

## 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.



#### Yolanda Villarreal

##### Bio

All my life I have been around our family and my sister Maria is/was our center block. Ever since I was young I would help my mom translate when needed for the doctor and things like that. We were 7 years apart but grew up together and very close. When I got married I still remained close to my mom and helped in any way that was needed. But when mom passed away in 2004 I became Maria's sister-mom, caretaker, and advocate. She lived with me and my family until she passed away in 2023. I was not expecting or knew anything about Alzheimer's disease, nor where to look for help. The Regional Center did not help either. The support groups I stumbled on were my greatest help. With the pandemic and Maria's day program not opening I had to retire early to care for her until she became bedridden and the unfortunate ending.



#### Dashiell Meier

##### Bio

Dashiell Meier is a storyteller, disability rights advocate, speaker, college student and filmmaker. In addition to making animated and live-action films in his quest to someday work at Pixar, he hosts a talk show called *Playing Favorites*. As a National Down Syndrome Society Ambassador and Special Olympics Global Messenger, Dashiell advocates for people with Down syndrome and other disabilities in the Bay Area, Sacramento, and Washington, D.C. He spoke about health equity at the United Nations in New York at the 2024 World Down Syndrome Day Conference. In addition to health advocacy, Dashiell recently began a disability education movement that aims to get disability history taught in schools and is working on a video series about Down syndrome. Learn more about Dashiell at [www.100YardDashiell.com](#), and watch his shows, speeches, and films on his [YouTube channel](#).



#### Sue and Scott Digre

##### Bio

Sue Digre is a mom of four wonderful children. Their youngest is Scott. Scott has Trisomy-21 and is a happy, busy adult. Sue is a successful General Education Teacher. When Scott was 22 and left school, Sue switched to PARCA and became the Director of Family Support Services and Advocacy for persons who have a developmental disability.



#### Marianne Iversen

##### Bio

Marianne Iversen is the Director of Mental Health and Aging Support at the Down Syndrome Connection of the Bay Area (DSCBA). She has been with the organization for the past 15 years, previously in the roles of Director of Programs and Teen & Adult Services. Her work with families led her to facilitating a national support group for caregivers of those with Ds and Dementia and to the understanding that much work is needed in the areas of both mental health and aging. Marianne has been the lead in the DSCBA's Mental Health Alliance (MHA) pilot program since 2021 and currently sits on several advocacy groups pertaining to aging in the IDD population.



#### Justin Steinberg

##### Bio

Justin Steinberg is a research assistant at the Stanford Center for Biomedical Ethics and a member of the IDD-TRANSFORM research team. In addition, he helps moderate a Responsible Conduct of Research course for graduate students, postdoctoral scholars, faculty and staff. He has a visual disability, motor nystagmus, and is on the autism spectrum. He completed his bachelor's degree in history from San Francisco State in 2014, graduating *cum laude*. He then graduated with his master's degree in special education with an emphasis in visual impairments/disabilities from San Francisco State in 2016. He also received the Graduate Student Award for Distinguished Achievement.

Justin is also a Special Olympics athlete, athlete leader and board member. He competes in flag football, floor hockey, basketball, track and field, swimming and softball. In 2019, he was selected as the Special Olympics Athlete of the Year and was inducted into the San Jose Sports Hall of Fame. In 2020, prior to the COVID pandemic, he went to Washington DC to advocate for federal funding for the Healthy Athletes and Unified Champion Schools Partnership programs for Special Olympics. And in 2022, he received the Change Maker Award from the Wender Weis Foundation for Children for his work at Stanford and for his leadership with Special Olympics Northern California. When Justin isn't working or competing in Special Olympics, he enjoys playing the drums in a symphonic band in Palo Alto and spending time with his friends and family.

Justin is very excited to be a member of this workgroup! He is eager to learn more about Alzheimer's and Trisomy 21 and looks forward to conducting research on this important area as a means of giving back to the disability community.



#### Carole Fogelstrom

##### Bio

I was just a young mom back in 1969 when our son, Greg, was born with Down syndrome. The term used back then was Mongoloid. Shortly after, my uncle was diagnosed with Alzheimer's. It was then that I discovered the link between the two conditions. It was also the beginning of my journey to learn as much as possible about these conditions, the link between them and if there was anything that could be done to prevent Alzheimer's in our family. While I have no credentials next to my name, I have worked alongside other moms to start a pre-school for our DS children when schooling was not available for them in the 1970's. In 2004, and for about 20 years, professionally, I worked with non-profits and the State of California to help find homes for all developmentally disabled adults upon the closing of Agews State Hospital. I strive to help my son be independent, happy, healthy and productive; to advocate for him and to research and strive to prevent Alzheimer's. That's my goal.

### Resources

Alzheimer's Disease & Down Syndrome

#### Alzheimer's Disease & Down Syndrome

Adults with Down syndrome are at increased risk of Alzheimer's disease as they grow older. But not all changes in behavior or loss of skill are due to Alzheimer's disease. This webpage provides a general definition and overview of Alzheimer's, information about the span of Alzheimer's Disease, and tips on how to recognize Alzheimer's Disease in a loved one.

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