

NTG CAREGIVER NEWS

Volume 1 Issue 3

NTG Caregiver News

July—August, 2017

NTG IN ACTION

The NTG volunteers are a busy group, working diligently to support individuals with intellectual disability and dementia, and their families. In addition to their ongoing advocacy efforts, several NTG members have participated in some exciting national and international activities in the past few months.

International Summit

In October 2016, the NTG co-sponsored an International summit on intellectual disability and dementia, which was held in Glasgow, Scotland. Its purpose was to discuss many issues related to dementia and people with intellectual disability, and then produce statements relevant to new findings and practices. Participants came from Europe and North America, and included representatives from several international and national dementia and intellectual disability organizations. The participants discussed (1) *Human rights and personal resources* (applications of the Convention for Rights of People with Disabilities and human rights to societal inclusion, perspectives of persons with intellectual disability), (2) *Personalized services and caregiver supports* (advancing and advanced dementia, post-diagnostic support community, dementia-capable care practice, end-of-life care practices, support for family caregivers), and (3) *Advocacy and public impact* (Nomenclature / terminology and the use of language, and inclusion of persons with Intellectual disability in national plans). Several reports have now been written from the Summit, including end-of-life and dementia, advanced dementia and terminal care, terminology and nomenclature, and inclusion in national plans. In process are reports on advanced dementia, families and caregivers, perspectives of adults with

intellectual disability, post-diagnostic supports, and a summary report. Completed reports can be read at <http://aadmd.org/ntg/collaborative-projects>.

AADMD Educational Conference

In June 2017, NTG members participated in the annual AADMD Educational Conference in Houston, Texas. The keynote and session speakers provided information to attendees that created lots of lively dialog and thoughts to carry us forward as we continue to advocate for and support people with intellectual disability and dementia.

On advocacy: “Advocacy is in your blood—your soul” Katie Beckett (for whom the first Home and Community Based Medicaid Waiver is named)

On strength: He had “no choice but to be brave and trusting.” George Will in a column written about his son Jonathon on his 40th birthday (Jonathon was born with Down syndrome)

On healthcare: “All forms of inequality in healthcare are also inhumane.” Rick Rader, MD, Director, Morton J. Kent Habilitation Center, Orange Grove Center, Chattanooga, TN; Editor, Exceptional Parent Magazine

On decision-making: “There are two kinds of decisions—the right decision and a lesson learned.” Joe Macbeth, Executive Director at the National Alliance for Direct Support Professionals

Every year, the NTG conducts sessions specifically focused on intellectual disability and dementia. Next year’s conference will be held in Seattle, Washington.



Inside this issue:

Did You Know?	2
Books & Documents on Our Radar	2
A Tribute to Siblings	3
The National Task Group	4
NTG Family Support	4
DS-Connect®	4
Resources	4

International Summit Comments

- The essence of each person remains throughout the progression of dementia.
- Inclusive and thoughtful planning for dementia must include people with intellectual disability.

OH MY GOODNESS... DID YOU KNOW?



There appears to be a connection between sleep and Alzheimer's disease. Researchers have been interested in this connections for several years.

It has long been known that people with Alzheimer's may have sleep disturbances that include waking more often and staying awake longer during sleep time. In addition, some people may have difficulty falling asleep (which could lead to wandering or other activities that can impact the sleep of their caregivers, as well). Those who have problems falling asleep may feel tired during the day resulting in napping.

The latest research is now raising a question of which comes first—sleep disturbance leading to Alzheimer's or very early Alzheimer's with symptoms of sleep issues. Some of the most recent studies have found that people who have pre-clinical Alzheimer's (the period where someone shows some subtle mental decline but before he meets the criteria for diagnosis with a mild cognitive impairment) had poorer quality of sleep than those without any symptoms of cognitive decline. Although they spent the same amount of time in bed, those with preclinical Alzheimer's spent less time sleeping and often napped more.

One thing that is known is that during sleep our brains clean out the buildup of Amyloid. If we have difficulty sleeping, we may not be experiencing that benefit and brain changes can occur.

Our take-away is to pay attention to the sleep patterns of your loved one with Alzheimer's—and your own sleep patterns. Be aware that people with Down syndrome have a high incidence of sleep apnea. If you notice there is sleep disturbance, discuss it with your PCP or Neurologist. A sleep study may be a good idea. Our brains need to rest so that our bodies can function most optimally.

For more information on this interesting topic check out the following articles:

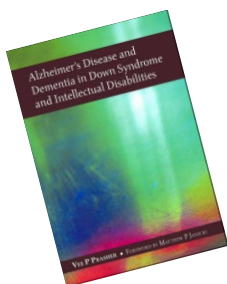
Alzheimer's Disease and Sleep, The National Sleep Foundation, <https://sleepfoundation.org/sleep-disorders-problems/alzheimers-disease-and-sleep>

Sleep Problems May Be Early Sign of Alzheimer's, Science Daily, <https://www.sciencedaily.com/releases/2017/07/170705164548.htm>

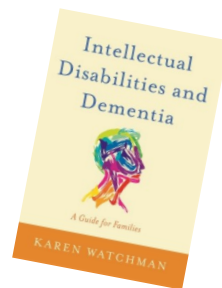


BOOKS & DOCUMENTS ON OUR RADAR

Intellectual Disabilities and Dementia, Karen Watchman, Jessica Kingsley Publishers, 2017 This understanding guide acknowledges and answers questions on the progression of dementia, medication, short-term and long-term care plans, and presents need-to-know information in an accessible way.

