

NTG CAREGIVER NEWS

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NTG Caregiver News

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LEND YOUR VOICE

A Little History

Back in 2011, the NTG was formed as a coalition charged with ensuring that the interests of adults with intellectual and developmental disabilities (IDD) who were affected by Alzheimer's disease and related dementias (AD/ADRD), as well as their families and friends, were taken into account as part of the National Plan to Address Alzheimer's Disease. So what does that mean?

The National Alzheimer's Project Act (NAPA) was signed into legislation in early 2011 and was intended to help change the trajectory of Alzheimer's disease and related dementias. The NAPA required the development of a National Plan with annual updates. The Advisory Council on Research, Clinical Care and Long Term Supports and

Services (LTSS) was formed with 22 members, 11 from the federal government and 11 from the private sector. The Council was charged to provide input to the Department of HHS to improve the health outcomes of people with AD/ADRD and reduce the burden of these conditions on those with the diseases, their families, and society.

The NTG actively lobbied for the inclusion of people with IDD into the first National Plan and has continued to do so in all subsequent Plans.

Today in Washington

Every three months, when the Advisory Council meets in Washington, D.C., the NTG has a presence! We are there to remind the Council members that those with IDD should be considered when looking at all

aspects of the National Plan. There are many interesting care models across the USA that would benefit those with IDD. How can we better access them?

Despite our best efforts, there continues to be disparities in Research, Clinical Care and LTSS for those with IDD. So, we encourage you to submit a public statement. The next meeting is being held on July 28, 2017. You are encouraged to send comments for this and other upcoming meetings to Rohini.Khillan@hhs.gov. Our stories are real and powerful. Submitted comments are published on the [NAPA](http://www.aspe.hhs.gov) and [NTG](http://www.aadmd.org/ntg) websites (www.aspe.hhs.gov) (www.aadmd.org/ntg).

If you would like to attend a meeting and make a public statement contact Brenda.Veazey@hhs.gov.

For more detailed information type National Alzheimer's Project Act/ASPE into your server. It is a fascinating glimpse at our government at work!

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Advocacy Tips

- Explain why you care
- Keep it simple
- Focus on one topic
- Don't complain
- Keep it short
- Add data and facts if you have them
- Be polite
- Keep it honest
- Add a photo



OH MY GOODNESS... DID YOU KNOW?



As our loved ones with an intellectual disability age, we start noticing changes that may be of concern. We watch and wait...and there are more changes. Perhaps, our loved one got lost in the neighborhood where he grew up. Perhaps she just seems tired all the time. Could it be that it is just part of aging—or is it something more?

It's time to put on our detective hats; we need to discover what is going on. It is important that we be strong health advocates for our loved ones because they often can't tell us what they are experiencing. We know that Alzheimer's is a big risk for our loved ones with Down syndrome but we shouldn't jump on that train right away. There are many conditions that can look like dementia but are reversible with appropriate treatment. We must *leave no stone unturned*. We call this investigative work Differential Diagnosis.

One gentleman we know has been showing some signs of possible Alzheimer's. He recently had a 24-hour EEG (electroencephalogram) that showed frequent small seizures when he was awake and asleep. When his mother asked questions of his neurologist, the answers she got didn't seem to fit with his history. The more she asked, the more confused she became. She made a call to an out-of-state friend

who is a neurologist with lots of experience with Down syndrome and Alzheimer's. After informing the doctor of her son's history with seizures, recent events and what the report seemed to be saying, he recommended that her son be seen by an *epileptologist*.

Did You Know that an *epileptologist* is a neurologist who specializes in the evaluation and care of individuals who have had a seizure or who have had a number of seizures? The occurrence of multiple seizures is known as a seizure disorder or epilepsy. All neurologists are trained in being able to treat those with seizures; however, they also may treat a number of other neurologic complications including migraines, multiple sclerosis, strokes, Parkinson's, Alzheimer's and other conditions. An *epileptologist* only treats those with seizures and therefore has further education and training in this area. As a result he or she has more experience in caring for those individuals who might have more challenging and complicated seizure issues. Most *epileptologist* are associated with a University Hospital and teaching center, where procedures such as EEG overnight, EEG monitoring and even brain surgery for severe seizure disorders can be performed.

