

"The Aging Brain: Dementia Risk in Individuals with Down Syndrome and IDD"

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CATHOLIC CHARITIES
HAWAII
CIRCLE OF CARE FOR DEMENTIA



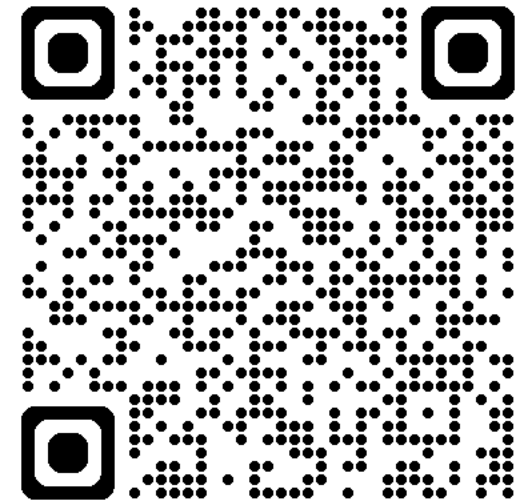
Supported in part by grant No. 90ADPI0108-01-00 from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy. The grant was awarded to Catholic Charities Hawaii for the Alzheimer's Disease Programs Initiative.



National Task Group on Intellectual Disabilities and Dementia Practices

“Your one-stop shop for resources and training related to aging, IDD and dementia.”

A screenshot of the NTG website homepage. The header includes a language dropdown set to "English", a "Donate" button, a search bar, and "Subscribe" and "Join the NTG" buttons. The main navigation bar lists: Home, About Us, Family Support, NTG-EDSD, Education, Webinars, Events, Contact Us, Publications, Resources, and Projects. The main content area features a "Welcome to The NTG" section with a mission statement: "Our mission is to advocate for services and supports for people with intellectual disability who are affected by Alzheimer's disease and dementias and for their families." A "Quick Links" sidebar on the left lists: Facts about Dementia, Family Support, NTG-EDSD, Publications Library, Upcoming Trainings, Upcoming Webinars, Canadian Consortium, and Join the NTG. A "Resources" sidebar on the right lists: Dementia PLUS (Autism/ASD, Cerebral Palsy, Down Syndrome), COVID-19, Drug Info, DS 'Regression', and Guidelines.



Introduction

Overview of Cognitive Decline and Dementia

- Dementia is a progressive decline in cognitive function, affecting memory, thinking, and daily activities.
- Dementia is NOT a disease.
- Individuals with intellectual and developmental disabilities (IDD), especially Down syndrome, are at a higher risk.

Why This Topic Matters

- Increased life expectancy of individuals with IDD means more aging-related health challenges.
- Early treatment for potentially reversible causes.
- Future planning – programmatic, end-of-life, etc.
- Early recognition and intervention can improve quality of life.



Understanding Dementia in Intellectual and Developmental Disabilities (IDD)

What is Dementia?

- A neurodegenerative condition causing cognitive and functional decline.
- Common types include Alzheimer's disease (most prevalent in Down syndrome), vascular dementia, and Lewy body dementia.

Increased Risk in Down Syndrome

- People with Down syndrome have a higher prevalence of Alzheimer's disease due to genetic factors (extra chromosome 21 carrying the amyloid precursor protein gene).
- Dementia may present differently in individuals with DS, making diagnosis more complex.
- Personality and behavioral change (and seizures) vs. short term memory loss



Percentage of people with Down syndrome who develop dementia at different ages:

30's	2%
40's	10-15%
50's	20-50%
60's	60-90%

McCarron et al., (2017). A prospective 20-year longitudinal follow-up of dementia in persons with Down syndrome
Journal of Intellectual Disability Research Sep;61(9):843-852

Understanding Dementia in IDD (continued)

Non-Down Syndrome

- The great unknown
- Thought to be the same as general population

Early Warning Signs in Individuals with IDD

- Changes in behavior, personality, or mood
- Increased confusion or difficulty following routines
- Loss of previously acquired skills or abilities
- Changes in social engagement and communication
- Seizures (Down syndrome)

