

State of Connecticut
GENERAL ASSEMBLY



NEEDS OF PERSONS WITH INTELLECTUAL DISABILITY TASK FORCE

MEETING SUMMARY

December 4, 2019

Co-chairman of the task force, Mark Weinberg, convened the meeting.

Co-chairman of the task force, Orv Karan, stated that task force meetings will comprise of theme presentations and focus on one need at a time. Today's presentations will focus on seniors with intellectual disability who also have Alzheimer's and other dementia related disorders.

Mr. Karan added that in future meetings, he would like presentations about individuals with behavioral disorders in addition to medical fragilities. Additionally, he requested that members provide the task force with suggestions for future topics.

Stephani Shivers, MEd, OTR/L, CDP Chief Operating Officer of Community Services, LiveWell, presented:

Ms. Shivers elaborated on the history of LiveWell which was founded and known in 1990 as the Alzheimer's Resource Center. LiveWell provides education and advocacy to advance the wellbeing and inclusion of people as they age. Its Southington, CT campus houses 133 people living with dementia where memory and cognitive services are provided, support groups, and workshops.

Ms. Shivers explained that dementia is the general term used for conditions that deteriorate the brain, and Alzheimer's disease is the most common form of dementia. In America, every 67 seconds someone develops Alzheimer's, and 5.8 million people live with it making it the sixth leading cause of death with over 500,000 annual deaths. Individuals with down syndrome are particularly at risk with 30% developing Alzheimer's by age 40, and 50% by age 50.

Other forms of dementia include vascular dementia, frontotemporal degeneration, Parkinson's disease, Lewy body disease, Huntington's disease, Creutzfeldt-Jakob disease, and Korsakoff syndrome. While many conditions such as depression, medications, inflammation, cancer and tumors, can affect memory and cognition, it cannot be assumed that all changes are due to dementia. The dementia changes include those affecting memory, executive

function, visual spatial function, language, processing, muscle movement and sensory functions.

Executive function serves for planning, sequencing, problem solving, cognitive flexibility, abstract thinking, rule acquisition, initiation of action, self-control, emotional regulation, behavior initiation, moral reasoning and decision making. A change in this function causes organizational difficulties, future planning and initiation difficulties, inability to multitask, a lack of concern for others and unawareness or denial that such behavior is a problem, among other issues.

In addition to executive function, individuals with dementia also struggle with cognitive function. In order to provide appropriate care, a Functional Assessment Staging Test (FAST) is used to determine the stage of Alzheimer's in an individual. Stages include early Alzheimer's, Moderate Alzheimer's, and late Alzheimer's.

Care recommendations for individuals living with dementia in addition to intellectual disabilities include diagnosis, non-pharmacological interventions, medication management, palliative care and advance directives. Multiple resources for newly diagnosed individuals can be accessed through the Alzheimer's Association, the Association for Frontotemporal Degeneration, the Lewy Body Dementia Association, the National Institute on Aging, and the University of California San Francisco Memory Center.

Lynn McMunn, Ph.D., presented:

Dr. McMunn remarked on the mission statement of the National Task Group on Intellectual Disabilities and Dementia Practices (NTG). The NTG is charged with ensuring that the interests of the families and of adults with IDD who are also affected by dementia and Alzheimer's are taken into consideration when planning and addressing Alzheimer's disease. NTG activities include Early Detection Screening (EDS), practice guidelines for community supports, health practitioners, dementia care setting guidelines and many others. Training activities include workshops, webinars, meetings of professional groups and others.

Dr. McMunn conveyed that dementia and Alzheimer's diagnoses can only be confirmed during an autopsy upon death. Consequently, it is especially difficult to differentiate symptoms in individuals with developmental disabilities (IDD) and dementia because screening tools may not always articulate which symptoms are due to IDD or dementia. Dr. McMunn added that medications for IDD may have paradoxical effects because they metabolize them differently. As such, it is of utmost importance that a prescriber begins with the lowest dosage. There are also medications that work on other individuals that do not have any effects on an individual with developmental disabilities. Additionally, medications may work today but not tomorrow so it's important to always be aware of a patient's behavior so that medications may be altered appropriately.