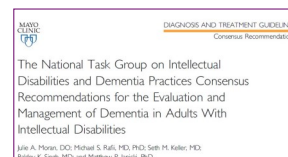


Alzheimer's Disease and Dementia in Down Syndrome and Intellectual Disabilities, Vee P. Prasher, Radcliffe Publishing, 2005 This book was written for professionals and caregivers to increase their understanding of Alzheimer's disease and other forms of dementia. It relates research to clinical practice and shows how early diagnosis, appropriate treatment and compassionate care can be used effectively to maintain dignity and quality of life.



The National Task Group on Intellectual Disabilities and Dementia Practices Consensus Recommendations for the Evaluation and Management of Dementia in Adults With Intellectual Disabilities Specialists who work extensively with adults with Intellectual and Developmental Disability (I/DD) have developed recommendations for evaluating and managing dementia in adults with I/DD. This paper serves as a framework for practicing physicians who seek to practically, thoughtfully, and comprehensively approach concerns related to aging and suspected cognitive decline or dementia. Families and other caregivers may also find this resource a helpful tool in their role of informed healthcare advocates. The document can be found at:

[http://www.mayoclinicproceedings.org/article/S0025-6196\(13\)00371-6/pdf](http://www.mayoclinicproceedings.org/article/S0025-6196(13)00371-6/pdf)



A TRIBUTE TO SIBLINGS

Jadene S. Ransdell

As a volunteer with the NTG, I have had many wonderful opportunities presented to me over the past couple of years. I believe the best part of the work I get to do is meeting other families who are sharing this path on aging with a loved one who has an intellectual disability and has or is suspected of having dementia.

I have not been surprised at the number of siblings I've met who are helping a parent or are totally responsible for their brother or sister. Every month, I share with many people how incredibly loving, loyal and caring the siblings I know are. Many of you give priority to the care of your brothers and sisters. As a mother, I take great comfort in witnessing the love you all have and I know that your siblings feel that special connection between you.

I would like to take this time to say thank you to all the siblings who are part of this journey. In 1991 I wrote about my older son's influence on raising my son with Down syndrome. I would like to share it again.

When he was born I knew he was the most beautiful infant in the universe. Gazing at me in wide-eyed wonder, he looked so perfect; I knew he was destined to do great things. Michael was special.

Indeed he was a special child. Oh, not because he had some typed of disability or because he was my baby, but because of the way he would live his life.

His earliest years were typical of most little ones, filled with love and admiration from mom and dad and all the relatives. We swelled with pride at each new first. And then one day, just before he was two and a half years old, his world was put into a different tilt. He became the older brother—the "other" child.

It came as a shock to us when we were told that Michael's brother had Down syndrome. I have learned a lot about the world of disability over the years. I have come to view Matthew as a great teacher of life. Some of my most valuable lessons, however, have come from Michael. He has been the quiet hero in my life, sneaking my education in while I didn't realize I was being taught.

Michael has helped me maintain balance—reminding me not to live my life wrapped up in disability. He has kept me smiling and laughing, always best at helping me laugh at myself. He has taught me humility and acceptance of my own weak-

nesses and mistakes. Most of all he has taught me to see his brother through different eyes. Michael never saw a baby with Down syndrome—he only saw a little brother. He was the first in our family to see beyond the disability. He has taught me that each of us has a role in the family. He has modeled "acceptance" to his peers and shown me the way of life as a typical kids—at the same time giving me a barometer for Matthew's life.

Michael has begun a life of his own, having just recently left home. I have never been so keenly aware as I am now of the positive influence siblings of children with disabilities can have on the quality of life in a family. I am so proud of the contribution.

To Michael and all the siblings in our families—"Thanks for all you do!"

This is the first, in an occasional series by guest authors. If you would like to share a short article that you have written please contact us for more information at the email below:

ntgfamilyadvocate@gmail.com

Sibling

RELATIONSHIPS

outlast marriages, survive
the death of parents,
resurface after quarrels that
would sink any friendship.

They flourish in a thousand
incarnations of

closeness and distance, warmth,
loyalty and distrust.

Erica E. Goode

RESOURCES FOR SIBLINGS

The [Sibling Leadership Network](#) provides siblings of individuals with disabilities the information, support and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families.

The [Sibling Support Project](#) is the first national program dedicated to the life-long and ever-changing concerns of millions of brothers and sisters of people with special health, developmental, and mental health concerns.

[Sibnet](#) the Internet's oldest and biggest online community just for adult brothers and sisters. It is a remarkably caring and thoughtful community that will welcome you regardless of how you are feeling about your sib and your family today!

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.

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.*



DS-CONNECT®: THE DOWN SYNDROME REGISTRY

In early 2006, the Director of the National Institutes of Health (NIH) asked the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) to lead the formation of a Down Syndrome Working Group that would include scientists from across the NIH. The Working Group was charged with coordinating ongoing research already supported by the NIH related to Down syndrome, and to enhance new, NIH-supported research efforts.

After several years of working with scientific and family communities to achieve the various goals of the plan, the NIH created the Down Syndrome Consortium to foster communication and idea-sharing among NIH, individuals with Down syndrome and their families, national organizations interested in Down syndrome, pediatric and other groups. One of its first activities was to create a Down syndrome registry, now called DS-Connect®: The Down Syndrome Registry.

The registry is a voluntary, confidential, online survey that collects basic health information about people with Down syndrome. Through the registry you can print out a summary of your loved one's health history, find healthcare providers and help improve the care of people with Down syndrome. In addition, through the registry, participants can learn about new studies for people with Down syndrome. For more information about the registry go to <https://dsconnect.nih.gov>.

RESOURCES

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, Online Support Groups Facilitator: jadeneransdellalz@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 ntgfamlyadvocate@gmail.com.