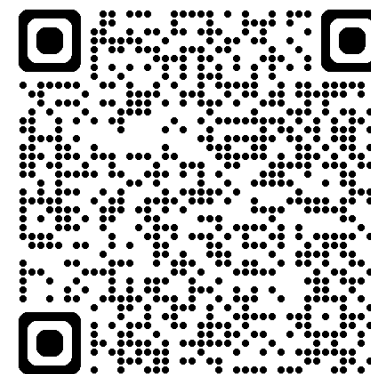


Catholic Charities Hawaii's Collaboration with NTG

- Catholic Charities Hawaii was awarded Alzheimer's Disease Programs Initiative (ADPI) grant from Administration for Community Living (ACL).
- **Catholic Charities Hawaii's Vision:** To strengthen and expand the circle of care supporting persons living with memory loss and their caregivers by providing effective person- and family-centered dementia-capable programs, services and resources to help them remain independent and safe in their communities.
- The goals and objectives of the grant are:
 1. Objective 1: Improve and deliver effective and supportive services to persons living alone with Alzheimer's disease and related dementias (ADRD) to help them live independently and safely in the community for as long as possible
 2. Objective 2: Increase the availability, quality and effectiveness of programs, resources and services for persons aging with Intellectual and Developmental Disabilities (IDD) with and at higher risk for dementia, and their caregivers
 3. Objective 3: Deliver behavior symptom management training and expert consultations for family caregivers, and support persons with Early-Stage dementia with evidence-based and -informed interventions and activities To empower and educate the public and workforce on caregiving, dementia, and brain health.
 4. Empower and educate the public and workforce on caregiving, dementia, and brain health.




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<https://www.catholiccharitieshawaii.org/intellectual-disabilities-aging-and-dementia/>



Aging with Intellectual and Developmental Disabilities: Hawai'i's Resources: Collaborations, Hopes, Challenges and Accomplishment

- ▶ Kathie Bishop, PH.D. Gerontologist, Author,
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Why the EDSD?

Working in partnership
with health care
providers

Why are we focusing on the use of the NTG EDSD?



Why specifically for adults with IDD? Aging is aging is aging but

- ▶ Each of us ages uniquely within patterns of aging.
- ▶ **Many health care providers do not understand the differences in capacity in areas of communication or cognitive and functioning ability between their patients in the general community and those with IDD.**
 - ▶ Health care providers often have little experience with or training on adults with IDD.
 - ▶ **Knowing the baseline helps understand changes in the patient that may be TREATABLE symptoms communicating pain, disease, or illness.**

Why baseline?

A way to gather essential health and functioning information to track changes over time.

Many health care providers do not understand the differences in capacity in areas of communication or cognitive and functioning ability for adults with IDD as compared to the general community.

Cannot compare to another person in the general population, only to each patient.

Knowing the baseline helps understand changes in the person with IDD that may be *TREATABLE* symptoms communicating pain, disease, or illness.

Helps in the Differential Diagnosis Process to rule out underlying causes for the changes.

Why is change the most important factor to monitor and report to health care providers?



It is essential to compare to the cognitive capacity over a lifetime of an individual with IDD rather than to adults in the general population.



Sensory challenges, onset or worsening of diseases and conditions, changes in daily patterns of behavior, and new behaviors are important tools to determine the underlying causes for decline. The specific information can provide clues of how to modify the physical and sensory environments.



Changes can be rapid or slowly over time. Quick changes are usually indicative of an acute condition while slow change could be the result of loss such as an increased visual or hearing impairment.

Differential Diagnosis?



The process of using clues, symptoms, screening tools like the EDS, lab tests, and behavioral communication to detect underlying cause for the changes.



Ruling in or out any possible underlying causes for decline, changes from lifelong functioning, and behavioral changes to treat with interventions when appropriate.




Some age-related/associated diseases such as Alzheimer's disease are diagnosed through a process of exclusion.




