

# NTG CAREGIVER NEWS

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NTG Caregiver News

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## BARRIERS TO ACCESSING SERVICES

Mary Hogan

*Editor's Note: The following is the text of the presentation Mary Hogan prepared for the October 19, 2018 National Alzheimer's Project Act (NAPA) Advisory Council Meeting. Mary participated in a panel on **Heterogeneity and the Barriers to Accessing Services**. Mary used this text to guide her as she spoke, so it is not a word-for-word match of the actual presentation.*

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Good morning. Thank you for the opportunity to participate in the panel.

In the past 8 years I have come to know many families who are struggling to provide the best of care to their family member with Down syndrome, who has developed Alzheimer's Disease. They are aging mothers, fathers, sisters and brothers. I thank them for the help they gave me as I prepared for today's panel and for the photos of family members that they have shared. Collectively we offer you not just one story but offer our shared experiences.

Today people with Down syndrome, the most common chromosomal condition that results in an intellectual disability, have a life expectancy of approximately 60 years of age. Some even live into their 70's. They are at increased risk of developing Alzheimer's Disease at an earlier age than the general population due to the extra copy of



Chromosome 21, the chromosome that carries the APP (Amyloid Precursor Protein) gene. Estimates suggest that more than 50% of people with Down syndrome are expected to develop Alzheimer's Disease in their lifetime.

Most people with Down syndrome live with their families. Some live in congregate living and others live more independently in their communities. Wherever they reside, those of us with an aging family member with Down syndrome live in fear of this dreaded diagnosis.

People with intellectual disability, such as Down syndrome, often have complex health issues, have poorer health outcomes and a history of documented health care disparities. They also require more time and patience during a standard office visit. As health issues become even more complex, health care disparities become increasingly more evident.

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### AN IMPORTANT QUESTION

*How do we ensure that the work force is knowledgeable and will act in their (people with intellectual disability) behalf and support them as "people?"*

## ***Barriers to Accessing Services Continued***

Our family members cannot generally self-report the cognitive changes that they may be experiencing. They are dependent on those around them to note subtle and not so subtle changes that might suggest the presence of a brain disease process. Observation of progressive changes from a longstanding level of ability are critical to note and factor into the diagnostic process.

**What we need** is *access to trained empathetic healthcare providers who are knowledgeable about aging with Down syndrome and invested in the well being of our family members.*

**We need** *best efforts to reach an early, accurate diagnosis for our family member* for all the same reasons that are noted for the general population.

**We need** *providers who listen, problem-solve and offer insight into the disease process and how it may unfold.*

**We need** *resources and supports at the time of diagnosis.*

**We need** *healthcare providers who understand that this life limiting diagnosis is yet one more blow to individuals and caregivers who have faced many lifetime challenges.* So few understand the emotional toll that this added diagnosis takes.

### **So what happens to our families with a diagnosis and decline?**

The responsibility of care is most often assumed by emotionally invested, aging, lifetime caregivers who have been, and remain devoted advocates. Families are often left to their own devices.

In this day and age of “No Wrong Door” we often cannot find *any* door...leaving us with no support or resources.

We struggle to connect with other families making the same journey and are grateful when we are able to feel supported, share information, experiences and heart-break. We are often isolated with no support system in place.

With a diagnosis of Alzheimer’s Disease, our family members all too often “*become the diagnosis.*” Their behavioral manifestations are attributed to Alzheimer’s Disease with little regard to other co-occurring conditions. Efforts to understand behavioral communication can be marginalized. This results in frustration, escalation in behaviors, increased suffering, untreated conditions, and the overuse of psychotropic medications.

We worry about support services for our family member...services that will keep them engaged and safe while allowing them to live with dignity and experience a meaningful life. How do we ensure that the work force is knowledgeable and will act in their behalf and support them as “people?”

At times we are unable to move our family member because Medicaid funding in the intellectual disability community is not transportable and does not follow the person. A move to a new state where family caregiving opportunities might be more available often results in the loss of services...a Medicaid dilemma.

Respite care eludes us. So, we do not get an opportunity to step away and re-energize. We can be over-



whelmed by our day-to-day caregiving responsibilities. We struggle to find trained competent Respite Care providers who know how to engage with our family member. We spend down our family resources in order to maintain our family member at home.

We face the same agonizing struggle that other families in the general population experience with the realization that we may no longer be able to care for our family member at home. However, we may have fewer choices as some facilities are resistant to admitting our family member with Down syndrome or other intellectual disability and dementia.

