



NATIONAL TASK GROUP ON INTELLECTUAL DISABILITIES AND DEMENTIA PRACTICES

CAREGIVER NEWS

A Message from the Co-Editor

Jadene S. Ransdell

On behalf of the National Task Group on Intellectual Disabilities and Dementia Practices, I want to apologize for the break in delivery of the Caregiver News. Due to some personal issues earlier this year, it was necessary for me to take some time off.

Although publication was interrupted, the newsletter was never far from my mind. With the support of the NTG Steering Committee we have made some changes that we believe will make this newsletter even better.

As you already noticed, we have a new layout, but that is just the beginning. We have added Rachel Grimm from the National Down Syndrome Society as a co-editor, and she has already proven to be a wonderful addition.



Rachel Grimm

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"In the USA, an estimated 9,000+ adults with intellectual disability may be affected by Alzheimer's or other dementia and this number is expected to triple in the next 20 years."

The NTG Education and Training Curriculum on Dementia and Intellectual & Developmental Disabilities

**NDSS Adult Summit
May 7—9, 2020
Scottsdale, Arizona**



See page 3 for information

"Worry never robs tomorrow of its sorrow, it only robs today of its joy."

*Leo Buscaglia,
author, professor,
motivational speaker*

Dementia and Intellectual/Developmental Disability

With the passage of the National Alzheimer's Project Act (NAPA) in 2011, the federal government was directed to develop a national plan to deal with Alzheimer's disease in the United States. Since then, members of the NTG have attended nearly every quarterly public meeting of the NAPA Advisory Council. Although people with Down syndrome are at a very high risk to develop Alzheimer's there was little discussion about this population.

Several national groups began receiving myriad requests for specific information about providing quality care for people with an intellectual disability who are affected by dementia. As a result, the National Task Group on Intellectual Disability and Dementia Practices (NTG) was created by the American Academy of Developmental Medicine and Dentistry, the Rehabilitation Research and Training Center on Aging with Developmental Disabilities—Lifespan Health and Function at the University of Illinois at Chicago, and the American Association on Intellectual and Developmental Disabilities.

Through the collective efforts of many of its members, the NTG adopted a set of guidelines to help families and organizations plan for the extended care needed with a diagnosis of dementia. According to the *Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia*, the goal of the document was to update and add to the methods agencies use to deliver supports and services to adults with intellectual disability (ID) and dementia.

The document includes care guidelines from the pre-diagnostic stage through the end-stage of dementia, with a recognition that a proactive approach to planning would best serve those with intellectual disability and dementia. Such an approach "requires preparation, strategic planning, redesign, and integration of services... (and) includes support to families and other direct caregivers."



Families and direct caregivers around the country still struggle to find quality services when the person for whom they provide care receives a diagnosis of dementia. In many communities it is difficult and sometimes impossible to find healthcare providers who understand the changing needs of adults aging with Down syndrome or other intellectual disability. Direct caregivers may not receive the training they need to successfully support a person with ID and dementia, yet, as found in the *Guidelines*, "support from programs with staff trained in aging and dementia care is a critical aspect of the system."

The *Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia* contains many practical steps that can be taken to provide services that best support people with ID and dementia. You can find a copy of the *Guidelines* on the NTG website through this link: <http://aadmd.org/sites/default/files/NTG-communitycareguidelines-Final.pdf>.

If you are a family member or a direct caregiver feeling frustrated, please do not despair. Change begins with a first step, a simple action.

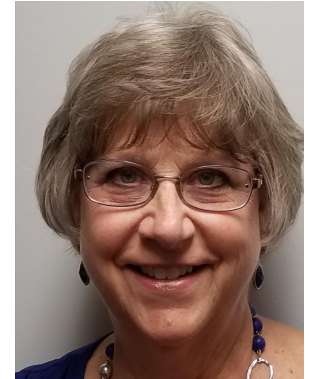
- Talk with other families and caregivers in your community.
- Join an NTG Family Support Group.
- Reach out to your state Developmental Disabilities Council and other statewide advocacy organizations.
- Attend the meetings of the Alzheimer's committee in your state (and share your concerns with us so we can take them to the NAPA Advisory Council meetings on your behalf).
- Connect with provider agencies and healthcare providers to establish local aging coalitions focused on the support needs of individuals with ID and dementia.

ONE MOM MAKING A DIFFERENCE

Jadene S. Ransdell

In the last issue of this newsletter, we highlighted three members of the NTG who had received national honors for the work they are doing. I recently had an opportunity to catch up with Janet Miller, the recipient of the 2019 Spirit of the NTG award. Janet's daughter, Jennifer had Down syndrome and passed away from complications of Alzheimer's disease in November 2018.