Most older adults rarely have one condition only or can be healed after one visit to a health care provider.



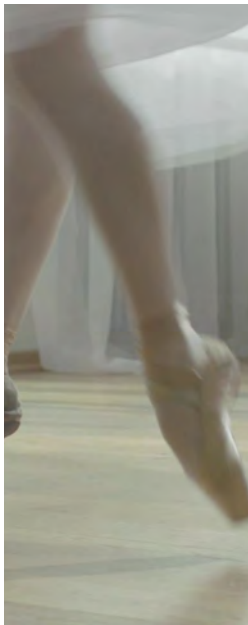
The more relevant information the health care provider, the increased likelihood for appropriate diagnoses.



What can you gather as a family member to help health care providers and other carers know your family member's life story?

- ▶ Family and home photos
 - ▶ Hobbies and interests
 - ▶ Pets
 - ▶ Activities, honors, trophies
 - ▶ At least annual videos showing skills, movement, and things that cause happiness, comfort, peace, and how pain is expressed
 - ▶ Documentation of diagnosis and related diagnosis
 - ▶ Health history
 - ▶ Capturing the essence!
- 

Life Stories and Essence

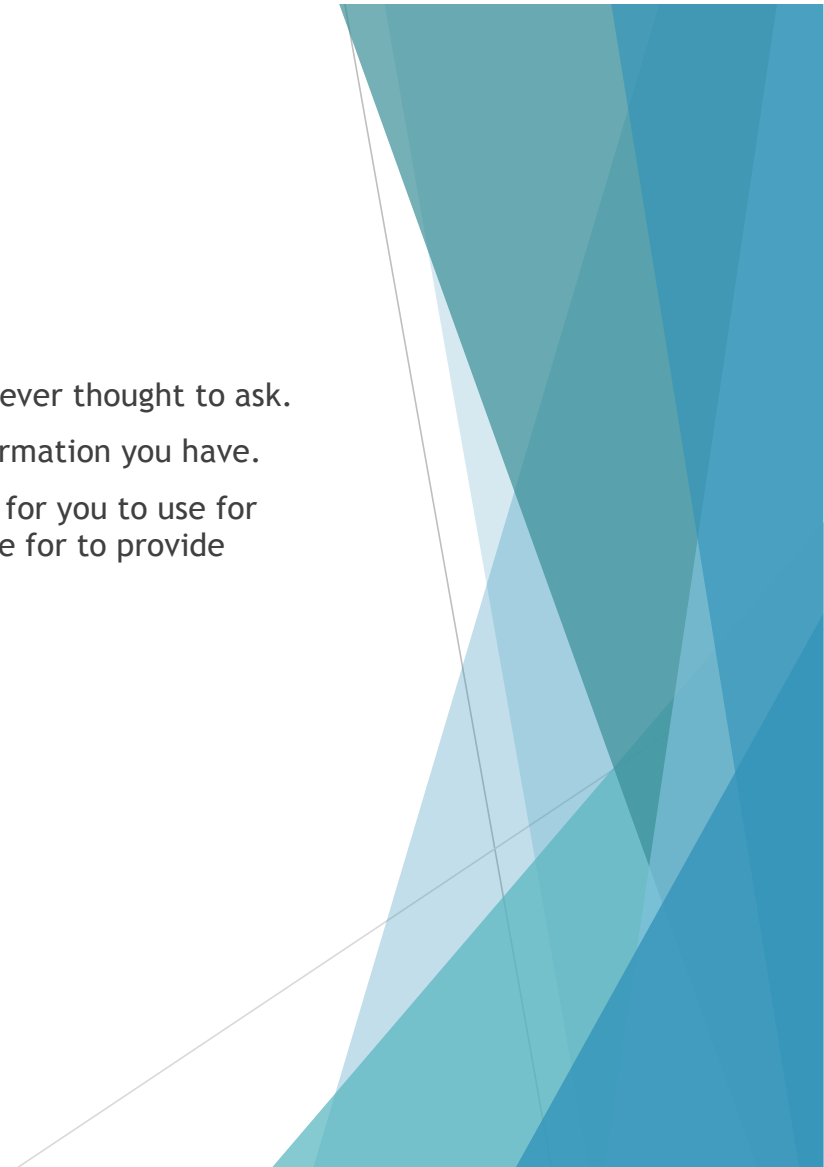


- ▶ Example of a dancer -
 - ▶ Loves to dance and an important activity over a lifetime (part of the patient's lifestory).
 - ▶ Dancer grows older and can no longer dance as before, quits dancing and refuses to go to activities involving dancing. (Major Change)
 - ▶ The essence for this individual may be that it is the ability to feel free and have control over the body; to feel part of nature as in Hawaii the dances are held outside on the beach. Why did she/he love to dance?
 - ▶ Treatment - Pain management? Opportunities to be on the beach to feel in the breeze? Playing favorite music and moving to the music sitting in a rocking chair?

Never assume this change is behavioral (Non-compliant, stubborn, angry) or dementia!!!!



Conclusion

- ▶ Learn to ask the questions about changes you never thought to ask.
 - ▶ Be part of the team providing the valuable information you have.
 - ▶ The EDSO is a free tool with a manual designed for you to use for your family member or person with IDD you care for to provide information to health care provider(s).
- 



Thank
you!



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“Growing the Circle of Care” Alzheimer’s Disease Programs Initiative (ADPI)

A second 3-year Federal Award

July 1, 2023 – June 30, 2026

**Given to CCH by the Administration for Community Living,
Department of Health and Human Services**

Ritabelle Fernandes, MD, MPH
Co-PI ADPI Grant for Catholic Charities
Associate Professor, JABSOM Dept of Geriatric Medicine
Panel presenter
Friday, February 28 2025



Grant No. 90ADPI0011-01-00 from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.

Accomplishments:

First ADPI Grant awarded to CCH

