

## Down Syndrome, Alzheimer's, & Healthy Aging



### Background

Adults with Down syndrome (DS) are at increased risk of Alzheimer's disease as they age. Although researchers have studied Alzheimer's for a long time, not much is known about the cause and challenges of Alzheimer's in adults with Down syndrome in particular. In addition, studies that have focused on Alzheimer's in adults with DS have not looked at the lived experiences and health and healthcare access challenges of aging adults with DS themselves.

Several recent studies have also highlighted racial and ethnic disparities, including greater risk of death due to Alzheimer's, earlier age of death due to Alzheimer's, and more significant underreporting, misreporting and diagnostic overshadowing among patients with DS from racial ethnic minorities, including Hispanics.

There is a critical need to characterize the issues underlying these disparities by engaging with the patients/caregivers themselves, in order to facilitate the development of interventions that are likely to improve health outcomes, health access, and quality of life for adults with DS.



### Our Research

Our research aims to center the voices of adults with Down syndrome and their family members/caregivers about aging, dementia, and Alzheimer's.

We have convened a workgroup made up of adults with Down syndrome, family members/caregivers of adults with Down syndrome, community organizations, and clinicians/researchers to collaboratively design and carry out the research together. The research seeks to understand the experiences and perspectives of a diverse group of adults with Down syndrome and their family members/caregivers about aging and Alzheimer's. Meet the members of our workgroup below.

### Workgroup Members

This section is in progress and does not currently reflect all of our workgroup members.



#### Nicole Adler

##### Bio

Nicole Adler is a speaker, host and human rights advocate for the developmental disabilities and LGBTQ communities. Since 2014, Adler has been a governor-appointed member of the State Council on Developmental Disabilities, a board member for The Next Step Program, and was recently on the advisory committee for California's Disability Thrive Initiative, which provides statewide training, support, and resources to Californians of all abilities. She is a passionate advocate for inclusion, acceptance, equal rights, mental health, voting accessibility, disability representation in the media, housing rights, and ending the R-word. You can listen to Adler express her views on these topics and more in a series of videos and public speaking engagements on her

[YouTube](#)  
channel or website  
[NicoleforLove.com](#)



#### Dana Hooper

##### Bio

Dana Hooper has been the Executive Director of [Life Services Alternatives \(LSA\)](#) for the past 16 years, but his journey started many years ago when his son Brent was diagnosed with an Intellectual Disability. Over the years, he has become involved in many areas of the IDD world. He became a leader in our community, working with government and nonprofits such as Branch Services (Board), Lighthouse for the Blind and Visually Impaired (Board), the State Department of Developmental Services and the San Andreas Regional Center (Past Board President), where his son, Brent, is a client in Supported Living. It also led him to his leadership role at LSA, where he can make a difference every day in the lives of the individuals LSA serves.



#### Janet Van Zoeren

##### Bio

In 1976, when my daughter, who has Down syndrome, was born, I was a tenured professor of biology at the University of Pittsburgh. A few months later, we moved to California, where my husband had accepted a position in the high-tech industry. I have been advocating for appropriate services for people who have intellectual and developmental disabilities ever since. My recent advocacy has centered around addressing the dementia care needs of individuals with intellectual and developmental disabilities, particularly those with Down syndrome.



#### Colleen Vega

##### Bio

Dr. Colleen Vega (DNP, CNS, APRN, CEN, ACHPN) is the Lead advanced practice provider (APP) at Stanford Health Care (SHC) in the Palliative Care Department and a lecturer at San Francisco State University. Her 24-year health care career spans clinical practice in telemetry/cardiac, emergency care, and palliative medicine. Dr. Vega's scholarship and professional work has focused on palliative care and emergency nursing care, advanced practice providers scope of practice and education, and improvements in care for individuals with intellectual and developmental disabilities (IDD). Most recently, Dr. Vega has been working on quality initiatives to improve healthcare access for individuals with IDD. One of her most important roles is supporting her beloved brother, Scott, who has Down Syndrome. She is nationally certified as an advanced practice provider in hospice and palliative care and certified as an emergency nurse.