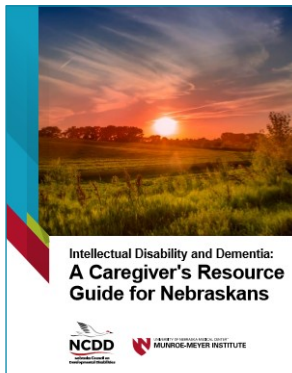
As sometimes happens to parents of children with disabilities, Janet has long been a strong advocate for Jennifer and others with developmental disabilities in Nebraska. She explained to me, "I was a pioneer in the Parent to Parent (Pilot Parent) movement in the early 80s. And when Jennifer wanted a job in the community, I began supported employment programs for people with disabilities in Nebraska. As a parent when I saw a need, I found a way to address it. It's just what parents do."



Janet Miller

Janet and her husband, Tom, became concerned about changes they were seeing in Jennifer which prompted her to complete a certification in Gerontology with a focus on aging in intellectual disability (ID). She recognized that there was work to be done in support of an aging ID population. She learned about the NTG and the dementia capable care training in 2017 and attended the session offered in Houston, Texas in June of that year. Since then, Janet has been instrumental in bringing the NTG three-day training to Nebraska on three occasions, working with the Alzheimer's Association and the Nebraska Developmental Disabilities Council. Janet works part time at the Munroe-Meyer Institute/University of Nebraska Medical Center and is working now to create aging coalitions with direct support provider agencies and adults with developmental disability. In addition, she has invited Dr. Lucy Esralew to do a webinar on the NTG Early Detection Screen for Dementia (EDSD) later this month.

Janet managed a project to adapt the NTG's Caregiver Guide specifically for use in Nebraska. The new publication, *Intellectual Disability and Dementia: A Caregiver's Resource Guide for Nebraskans* is now available and covers everything you need to know about dementia and intellectual disability. It also provides helpful resources and links to services within Nebraska. An on-line copy for printing is available through this link: <https://www.unmc.edu/mmi/community-resources/lifespan-resources/adult-NE-caregiver-resource-guide.pdf>.



In her quest to provide support to families, Janet has created a Facebook group for caregivers of individuals with developmental disabilities in Nebraska. In addition, Janet works with the Down Syndrome Alliance of the Midlands to provide bi-monthly educational programs for caregivers. When we spoke, Janet talked of one of her concerns — one I've heard from others around the country. "It's been difficult locating caregivers of aging adults with intellectual disability. I have just recently reached out to direct support agencies across Nebraska in a further attempt to find them."

If you would like to learn more about the work Janet does or participate in caregiver activities in Nebraska, contact her at janet.miller@unmc.edu. To join the Nebraska caregiver group on Facebook, request membership through this link: <https://www.facebook.com/groups/654238328376047/>.

Janet is one person who is making a difference. She is a great example of what we can do to improve the lives of people aging with intellectual disability. Not everyone is going to accomplish all that Janet has in the past few years, yet each of us can do something. It can be as simple as joining a group of caregivers. Even that is a big step forward in getting better services and better outcomes for people with intellectual and developmental disability and dementia in our local communities and our states.

A Message from the Co-Editor

(Continued from page 1)

Rachel and I have spent time discussing the newsletter content and delivery schedule. As we considered making some changes, we chose to make this a quarterly publication in order to provide a quality of product that our readers deserve. Beginning with this issue, *The Caregiver News* will be sent to those who have provided us with their email addresses and will be available on the NTG and NDSS websites on the 21st of December, March, June and September. Our delivery just happens to coincide with the change of seasons—a happy coincidence, for sure.

Each issue will focus on a specific topic and we will be soliciting articles from our readers (that's you) - family members, professionals in the field and others. The themes will be announced on an annual basis to provide plenty of time to submit articles. See page seven for information about submitting articles for consideration and the schedule of topics for the upcoming year.

NEW SECTION ANNOUNCED BY THE AMERICAN ACADEMY OF NEUROLOGY



The American Academy of Neurology (AAN) has announced the creation of a new Section within its organization, titled "*Adults with Intellectual and Developmental Disabilities.*"

A Section is a group within the AAN focused on a specific sub-specialty in Neurology such as epilepsy, women's health, child neurology, genetics, and more. A Section can help to advance education, training and awareness of a particular disease or condition.

According to Dr. Seth Keller, the founding father of this Section, "The new Special Interest Group will help the AAN bring attention to the neurologic needs of adults with I/DD."