WISE AS AN OWL

As our loved ones with intellectual and developmental disabilities age, it is important for us to be advocates with and for them. We may need to advocate for medical reasons as well as for additional or improved services. To be the most effective advocates we can, sometimes we need more information.

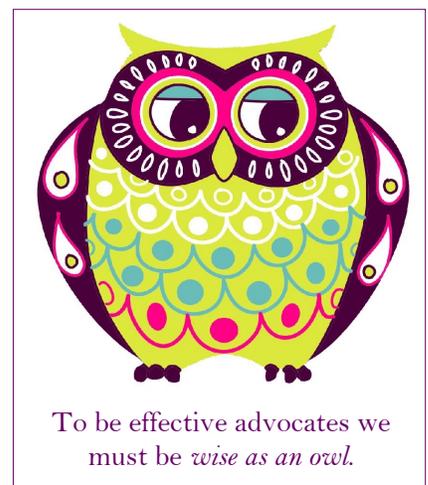
In this highly technological world, it is easy to do an internet search for answers. However, that can be a scary place at times. Reading about all the things that can go wrong can send us down rabbit holes we don't need to travel through.

However, we can access training that

is specifically focused on the needs of our loved ones. The NTG frequently has opportunities to learn more about providing supports and dementia capable services. Many family members have already participated in these workshops and found valuable information they could use immediately.

The [NTG website](#) lists workshops that are offered and a schedule of upcoming locations.

Workshops include "*Capacity Building*," and "*Dementia Capable Care*." In addition, the NTG has a webinar series that are two-hour lectures on one or more aspects of dementia and adults with intellectual disabilities.



To be effective advocates we must be *wise as an owl*.

If you would like to have the NTG or one of the Affiliated Trainers conduct a workshop in your area, contact Dr. Kathie Bishop at bisbur1@earthlink.net

FAMILIES HAVE ASKED ABOUT: VALIDATION THERAPY

Validation Therapy...that sounds like something interesting, doesn't it? We all know how good it feels to be validated! It's no different for our loved ones with intellectual disabilities and dementia.

Validation Therapy was developed in the 1960s as a holistic and empathetic approach to caring for elderly, disoriented patients. If you are a Facebook user, you have probably seen the video in which Naomi Feil, the therapist who created this method, reaches an elderly woman (Gladys Wilson) who sings and speaks after being silent for a very long time. The video demonstrates how Naomi goes into the place where Gladys is—in her mind. She shows empathy and explores what Gladys might be feeling, as evidenced by a tear running down her cheek.

Validation Therapy is a methodology that recognizes the uniqueness of every person. Although most writing on Validation Therapy is about its use with the elderly who have become disoriented, it is a tool that can be utilized with our loved ones, as well.

The belief that all people are unique and should be treated as individuals is the same principle that drives a person-centered approach to services for people with developmental disabilities. Many of us are already familiar with that basic tenet of Validation Therapy.

Validation Therapy looks at each person and supports them in a non-judgmental way. It recognizes that behaviors are communication, and what the person is doing is a clue to help us meet their basic human needs—to be loved, to be valued, and to be heard!

Our loved ones may communicate to us through repetitive motions, repeated vocalizations or other unusual behavior. Our first thought may be to attempt to stop or eliminate the behavior. Through Validation Therapy we can look at behaviors in a different way and enter our loved one's reality, with respect and dignity.

As family members, we know our loved one's history and can use that information to identify what he or she is attempting to communicate. For

example, if your loved one tells you that he needs to go home (and he is at home) you can ask him

some questions that will let him know you hear him. You could say, "Tell me about home. What did you like about that house? You lived there with your brother and sister, didn't you? Tell me what you used to do with your brother? Do you miss your brother? You love your brother a lot, don't you?" You can reassure him that his brother loves him and so do you. Give him a hug and tell him you will always be there for him.

In this example, your loved one is saying he wants to go home, but what he may be expressing is the need for love from his brother who he misses. You can acknowledge his need for love and affection with a hug and reassurance.