Catholic Charities Hawaii (CCH) received its first 3-year Alzheimer's Disease Programs Initiative grant from the Administration For Community Living in September 2018 to implement the [Hawaii Circle of Care for Dementia](#) project supporting persons living with dementia (PLWD) and their caregivers, with the overall goal:

Help PLWD remain independent and safe in their communities.

Grantees were required to address these gap areas:

- Provide effective and supportive services to Persons Living Alone with Dementia
- **Increase the availability, quality and effectiveness of programs, resources and services for persons Aging with Intellectual & Developmental Disabilities (IDD) at higher risk for dementia, and their caregivers**
- Deliver behavior symptom management training and advice for family caregivers, including delivery of an evidence-based or -informed intervention or program

Live and Zoom trainings were given for IDD service providers and caregivers and health professionals with archived sessions on the CCH website IDD page

Trainings on Dementia Capable Care of Persons aging with IDD at higher risk for dementia, like this one at The Arc in Hawaii in 2019.

Covid caused us to pivot to Zoom trainings.



www.catholiccharitieshawaii.org/intellectual-disabilities-aging-and-dementia/



Opportunities to Sustain and Grow the Circle of Care for Dementia

A second 3-year ADPI grant was awarded to CCH to
“Grow the Circle of Care” for Dementia, July 2023-June 2026
There are new Collaborations, Activities and Objectives

Including the following:

- Collaborate with Developmental Disabilities (DD) Council and the Hawaii DD networks to operationalize usage of a unique screening tool for persons aging with Down syndrome and other intellectual disabilities at higher risk for dementia that will help families and providers track memory changes over time – The National Task Group on Intellectual Disabilities and Dementia Practices Early Detection Screen for Dementia (the NTG-EDSD).
- Provide Zoom training series for caregivers and providers of persons aging with IDD with interdisciplinary panels to allow more quality time for attendees to receive expert advice and guidance on specific topics, like wandering, repetitive behaviors, safety issues, caregiving tips and tools, major risk factors for dementia, brain health, and more
- **Today’s session is the first of this series with expert panels.**

FACTS ABOUT THE GAPS IN DEMENTIA CARE

And why these grants are important!