The first gathering of the group was held earlier this year during the annual AAN meeting in Philadelphia.

Dr. Keller stated, "The initial focus of this Section will be to bring an awareness to all neurologists across the US, as well as around the world, that people with I/DD matter and their neurologic concerns should be taken seriously. They are people too!"

Dr. Keller told us, "Creation of specific care guidelines will be developed on epilepsy in adults with I/DD, as well as on aging and dementia. The success of this Section will depend on a team effort with support from advocates and from state and federal I/DD and aging sectors. The Adult I/DD Section will be partnering with the Child Neurology Foundation (CNF) on the issues and concerns of transitioning from pediatric to adult neurologic care."

The next meeting of the AAN will be in Toronto, Canada in April 2020.



Seth Keller, MD

Dr. Seth M. Keller is a neurologist in private practice and the Chair of the American Academy of Neurology's Special Interest Group on Adults with Intellectual and Developmental Disabilities. He is also the co-chair of the National Task Group on Intellectual Disabilities and Dementia Practices and the Past-President of the American Academy of Developmental Medicine and Dentistry.

STILL THE SAME PERSON INSIDE

We are all aware of the high turnover in care providers for people with disabilities. One mom we spoke with recently told us that her son was assigned a new physician at every check-up with his primary care provider. Because he is unable to communicate with words, she repeatedly “had to tell the same story that included the loss of some skills. And he gets upset when I talk about things he can’t do.” She also told us that her son had several changes in direct care staff after years with the same caregiver. “The people who are with him now seem to care about him, but they don’t know who he was just a few years ago. They don’t know how much he loves his nephews or what he loved to do,” she said.

The high turnover in direct caregiving can result in a loss of knowledge of what is important to the individual with ID and dementia. It is important to remember that everyone has a history filled with a rich tapestry of events that make them who they are. Maintaining focus on the individual is important in the provision of supports and services. *Alzheimer’s Disease & Down Syndrome: A Practical Guidebook for Caregivers*, recently published by the National Down Syndrome Society in partnership with the NTG and the Alzheimer’s Association, conveys the importance of person-centered care.

Key to providing person-centered care is knowledge of the person’s life story. Best practice will consider various aspects of the person including their life history (information about their family, where they grew up, went to school, worked and what they liked to do for fun). Knowing about the culture in which they were raised will be important, as well as understanding their unique personality traits. It’s important to know about the skills the person developed throughout their lifetime in order to know what he or she might still be capable of doing.

Additionally, knowledge of relationships that are important to the person will be beneficial to offering quality supports and services. Knowing who the person has an emotional connection to, and making serious attempts to nurture those connections can go a long way to create caring supports.

It is important to remember that as dementia progresses, the person who has an intellectual disability and dementia will forever be the person they were before the disease was diagnosed. From the *Guidebook*, “...the person being cared for is still the same unique individual, still continuing on their own evolving and meaningful life story. Through the ebb and flow of the disease, the person’s essence remains, whether it’s felt directly or kept alive in the memory of those that love and care for him or her.”

Person-Centered Principles Include the Following:

- To be acknowledged as a person with a unique life story.
- To feel loved and safe, while being treated with respect and dignity.
- To be valued and included in his/her community throughout life.
- To be self-directed in choice and decision-making to the greatest extent, whenever possible.
- To be involved in meaningful activity, to feel useful and a sense of belonging.
- To be provided comfort, care and support with patience, compassion and empathy.
- To have care that is focused on what an individual *can* do and not what they can not.

Adapted from *Alzheimer’s Disease & Down Syndrome: A Practical Guidebook for Caregivers*, National Down Syndrome Society, Alzheimer’s Association, National Task Group on Intellectual Disabilities and Dementia Practices, 2019.

To access an electronic copy in English or Spanish go to:

<https://www.ndss.org/about-down-syndrome/publications/caregiver-guide-order-form/>

Planning Underway for the Third NDSS Adult Summit



Three years ago, it was merely a dream.

And now the National Down Syndrome Society is making plans for the third Adult Summit to be held in Scottsdale, Arizona on May 7 – 9, 2020. Rachel Grimm, NDSS Manager of Special Events and Conferences, recently told us, “The **2020 NDSS Adult Summit** is **open to all who play any role in the life of individuals who have Down syndrome or are within the I/DD community**, with a specific focus on caregivers, family members, professionals, and individuals with Down syndrome. We want to make sure that everyone understands that even though the Summit’s focus is adults with Down syndrome, *much of what is planned will be applicable to all adults who have an intellectual or developmental disability.*”



This third NDSS Adult Summit will cover important and critical topics for all adults with Down syndrome and I/DD. As in past Summits, speakers and topics will align with NDSS’ robust, comprehensive programs and pillars – including healthcare & research, inclusive education, community integration, economic self-sufficiency, aging-related health issues, employment and their **NDSS #DSWORKS® Campaign**. This year the Program

Selection Committee and the NDSS staff are encouraging speakers to create breakout sessions that are very interactive with the audience.

