

Family Bonds

Jadene S. Ransdell

In just the past few weeks we welcomed another new year. For some of us, a new year brings a time for reflection and change. We make resolutions with good intentions—and we may (or may not) stick with them.

As we entered this new year, I found myself reflecting on the gift of a loving family. What I have learned, in my many years, is that family doesn't always fit the dictionary definition of parents and children, or those descendants of common ancestors. Sometimes family is created through friendships or other close relationships.

A family is that group who accept you unconditionally. A family is the people who do their best to be there whenever there is a need. A family supports each other, not just financially but emotionally, as well. The bond of family comes from spending meaningful time together.

Family bonds with parents are created through nurturing and shared experiences. Those may be as simple



as doing household chores together, going to the park, playing games or reading together. The key ingredient is giving of personal time on a regular basis.

The bonds that are built with siblings are similar, but may be the most important bonds we form in our lifetime. When disability is part of the equation, a protective attitude may develop along with a strong sense of loyalty. For some siblings, that protection and loyalty remains during the course of their lives.

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*"The bond that links
your true family
is not one of blood,
but of
respect and joy
in each other's life."*

Richard Bach

Family Bonds

Continued

Through the NTG, I have become part of a large family of caring and loving individuals. I have seen the unconditional love given to others within biological families and within this extended family.

As I write this newsletter, I am witnessing the bond of one sibling with her brother who is at the end stage of Alzheimer's and actively dying. The bond she shares with her brother was formed when they were children and remains strong to this day. She has moved mountains to ensure that his life and his passing were filled with dignity and love.

She has openly shared the final steps of her brother's journey with us through our social media connections. People around the world have connected with her, provided support at all times of the day and night, and remain vigilant in their expressions of concern and love.

The bond Lisa has shown us with her beloved Butch is just one example of the strong ties that our families have—within their family and within the larger group that has become family because of a common experience: the love of someone with an intellectual disability and dementia.

Through our social media interactions, I have read comments from others who have already walked this final path

with their own loved ones. My heart has broken into a million pieces at the same time it has filled with joy, as siblings, parents and other caregivers share the undying bond they have with their family members.

They share the difficulties that arise in ongoing caregiving; they discuss the bone-tiredness they feel. They write of the extreme pain they feel, or have felt, watching helplessly, as their loved one dies. At the same time, they share that no matter how heartbreaking the journey was or is, they couldn't imagine being anywhere but with their beloved family member.

That expression of love is given until the last breath is taken, and even then the bond can never be broken. In a few weeks we will celebrate another special day—the day we focus on love and loving thoughts. Shortly before the new year, stores were filled with candy hearts and Valentines. The cards express thoughts that some find difficult to share at any other time. However, for those of us on this journey together, we don't need Valentine's day to express the love we will forever feel for our family members.



Alzheimer's, Down Syndrome and Hispanics

By: Veronica Cool, CEO & Hispanic Strategist at Cool & Associates LLC

Editor's Note: At the October 2018 meeting of the National Alzheimer's Project Act Advisory Committee, Mary Hogan, Co-chair of the NTG Family Advocacy and Support committee, spoke on a panel on Heterogeneity and the Barriers to Accessing Services. Veronica Cool also participated on the panel. Mary asked her to share her insights.

Alzheimer's Disease affects well over 5 million people in the United States. Although there are more non-Hispanic white Americans with Alzheimer's disease and other dementias, studies indicate the probabilities of developing Alzheimer's Disease are one and one-half times higher for Hispanics, than other demographics.

Yet, the increased risk across racial groups has little to do with genetics, but rather variations in health, lifestyle and socioeconomic factors. In fact, health conditions such as cardiovascular disease and diabetes, which are highly associated with Alzheimer's Disease, are more prominent in African-Americans and Hispanics.

Lower socio-economic conditions often affiliated with Hispanics in the U.S. lead to poorer health conditions and increased stress. Other factors that correlate to this outcome include education and awareness of health-related issues.

Consequently, Hispanics are more likely to have Alzheimer's disease, but less likely to have it diagnosed

and in turn, less likely to receive treatment.

In order to identify changes in the individual that may suggest the development of Alzheimer's, it is important to have a good understanding of that person's "baseline," what he or she is capable of doing at their best throughout their adulthood. Latino's often like to say "*Eso se le va a pasar*" (That will pass) or "*Es que se está poniendo viejito*" (He's just getting a little old), instead of recognizing these changes as big red flags of Alzheimer's disease.