- The Alzheimer's Association estimates that about 1 in 9 people age 65 and older (10.7%) has Alzheimer's disease (AD). This does not include Mild Cognitive Impairment or other forms of dementia, so this estimate is low. 28-34% of those with dementia live alone. In many cases they have multiple unmet needs and may be less likely to have an accurate medical assessment, diagnosis and management.
- Adults with Down syndrome (DS) are at increased risk for developing dementia as they age. They share the same Amyloid Precursor Protein (APP) gene that causes AD (Trisomy 21). 40% of persons with Down syndrome aged 40+ will develop AD and 56% will have AD at 60+ years of age. They can develop AD even before age 40. Adults with DS are at risk for diseases and changes about 20 years earlier than the general population.
- **Yet no required training on IDD is given in medical schools. There are no medical textbooks on aging and IDD. There are few practitioners with expertise. My role in the current CCH grant is to train healthcare professionals in IDD, Aging and Dementia and the EDSD. Develop a medical school curriculum as well.**

Data taken from: Alzheimer's Association 2024 Facts & Figures; National Task Group on Intellectual Disabilities and Dementia Practices (The NTG) training curriculum;

Other Catholic Charities ADPI Grant Activities Related to IDD

- **Neurologist and NTG founder Dr. Seth Keller will provide 2 trainings via Zoom for Hawaii physicians.**
- **Adapt a half-day curriculum from a previous Wisconsin Alzheimer's Institute GUIDE "Implementing Effective Dementia Screening for Persons Living with an Intellectual Disability." This guide is a roadmap we can follow to implement the NTG's Early Detection Screen for specialists in the IDD field.**
- **If you have questions or are interested in staff training, please make inquiries to Jody Mishan at jmishan@Hawaii.rr.com**

Aging with Intellectual and Developmental Disabilities: Hawai'i's Resources: Collaborations, Hopes, Challenges and Accomplishments

Bridging Aging & Disabilities Grant

By Daintry Bartoldus, Executive Director
Hawaii State Council on Developmental Disabilities



Why This Work Matters



People with I/DD are living longer, but aging services often don't address their unique needs (average is 80.7 years)



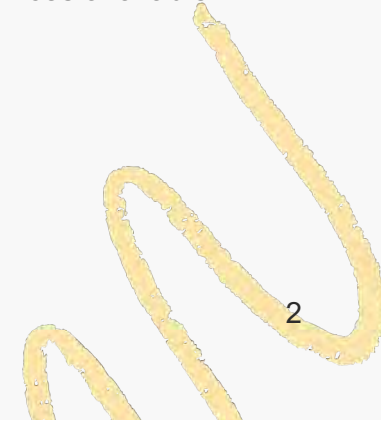
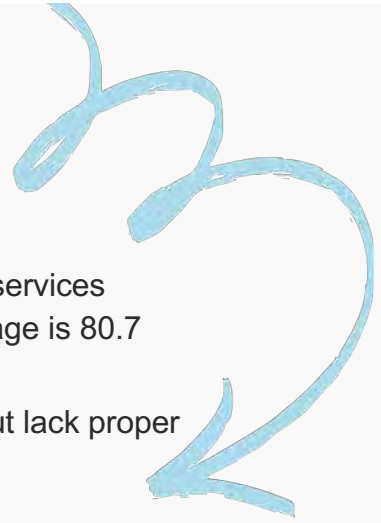
Many aging individuals develop disabilities but lack proper support.



Challenges in Hawai'i: Fragmented systems, need for better training and collaboration.



There is a lack of direct support professionals and kupuna caregivers across the state, impacting the services available.



The Bridging Aging & Disabilities Grant

Goal: Strengthen collaboration between Aging & Disability Networks.

Funded Initiatives: Bridging Aging and Intellectual/Developmental Disabilities Grant ACL Grant # HHS-2021-ACL-AOD-DNCE-0099

- ✓ Internship program to develop work force
- ✓ Workforce training (NTG training)
- ✓ Resource development (emergency form, dementia resource guide, web content, fridge magnets)
- ✓ Advocacy for system improvements
- ✓ Health Fairs to connect communities with resources.