When our family member lives in a group home, we are constantly engaged with direct support professionals to ensure that the needs of our family member are being met... this is a demanding role to play as many staff members are not trained in the unique needs of individuals with a progressive disease such as Alzheimer’s. The inconsistency of staff presence requires vigilance and almost constant training. By default, we often assume the role of trainer.

Our drive to maintain the best for our families cannot be underesti-

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## ***Barriers to Accessing Services Continued***

mated, yet the route to Long Term Services and Supports (LTSS) often remains out of reach. **What we need is access to the same supports and services that have been and are being created for the general population.** Our collective charge is to see that this materializes.

I leave you with my “take away” slide and a quote from my brother Bill. He advocated for himself in a moment in time when he felt like he was being disenfranchised and his personhood disregarded. How I wish that we were as articulate on his behalf in the days of his decline.

We urge you to acknowledge that ***all people need to be authentically at the heart of person-centered care*** and that we cannot perpetuate the myth that this is today’s reality. We believe that good dementia care is a right for all people. We must reflect on how we treat those with disabilities and dementia and act in their behalf. Your support and acknowledgement will be required to make this happen and bring about change.

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*Editor’s Note: At the Council meeting, Mary opened her statement with a message of inclusion...one of the purposes of the panel. She implored the Council members to look closely at the photos of the people in her first slide (page 1). Mary informed them that the parents of these individuals were pioneers 50 and 60 years ago, at the beginning of their sons’ and daughters’ lives, as they fought for inclusion of their children in their local communities and in their public schools. The sad part, she said, is that these same parents were, once again, forced to fight for inclusion at the end of their loved ones lives. Inclusion means to receive equality in care, and equality in supports and services. Our family members should have access to the same services as the general population diagnosed with Alzheimer’s or other dementias.*

***“I be a PERSON too.”***



- Person Centered Care assumes that you know and value the person and that you address what they need rather than require them to fit into what you have to offer
- An important part of Healthcare is the Caring
- The True Measure of Any Society Can Be Found in How They Treat Its most Vulnerable

## **NTG Research Project—A Step in the Right Direction**

The American Academy of Developmental Medicine and Dentistry (AADMD) and the National Task Group on Intellectual Disabilities and Dementia Practices (NTG), in partnership with the Department of Occupational Therapy at Thomas Jefferson University in Philadelphia, is developing a tool that hopefully will improve communication with healthcare providers and their patients. Most healthcare providers lack education and training in addressing age-related decline and dementia among adults with Intellectual Disability (ID). This can lead to poor care outcomes and reduced patient and family satisfaction.

Individuals with dementia and their caregivers are often not sure how to describe and document the various complex health, behavioral

and support issues that they are experiencing. Lack of precision and certainty in providing objective information can result in delivery of imprecise care and can impact the measurement of the effectiveness of treatment.

Through this two-year project, the *Serial Assessment of Function in Dementia* (SAFD), adapted from the NTG-Early Detection and Screen for Dementia (EDSD), will be used, following a diagnosis of dementia, to assess the functional decline in adults with ID. The SAFD can be completed by caregivers of adults with ID and dementia and then shared with their healthcare providers to assist in the care and management of their dementia over the course of this debilitating condition.

The prototype of the SAFD, once validated, has the potential to enhance the ability of community health care providers to more effectively evaluate treatment decisions and follow-up care, and improve health care outcomes to this underserved population. The *Evaluation of an Impact Assessment/Care Tool in Adults with Intellectual Disability and Dementia* project has been made possible by a major grant from the WITH Foundation (Working for Inclusive and Transformative Healthcare).

If you would like to know more about the SAFD or the research project, contact Principal Investigator, Seth Keller, MD, via email at [sethkeller@aol.com](mailto:sethkeller@aol.com).



## NDSS DOWN SYNDROME ADULT SUMMIT

Only five more months until we meet in Detroit. The program planning committee and NDSS staff had very difficult decisions to make, as they reviewed well over fifty workshop proposals. At this point, sessions have been selected and the staff are finalizing the program. It promises to be another exciting, informative and fun-filled event. Plan to join us in **Detroit, April 4-6, 2019**. If you haven't yet registered for the Summit be sure to do it soon. The registration page on the NDSS website can be found at: <https://www.classy.org/event/2019-ndss-adult-summit/e181498> The summit will be hosted at the **Detroit Marriott at the Renaissance Center**. Book your hotel through the link below to receive the exclusive discounted NDSS room rate. **This discounted room rate will be available until March 13, 2019.** <https://book.passkey.com/event/49730712/owner/437/home>



### Aging and Alzheimer's Sessions

The NTG is proud to be one of the partners who have joined with NDSS to bring a diverse program that has something for everyone. We worked hard to ensure that whenever there is a breakout session there will be a workshop related to aging issues or Alzheimer's disease. Although, at this time, the program is not final, the topics or sessions below were identified for inclusion:

- *Aging Well Together Panel, facilitated by Dr. Seth Keller*
- *Supports for People Aging with Down syndrome Panel, Down Syndrome Affiliates*
- *Introduction to Alzheimer's Disease and Pseudodementia*
- *Advanced Care Planning*
- *Behavior and Activity Planning with Dementia*
- *Home Safety & Alzheimer's*
- *Medications & Down syndrome*
- *Helping People with Down syndrome Understand Grief*
- *NIH Research—Down syndrome, Alzheimer's, INCLUDE Initiative*
- *Benefits of Family Leave for Caregivers*
- *Planning Ahead: Things to Know When Making Decisions About Dementia Care*
- *Creating and Facilitating Peer Support for Families and Caregivers*

### Exhibitor and Sponsor Opportunities

There are multiple opportunities to participate in the Adult Summit as an exhibitor or sponsor. NDSS anticipates that the Summit will be attended by more than 500 individuals. If you or someone you know would like to showcase an organization or program, please consider exhibiting at the Summit. And for even more exposure, sponsorships are also available. The links below will give you more information about both options. If you have any questions contact Collen Hatcher at [chatcher@ndss.org](mailto:chatcher@ndss.org) or 202.751.6013.

Exhibitors: [https://www.ndss.org/wp-content/uploads/2018/07/AS\\_2019\\_DSW\\_Sponsorships\\_v02.pdf](https://www.ndss.org/wp-content/uploads/2018/07/AS_2019_DSW_Sponsorships_v02.pdf)

Sponsors: [https://www.ndss.org/wp-content/uploads/2018/07/AS\\_2019\\_Sponsorships\\_v05.pdf](https://www.ndss.org/wp-content/uploads/2018/07/AS_2019_Sponsorships_v05.pdf)

## STORY COLLECTION on Guardianship/Conservatorship and People with Intellectual and Developmental Disabilities

Quality Trust for Individuals with Disabilities, the Arc of the United States, and the Autistic Self Advocacy Network are gathering stories about the impact of adult guardianship/conservatorship and alternatives on people with intellectual and developmental disabilities (ID/DD). The stories will be used in a report to be issued by the National Council on Disability. They are interested in hearing the perspectives of people with ID/DD, family members, lawyers, special education advocates, staff who provide transition services to youth with ID/DD, guardians, conservators, and other stakeholders. The questionnaire may take about 20 minutes to complete. <https://fs16.formsite.com/u024508129ncearc/form304/index.html>

## AN EDITORIAL COMMENT

By Jadene S. Ransdell

As I write this newsletter, I am struggling. I am proud to be a Family Advocate, and I have a long history of advocacy because of this fellow who chose me to be his Mom more than 44 years ago. I came out of retirement when I saw a need, and I now love being a champion for people with Down syndrome and Alzheimer's, and their families.

It's because of Matt, that I'm struggling with my emotions. As the author of this newsletter, I try to bring our readers information that is helpful, timely and accurate. I do extensive research and I talk with many people to develop each of the articles. Typically, this is a relatively easy and enjoyable task for me. However, as I write this edition, I have grown increasingly troubled.

In preparation for sharing resources I learned about at the October NAPA Advisory Council meeting, I looked to see what references were made to Down syndrome. I found nothing. I Googled several terms to try to find Down syndrome included in general writings about Alzheimer's. I found only a few. I remembered listening to presentations at the Advisory Council meeting about innovative pilot programs around the country and the healthy brain initiative—neither of which included people with Intellectual Disability or Down syndrome. That's when I felt anger creeping into my heart. After all, people with Down syndrome are an identified special population that has the highest risk to develop Alzheimer's disease. Yet our loved ones are ignored, over-looked and left out of most Alzheimer's research and pilot projects.

This is a disturbing pattern and we need to make a dedicated effort to bring about change. After seven years of advocating to for inclusion of Intellectual Disability and Down syndrome at the NAPA Advisory Council table, we were finally given an opportunity to present our perspective as part of a heterogeneity panel. It is my hope, and the hope of other advocates, that our presence on the panel is the beginning of a continuing and much needed dialog.

Those of you who are parents, like I am, probably feel the strain of a lifetime of providing loving care and support to your sons and daughters. As parents, and even as siblings, there have probably been an endless number of fights just to provide the services and supports your family members need and deserve. The opportunity to communicate with many families whose loved one is now aging with Down syndrome has shown me that we are still fighting—when we should just be parents or siblings to our loved ones.