Most importantly, Hispanics are less likely to use traditional health care services, as a result of the language barrier. Additionally, a leading majority of elderly Hispanics are first-generation immigrants whose proficiency in English is low. The lack of Spanish language fluency and cultural sensitivity in many healthcare systems impacts the ability to build trust among Hispanic elders. Needless to say, there is a tremendous need for change in our healthcare system to properly care for the growing Hispanic demographic. The following initiatives are seen as best practice:

- Hire bilingual and bicultural staff.
- Publish health related content in both English and Spanish to guarantee a

higher audience reach and awareness; especially health insurance resources in Spanish.

- Increase outreach and prevention programs to promote healthy behaviors and facilitate early detection of disease and disorders; engaging the community early and often is key to improving health literacy.
- Implement a more culturally competent treatment service model for Hispanic patients.

Alzheimer's disease and Down syndrome are an imminent public health issue that affects the lives of many, especially within the Hispanic community. Given the high percentage of Hispanics in the U.S. that lack proper healthcare services and their increased probability of developing dire health related issues such as Alzheimer's, it is important to begin creating a more accessible and equitable healthcare system to what represents over 57.5 million people of the nation's population.

Veronica Cool, CEO & Hispanic Strategist for Cool & Associates LLC (C&A). C&A helps corporations, nonprofits and government agencies effectively tap our nation's robust Hispanic market. C&A is a certified MBE firm, woman and Hispanic owned, proudly working to help clients penetrate the fastest growing segment of the population: Hispanics.

Get Your Motor Running!

It's almost time for the 2nd Annual NDSS Adult Summit!

We're building on the momentum created by the success of the *2018 NDSS Down Syndrome Adult Summit*, hosted by NDSS and its Self-Advocate Advisory Board (SAAB) in collaboration with the National Task Group on Intellectual Disabilities and Dementia Practices (the NTG) and the National Alliance for Caregiving (NAC).

The conversations will focus, again this year, on important and critical topics for all adults with Down syndrome. As the life expectancy for individuals with Down syndrome continues to increase, NDSS is committed to ensuring our adults with Down syndrome, their families, caregivers and other key stakeholders have the best, most accurate information throughout adulthood.



Who should attend?

- ♥ Individuals with Down syndrome (especially adults)
- ♥ Family members
- ♥ Caregivers
- ♥ Professionals who serve adults with Down syndrome

Summit Checklist

- ❑ **2nd Annual NDSS Adult Summit Registration:** Registration for the NDSS Adult Summit can be completed through this link:
<https://www.classy.org/event/2019-ndss-adult-summit/e181498>
- ❑ **Hotel reservation:** the **Detroit Marriott at the Renaissance Center**. A *Summit special discounted room rate will be available only until March 13, 2019*. To reserve your hotel room, do it online through this link:
<https://book.passkey.com/event/49730712/owner/437/home>
- ❑ **Travel Arrangements:** Guests can begin picking up their Adult Summit material on the afternoon of April 4th. All sessions will be completed by the evening of Saturday, April 6th.

NDSS Second Annual Adult Summit

Following is a sample of breakout sessions selected to be part of the Adult Summit program. For a complete listing (understand that the sessions may change) please visit the NDSS website at:

<https://www.ndss.org/ndss-adult-summit/2019-adult-summit-schedule/>

Breakout Session	Description
<p>Aging Well Together</p> <p>Seth M. Keller, MD, Co-Chair NTG, Chair, Special Interest Group Adult IDD, American Academy of Neurology</p> <p>Mark Peterson, PhD, Associate Professor, Physical Medicine & Rehabilitation Research Non-Clinical Faculty, University of Michigan</p> <p>Beth Marks, PhD, RN, Research Associate Professor, University of Illinois at Chicago</p> <p>Sarah Lenz Lock, JD, Senior Vice President for Policy, AARP; Executive Director, Global Council on Brain Health</p> <p>Self Advocate, (To Be Determined)</p>	<p>Getting older holds a great number of promises as well as challenges and uncertainties. A large body of research has shown that caring for oneself throughout life does matter and can have an impact upon the aging process. This panel will bring together national experts on wellness and health promotion as well as advocates who will discuss the current research and provide a practical approach that everyone should consider following. Aging Well Together will also describe how a team approach is best to ensure that living well as one ages can lead to a positive and productive future</p>
<p>A Conversation about Peer Support for Families and Caregivers</p> <p>Jadene Ransdell, BS, Down syndrome & Alzheimer's Family Advocate</p> <p>Phillip McCallion, PhD, Temple University</p> <p>Lisa Ferretti, MSW, Temple University</p>	<p>Please join our conversation about peer support—what it means to families, what works and what doesn't work, for example. The NTG and Temple University are collaborating on a project to increase the availability of online peer support for families and caregivers of people with Down syndrome and Alzheimer's Disease. We'll share information about the Peer Support Project and how you or an organization in your community can be involved. To be most effective we need to learn from you!</p>
<p>The Benefits of Paid Family and Medical Leave for Family Caregivers</p> <p>Maja Pasovic, MA, MEd, Manager, International Programs & Disability Advocacy</p>	<p>This session addresses the importance of paid family and medical leave for the families of persons with IDDs. The presenter will discuss how paid family and medical leave has a positive impact on the families and the overall healthcare system.</p>
<p>Advanced Care Planning</p> <p>Jane Boyle, Sibling, Fundraiser and Strategic Planner</p> <p>Jeanne R. Kerwin, DMH, CT.</p>	<p>Individuals with Down syndrome and their families have a right to excellence in palliative and end of life care. This session will provide a personal and professional perspective on end of life planning and share important tools (such as POLST- Physician's Orders for Life Sustaining Treatment) to ensure maximum quality of care through the end of life.</p>
<p>Things You Want to Know – Using Group Homes for Dementia Care for Adults with Down Syndrome</p> <p>Matthew P. Janicki, PhD, University of Illinois at Chicago, Co-Chair, NTG</p> <p>Kathy Service, ARNP</p>	<p>Little information is available related to facility-based care of people with Down syndrome and Alzheimer's Disease. In this session you will hear about one dementia group home care project as the residents have been followed over time. Information shared on best practices through the stages of dementia may be helpful to families seeking residential care for their loved one. In addition, those who may be planning homes that provide specialized dementia care may also find the session helpful.</p>
<p>An Introduction to Alzheimer's Disease and Home Safety Modifications</p> <p>Brandi Becker-Wright, MA, LLMSW, DDSSP Program Coordinator Alzheimer's Association – Greater Michigan Chapter</p> <p>Kate Pierce, LMSW, Dementia and Disabilities Supportive Services Program Director Alzheimer's Association – Greater Michigan Chapter</p>	<p>Maximizing independence while maintaining safety is important at all stages of life. However, as people age and/or are diagnosed with dementia, what was once working may no longer be effective. Come join us to learn how to assess the environment and individual for safety, common safety issues by stage of dementia, and dementia and aging-friendly home modifications.</p>
<p>An Overview of NIH-funded Research on Aging Issues and Alzheimer's Disease in Down Syndrome and The INCLUDE Initiative</p> <p>Sujata Bardhan, Scientific Program Manager, DS-Connect® Registry Coordinator, PregSource® Coordinator, (NICHD)</p>	<p>Learn about progress in studies being supported by National Institutes of Health (NIH) for Alzheimer's Disease in Down Syndrome, and other studies supported by NIH, such as aging issues and health care transition. NIH staff will also discuss DS-Connect®: The Down Syndrome Registry and what it can offer families.</p>

Online Peer Support Project: We Need YOU!

In the last issue of the *NTG Caregiver News* we announced the start of a project in partnership with Phillip McCallion, PhD, and Lisa Ferretti, LMSW, at Temple University. At the end of January, Matt Janicki, PhD, Seth Keller, MD, Mary Hogan, MAT, and Jadene Ransdell, BS will meet with Dr. McCallion and Ms. Ferretti to formalize a work agreement.

We are in the process of making edits to the Peer Support Facilitator Training, following a review and pilot of the materials in late November. As we move forward on this project to increase the availability of online support, we will select individuals and groups to participate with us.

One long-term goal has been to have support throughout the country for those caring for individuals with intellectual disabilities and dementia. A number of caregivers have wanted to participate in the current online support group but the day or time of the meeting doesn't work with their schedule. Building on the success of the online support group now offered monthly by the NTG, we plan to create more opportunities by scheduling the groups at different times and on different days.

If you are a family member or professional caregiver and would like to connect with others to share experiences, we want to hear from you. **We are also looking for individuals, both family members and those in a professional role, to serve as co-facilitators of the new groups.** For more information, please email Jadene Ransdell at jadeneransdellalz@gmail.com Put *Peer Support* in the subject line of your email.



We're on the web! 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

For *general information* about the NTG: Seth Keller, Co-Chair: sethkeller@aol.com or Matt Janicki, Co-Chair: mjanicki@uic.edu

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For information about *NTG Training*: Kathie Bishop, Co-Chair, Education and Training Workgroup: bisbur1@earthlink.net