Accomplishments So Far



NTG Training (2023): Educated providers on aging with I/DD.



Created a Hawaii specific I/DD Dementia Care Resource Guide



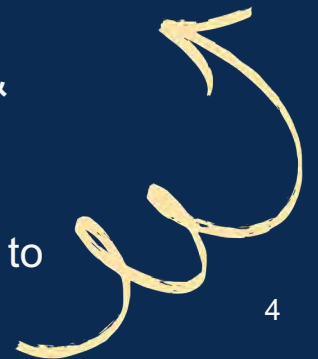
ADRC Website Inclusion: Ensured information accessibility.



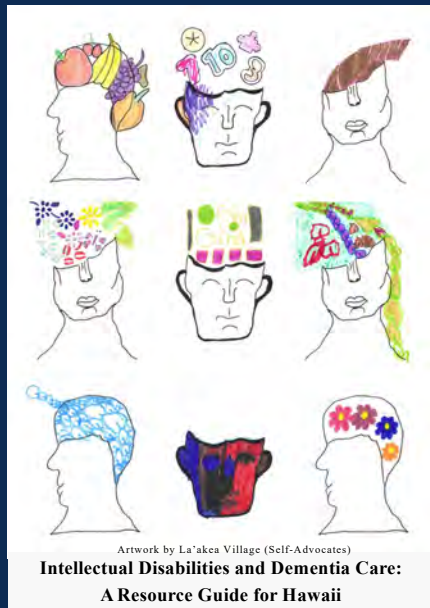
Advocacy & Policy Work: Strengthened representation in policies & funding.



Capitalizing on the diversity and breadth of our team, we were able to create new opportunities and collaborate with new partners



RESOURCE DEVELOPMENT



IMPORTANT INFORMATION ABOUT ME

PERSONAL INFORMATION

Full Name _____
Insurance Provider _____ I have a POLST Yes No

HOW I COMMUNICATE

Primary Language _____ Non Speaking
My way of communicating _____
Best way to communicate with me _____
Best way to assist me _____
Turn over for access and functional needs list I am part of SMART911 Yes No

HEALTH AND MEDICAL INFORMATION

My Medications and Dosages _____

Important Things I use _____

How I Eat (Food and Texture) _____
My Medical Conditions _____
 Blind or Low Vision Turn over to see more

MY EMERGENCY KIT IS LOCATED: _____

EMERGENCY CONTACT DETAILS








Contact Name _____	Primary Number _____
Relationship _____	Secondary Number _____
Contact Name _____	Primary Number _____
Relationship _____	Secondary Number _____
Contact Name _____	Primary Number _____
Relationship _____	Secondary Number _____



 Brochures & Booklets: Developed materials on aging with I/DD and caregiving.

 Web Resources: Created online guides linking individuals to services.

UPCOMING INITIATIVES

-  Health and Resource Fairs: Pili Me Ke Aloha (connected through love), across all counties (2025). 
-  Expanded Advocacy: Continued push for inclusive policies.
-  Continued collaboration with current and new agencies on strategic plans.
-  Continued Education on SMART 911.
-  Expanding the internship program to create sustainability of the adult day health internships.
-  Continue to develop resources based on community needs.



Why This Issue Needs More Work in Hawai'i



****Cultural Considerations:****
Hanai for children but not adults,
leaving gaps in decision-making.

****Limited Support Systems:****
Aging caregivers need more
assistance.

****Healthcare Barriers:****
Providers need better training.


****Need for Systemic Change:****
Without action, many risk
institutionalization.



Call to Action – What We Need to Succeed

- More collaboration between aging & disability organizations.
- Increased funding for targeted services.
- Continued advocacy for inclusive policies.
- Training for caregivers & healthcare professionals.





QUESTIONS AND DISCUSSION

Thank you for your time!