In September, Mary Hogan asked the NTG Family Caregiver Online Support Group members to share what they perceive as barriers to healthcare for their loved ones. The responses she received from families all over the country

shared a common theme. *Healthcare for a person with Down syndrome (intellectual disability) is different than for that of the general population.* Here are some examples:

- Doctors are often not fully informed about the special medical needs of adults with Down syndrome and other intellectual disabilities.
- Symptoms of unexplained crying, agitation and yelling are too often treated with yet another prescription, rather than looking for the underlying cause.
- Families have valuable information about their loved one's health. Yet, the medical professionals sometimes discount what we have to say.
- Specialists suggest the use of general anesthesia for simple procedures when it isn't necessary or used with patients in the general population—i.e. general anesthesia for a colonoscopy or insertion of a catheter.
- Medication dosages are increased without careful assessment of its current effectiveness.

For families who don't live near one of the specialty Adult Down syndrome Clinics around the country, it is extremely difficult to find a healthcare provider who has knowledge about aging with Down syndrome. I feel an extreme sense of urgency to change this.

How it will happen, I have yet to figure out. Throughout Matt's life I have felt this same sense of urgency several times. I have it because I recognize that it may take 20 years to make a change, which could

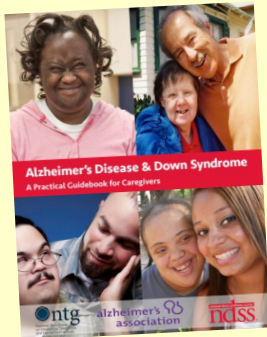


Matt Ransdell and his favorite horse, Reinger.

be too late to be of benefit to him. And *he* is the reason I advocate as passionately as I do.

I leave you with a question posed by Mary in her presentation, "How do we ensure that the work force is knowledgeable and will act in their behalf and support them as 'people?'"

I want to start a dialog about improving healthcare for adults with Down syndrome and other intellectual disabilities. I would urge you to join the discussion. Email me at [jadeneransdellalz@gmail.com](mailto:jadeneransdellalz@gmail.com) with "Let's Improve Healthcare" in the subject line. Let's see what happens.



## We are pleased to announce the completion of *Alzheimer's Disease & Down Syndrome A Practical Guidebook for Caregivers*.

From the forward: "The risk of Alzheimer's disease in adults with Down syndrome can stir deep feelings of fear and anxiety for family, friends, and caregivers who are otherwise trying to focus on supporting and celebrating a healthy and fulfilling adult life for an individual that they love. Education is one way to reclaim some power over a situation where it is impossible to have total control. This booklet was created to help empower families and caregivers with knowledge about the connection between Down syndrome and Alzheimer's disease, suggestions about how to carefully and thoughtfully evaluate changes that may be observed with aging, and guidance about how to adapt and thrive within an ever-changing caregiving role when a diagnosis is made."

We appreciate the National Down Syndrome Society for creating this important guide and collaborating with the Alzheimer's Association and with the NTG in its development. Download your copy at:

[https://www.ndss.org/wp-content/uploads/2018/11/NDSS\\_Guidebook\\_FINAL.pdf](https://www.ndss.org/wp-content/uploads/2018/11/NDSS_Guidebook_FINAL.pdf)

**We are also pleased to share** that after more than two years, the NTG is ready to expand the offering of online support to families who have loved ones with intellectual disability (including Down syndrome) and Alzheimer's or other types of dementia. Our dream is to one day have an online group available in every state, as we know there are considerable differences in supports and services around the country. We are currently communicating with Temple University to create a partnership on this expansion project. At the end of November we will conduct a pilot of the Facilitator Training and plan to bring on more groups after the first of the year. *We are looking for individuals, both family members and those in a professional role, to serve as co-facilitators of the new groups.* Please email Jadene Ransdell at [jadeneransdellalz@gmail.com](mailto:jadeneransdellalz@gmail.com) if you would like to discuss this opportunity further. Put *Peer Support* in the subject line of your email.



We're on the web! [AADMD.org/NTG](http://AADMD.org/NTG)



The NTG is a coalition of professionals and family members whose focus is on quality of life for people with intellectual and developmental disabilities who are affected by dementia. Through the work of NTG members, people with intellectual and developmental disability are included in the *National Plan to Address Alzheimer's Disease*. In addition,

our many volunteers provide technical assistance and have developed tools to help others deliver the best services and supports to individuals with IDD and dementia. 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 various university centers and the Gerontology Division of the American Association on Intellectual and Developmental Disabilities (AAIDD). The NTG is also a member of *LEAD* - "Leaders Engaged on Alzheimer's Disease" a Washington-based coalition working to focus attention on Alzheimer's disease and other dementia.

## NTG CONTACTS

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