If you want to learn more about Validation Therapy check out the resources listed on the back page.



Thoughts on Validation Therapy

- Each person is treated as an individual with respect
- Behavior is a communication attempt to meet a basic human need
- Empathy builds trust and reduces stress
- Unusual behavior that is acknowledged may diminish
- The truth is always known, on some level
- Visual, auditory and kinesthetic memories can be very real
- Explore feelings without judgment and with empathy

*All humans
have basic needs—
To be loved
To be valued and
To be heard.*

We're on the web!
AADMD.org/NTG

NATIONAL TASK GROUP ON INTELLECTUAL DISABILITIES AND DEMENTIA PRACTICES

The NTG is affiliated with the American Academy of Developmental Medicine and Dentistry and the Rehabilitation Research and Training Center on Developmental Disabilities and Health at the University of Illinois at Chicago and other partners, such as the Center

on Excellence in Aging at the University at Albany and the Gerontology Division of the AAIDD (American Association on Intellectual and Developmental Disabilities). The NTG is a member of *LEAD* - "Leaders Engaged on Alzheimer's Disease," a Washington-based coalition working to focus attention on Alzheimer's disease and related disorders.

For more information about the NTG, please visit the website.

BE ON THE LOOKOUT...

The National Down Syndrome Society (NDSS) will release a new publication on Down syndrome and Alzheimer's disease by mid to late summer. This publication comes from a partnership involving the NDSS, the NTG and the Alzheimer's Association. The companion publication, *Aging and Down Syndrome: A Health and Well Being Guidebook*, is on the NDSS website under publications. It is a must read for every family and self-advocate! Print versions of this older publication will be available this summer. English, Spanish, Italian and Dutch translations are available electronically as well.



NTG FAMILY SUPPORT

The NTG recognizes the valuable role family members play in support of loved ones with intellectual disabilities. The article on page 1 of this issue tells about the work Mary Hogan, Matt Janicki and others do in Washington, D.C. to advocate for our families.

In May, 2016, the NTG began hosting monthly online support group meetings for family caregivers. Participants have shared their gratitude to connect with others who are having comparable experiences. We know that there are many more families who are seeking answers or someone to just listen to them, yet to be effective, we know the group must remain small.

We have learned a lot this past year, and we continue to learn every month. There has been tremendous interest in online support and we have been asked to assist others with starting similar groups in their communities. Over the next few months the NTG will assemble a small workgroup to develop a process to set up more groups around the country. *If you would like more information about the online support group contact Jadene Ransdell at the email address listed in the resource section below.*

AND FOR YOUR 2018 CALENDAR...

World Down Syndrome Day Conference is on **March 21, 2018**.

Sponsored by The United Nation permanent Missions of Australia, Brazil, Canada, India, Israel, Japan, Republic of Korea, Mongolia, Poland, Qatar, and the United Kingdom, along with UNICEF, International Disability Alliance and Inclusion International. Hosted by DSi (Down Syndrome international).

Plan ahead and spend an exciting day at the United Nations with families from across the globe.



RESOURCES

Validation Therapy—The Validation Training Institute, www.vfvalidation.org;

Video: *Gladys Wilson and Naomi Feil*

NTG Contacts:

For general information about the NTG

Seth Keller, Co-Chair: sethkeller@aol.com or Matt Janicki, Co-Chair: mjanicki@uic.edu

For information about *Family Advocacy*

Mary Hogan, Chairperson—Family Advocacy Workgroup: maryhogan@comcast.net

For information about *Family Caregiver Online Support Groups*

Jadene Ransdell, Family Caregiver Online Support Groups Facilitator: jadeneransdellaz@gmail.com

For information about *NTG Training*

Kathie Bishop, Co-Chair—Education and Training Workgroup: bisbur1@earthlink.net

GOT IDEAS?

If you have an idea for a newsletter article, would like to share information, or have questions about the newsletter, contact the editor of the NTG Caregiver News at ntgfamilysupport@uic.edu or ntgfamilysupport@uic.edu.