You won't want to miss this exciting event! If you have questions about the Summit, feel free to contact Rachel Grimm at rgrimm@ndss.org.



To learn more about the Adult Summit check out the NDSS web site at:

<https://www.ndss.org/engage/ndss-syndrome-adult-summit-2020/>

Register for the Third NDSS Adult Summit at:

<https://www.classy.org/event/2020-ndss-down-syndrome-adult-summit/e227991>



The 2020 Adult Summit is being held at a beautiful venue just a short distance from the Phoenix airport. In addition to the Summit activities, there is a lot to explore at this site. Check out the Phoenician Resort, located at 6000 E. Camelback Rd, Scottsdale, AZ 85251.

NDSS negotiated reduced rates for rooms at the hotel. Follow this link to access the Adult Summit prices. This is the only link that will give you the Summit negotiated rates.

<https://www.marriott.com/event-reservations/reservation-link.mi?id=1557351283460&key=GRP&app=resvlink>



Have a Story to Tell? We'd Like to Read It!

Are you a caregiver, relative, worker, or friend of a person with an intellectual disability and dementia? If you have a story you would like to share about your experiences with caregiving, seeking supports, consoling, volunteering, or any other activity, let us know. We are looking for stories that might illustrate or tell of the personal experiences of adults with intellectual disability affected by dementia and their caregivers.



We are also seeking stories about accessing services needed by people with an intellectual disability affected by dementia in your state or community. We want to know what are they like? Is there easy-to-access diagnostic help? Is there financial aid to help with caregiving? What state or local agencies are the most helpful? What problems are there in getting services? What are some of the successes? We want this newsletter to be filled with practical information that can be of help to anyone who is caregiving or supporting people with an intellectual or developmental disability and dementia.

We are now accepting stories for future issues of the *NTG Caregiver News*. So write up your story (between 500-1,000 words) and send it to us in a Microsoft Word document file (doc or .docx). If you want advice on a story, or just want to explore an idea, feel free contact us and we can discuss your concept with you. We can also work with you to fill in any blanks, help with some editing, and let you know when we might be able to use your story in one of our upcoming issues.

If you don't want to submit an article but would be willing to speak with one of our writers about some of your experiences, we would love to hear from you, too. Write to us at ntgfamilyadvocate@gmail.com. Include "NTG Caregiver News Submission" in the subject line of your email.

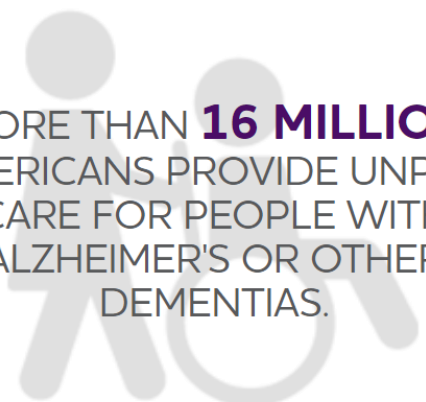
Below are the topics which will be the focus of upcoming newsletters. Although we are interested in receiving pieces on other subjects, additional consideration will be given to articles related to these topics.

NTG CAREGIVER NEWS FOCUSED TOPICS		
ISSUE	SUBJECT	SUBMISSION DEADLINE
December 2019	Caregivers	November 1, 2019
March 2020	Behavior Changes that Accompany Dementia	February 1, 2020
June 2020	Siblings	May 1, 2020
September 2020	Arts & Dementia	August 1, 2020

"Your heartache is someone else's hope.
 If you make it through, somebody else is going to make it through.
 Tell your story."

Kim McManus
 International speaker connecting those in need with solutions that work

Quick Facts



MORE THAN **16 MILLION** AMERICANS PROVIDE UNPAID CARE FOR PEOPLE WITH ALZHEIMER'S OR OTHER DEMENTIAS.

alzheimer's  association®



THESE CAREGIVERS PROVIDED AN ESTIMATED **18.5 BILLION** HOURS OF CARE VALUED AT NEARLY \$234 BILLION.

For more information about Alzheimer's facts and figures visit:

<https://alz.org/alzheimers-dementia/facts-figures>

**NTG
CONTACTS**

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

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