Trauma may also play a role in Alzheimer's. As an individual progresses through dementia, it is possible that they may remember traumatic events in their lives while forgetting other events. Consequently, this individual may be reliving this traumatic event over and over. Additionally, the caretakers may not always be aware of traumatic events in a patient's life because the medical history is limited and therefore when the patient becomes aggressive, possibly due to their reliving of this event, the caretaker may not know the reason.

Dr. McMunn emphasized that it is a common misconception that dementia is a normal part of aging. She remarked on a personal experience with a patient who was diagnosed with dementia by her primary care provider of 10 years. During the intake of the patient's medical history, the patient showed a keen memory and understanding of her life, including the ability for future planning. Dr. McMunn and the nurse accompanying her during the intake of the patient's medical history believed that the patient was incorrectly diagnosed with dementia. The unfounded diagnosis resulted in the patient's family getting Do Not Resuscitate (DNR) and Do Not Intubate (DNI) status for the patient. After much background work into her medical history, it was found that the patient had thyroid cancer. A poor functioning thyroid can mimic many signs and symptoms of dementia. Dr. McMunn, with the assistance of Dr. Karens, took the patient off one of the dementia medications and also took away the dementia diagnosis which as a result invalidated the DNR and DNI orders.

Dementia is most prevalent in the IDD community in individuals with down syndrome. Statistics show that in IDD, 3% of individuals over age 40 also have dementia, and 6% over age 60 have dementia. In individuals with down syndrome, 22% over age 40 have dementia and 56% over age 60 have dementia.

Medical school does not provide training in caring for individuals with developmental disabilities, and unless you specialize in geriatrics, they do not provide training in caring for the aging population either. As such, it is important that IDD and the general population with dementia have health advocates. This is important because of ageism, diagnostic overshadowing, and because they are not able to advocate for themselves. Diagnostic overshadowing is noteworthy because medical providers may overlook underlying causes in behavioral changes and incorrectly diagnose it as dementia.

Jill Hall, R.D., B.S.M., presented:

Ms. Hall emphasized the importance of the charge of the task force. She noted that she is here to speak about expanding the scope of Department of Developmental Services (DDS) so that their services include those for the most behaviorally complex clients. She stated that there have been mistakes made in the past, and programs have been closed instead of fixing the problems that led to the closure. This results in the underutilization of precious resources.

Ms. Hall remarked on her personal story as a caretaker for her son who is part of the IDD community. She stated that even though her son lives in a group home, DDS must address the severe lack of residential and day living for the IDD community. Her family faced many challenges in finding an appropriate living situation for her son. Still, while the living situation is appropriate, it is still not a good fit for her son because he wants to be in an active living situation and the group home does not provide activities. Ms. Hall reiterated and emphasized that DDS must address the needs of the community they serve.

Lois Nitche, Parent Advocate, presented:

Ms. Nitche began her presentation by stating that first and foremost she is a mother. She is a mother who has taken care of a disabled individual for 55 years and while she may lack medical credentials, she has learned a lot during these years as a caretaker. Ms. Nitche remarked on the lifelong struggles she has faced in caring for her son, going as far back as doctors not believing that her son had any developmental issues and referring to Ms. Nitche as only a nervous mother. The struggles continued for many years. Her family went through

a multitude of different medications and different hospitals in an effort to care for her son. Although many struggles have not stopped, Ms. Nitché's son has been living in the same home for 33 years now, the Oakhill School for the Blind.

A member of the public, Rose Petruzi, was given the opportunity to speak to the task force. Ms. Petruzi expressed her appreciation for the task force's work and emphasized the importance of not distinguishing people by the differences into "us" and "them".

The next task force meeting is scheduled for Wednesday, January 8, 2020 in Room 1C of the LOB.