), decline at a faster rate than the general population, and are at higher risk for seizures, especially during the advanced stage of Alzheimer’s disease.

A problem with short-term memory is usually the first sign of Alzheimer’s disease in the general population. However, people with Down syndrome have different early signs of Alzheimer’s disease or a related dementia. Often they display initial changes in behavior, mood, or personality, difficulty or unwillingness to follow directions, struggles doing routine tasks at work or home, or decreased self-care. After a while decline may be evident in short-term memory, language skills (speaking, understanding, reading, or writing) and other thinking functions such as decision-making or completing steps to a task.

Changes in the schedule, setting, and relationships may lead to increased sadness, irritability, or decreased interest in activities or social activities and present as a sign of depression or as an early sign of a fixable or progressive dementia in a person who has Down syndrome or a different IDD. Behavioral and personality changes, depression, high anxiety, high amounts of stress, fatigue, and problems with short-term memory, language or other thinking abilities may result from infections, pain, inflammations, or some other “fixable” condition. After treatment of such conditions, some people with

Down syndrome should return to their normal or close to level of functioning when they undergo a clinical evaluation six months later.

Importance of Early Medical Exam

Any changes from the person's regular way of functioning may be signs that a person with IDD has developed a treatable dementia or a progressive dementia such as Alzheimer's disease or a related dementia/disorder. Thus, an early medical evaluation at the beginning of such changes in behavior and function is important. People with such changes, who are diagnosed with a progressive dementia such as Alzheimer's disease, and who receive early treatment are likely to experience better and longer brain health and longer independence in their daily routines.

If the full medical evaluation indicates a diagnosis of Alzheimer's disease, the family should learn as much as possible about the condition and plan ahead as much as possible with the person who has the diagnosis. Several resources are available through internet links to identify educational materials and contacts that may provide services and support groups in the local community. The following resources and internet sites provide additional information about people with IDD, especially Down syndrome, and Alzheimer's disease or a related dementia.

Resources

Web Sites on Alzheimer's Disease

Administration on Aging: Washington, DC 20201; 202-619-0724; www.aoa.gov

Alzheimer's Association: 225 North Michigan Avenue, 17th Floor, Chicago, IL 60601; 800-272-3900; www.alz.org; online support groups; free educational materials.

Alzheimer's Disease Education and Referral Center (ADEAR): PO Box 8250, Silver Spring, MD 20907; 800-438-4380; www.alzheimers.org

Alzheimer's Foundation of America (AFA): 322 8th Avenue, 7th Floor, New York, NY 10001; 866-AFA-8484 (866-232-8484); www.alzfdn.org; www.alzquilt.org (a quilt to remember)

National Family Caregivers Association (NFCA): 10400 Connecticut Ave, Suite #500, Kensington, MD 20895; 800-896-3650; www.nfcacares.org

National Web Sites on Down Syndrome

Down Syndrome Affiliates in Action: resource repository, education and training webinars, brokered discount programs and discounted registration at annual conference. 5010 Fountainblue Drive, Bismarck, ND 58503; 701-425-7129; <http://www.dsaia.org/>; info@dsaia.org

Down Syndrome Education USA: USA-based, education; www.dseusa.org/

Global Down Syndrome Foundation: 3300 East First Ave, Suite 390, Denver, CO 80206; 303-321-6277; <http://www.globaldownsyndrome.org/about-down-syndrome/words-can-hurt/>; info@globaldownsyndrome.org

National Association for Down Syndrome: 1460 Renaissance Drive, Suite #405, Park Ridge, IL 60068; 630-325-9112; www.nads.org/; info@nads.org

National Down Syndrome Organizations: about four major national Down syndrome organizations; www.globaldownsyndrome.org

National Down Syndrome Congress: information, advocacy, public policy leadership, encourages research, annual conference. 30 Mansell Court, Suite 108, Roswell, GA 30076; <http://www.ndscenter.org/>; 800-232-NDSC (6372) or 770-604-9500; Fax: 770-604-9898; info@ndscenter.org

National Down Syndrome Society: information, National Policy Center works with U.S. Congress and federal agencies on equal, public awareness campaign in My Great Story, The National Buddy Walk Program, 666 Broadway, NY, NY 10012, 800-221-4602; <http://www.ndss.org/>; info@ndss.org

For People with Intellectual and Developmental Disabilities (IDD)

American Academy of Developmental Medicine and Dentistry (AADMD): information for healthcare professionals who provide clinical care; AADMD, PO Box 681, Prospect, KY 40059; <https://aadmd.org/>

Commission on Accreditation of Rehabilitation Facilities (CARF): accredits more than 50,000 programs and services at 23,000 locations. International. 888-281-6531; <http://www.carf.org/home/>

National Task Group on Intellectual Disabilities and Dementia Practices (NTG): provides advocacy, education and training, and informational materials related to people with IDD affected by Alzheimer's disease and related dementias; www.aadmd.org/ntg.

Florida Resources: Florida Department of Elder Affairs (DOEA)

Florida Elder Helpline (Florida Department of Elder Affairs - Elder Helpline): 800-963-5337; elderaffairs.state.fl.us/doesa/elder_helpline.php

Florida DOEA ADI (Department of Elder Affairs, Alzheimer's Disease Initiative): 850- 414-2000, www.elderaffairs.state.fl.us/

International Web Sites on Down Syndrome

Down Syndrome Education International: United Kingdom based: education; www.dseinternational.org/

International Down Syndrome Coalition (IDSC): free, accurate information about informed consent regarding pregnancy-related screenings and diagnostic tests; 901-413-2047; idsc.information@gmail.com; www.theidsc.org

International Down Syndrome Organizations: <https://www.ds-int.org/organizations/down-syndrome-association>

Suggested Readings

Moran, Julie. (2013). *National Down Syndrome Society. Aging and Down Syndrome: A Health and Well-Being. Guidebook*. NY, NY. 800-221-4602 · www.ndss.org.
<http://www.ndss.org/PageFiles/2594/Aging%20and%20Down%20Syndrome%20A%20Health%20and%20Well-Being%20Guidebook.pdf>

CARF (Commission on Accreditation of Rehabilitation Facilities) International. *2014 Aging Services Standards Manual*. **CARF** International is an independent, nonprofit accreditor of health and human services. Tucson, AZ, Toll Free: (888) 281-6531; TTY: (520) 495-7077; www.carf.org

Doty, L. (Ed.) (2012). *The Alzheimer's Disease Initiative Education Manual: Understanding & Dealing with Alzheimer's Disease & Related Disorders*. (17 Chapters). FL Dept. of Elder Affairs 24/7, free access at: elderaffairs.state.fl.us/doea/docs/adi_manual_2012_final.pdf

Healthcare Guidelines Record Sheet in English, courtesy of Anna and John J. Sie Center for Down Syndrome (PDF)

Healthcare Guidelines Record Sheet in Spanish, courtesy of Anna and John J. Sie Center for Down Syndrome (PDF)

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- Chapter 3: A Full Medical Exam
 - Chapter 7" Alzheimer's Disease Overview
 - Chapter 8; Comparing Alzheimer's Disease, Cardiovascular Dementia, & Lewy Body Dementia
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25. Seth M. Keller, MD; Neurologist at Advocare Neurology of South Jersey, Lumberton, NJ
26. Thomas J. Buckley, EdD, Chair of Specialized Dementia Programs of the Agency for Persons with Disabilities & President of Lucanus Developmental Center, Hollywood, FL