
Aging in Place with I/DD: How HCBS Must Evolve to Support Individuals with I/DD to Remain Living in the Community



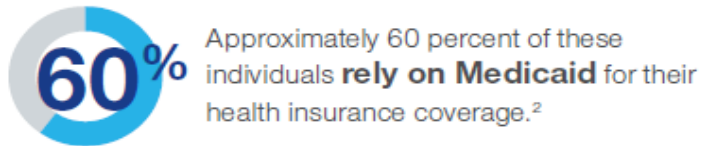
Ken Smith

**CEO, Dual Eligible and Long Term
Services and Supports**

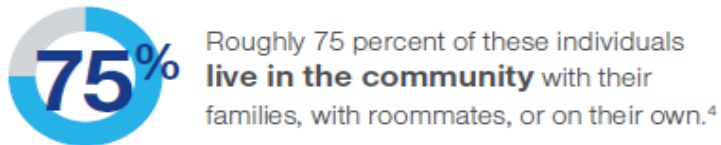
UnitedHealthcare Community & State

Landscape

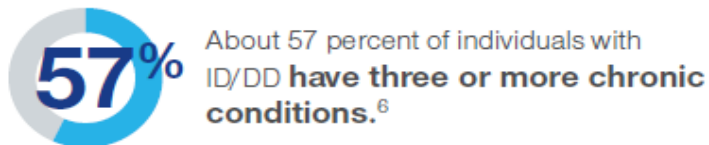
There are nearly **5 million individuals** in the US with ID/DD.¹



Almost **35,000 individuals** with ID/DD are in Medicaid managed care.³



Approximately **640,000 adults over the age of 60** have ID/DD and this number is expected to exceed **1.2 million adults in 30 years**. However, the majority of individuals with ID/DD are under the age of 60.⁵ It is important to note that many older adults have intellectual disabilities but **do not have developmental disabilities** due to brain injury, Alzheimer's or stroke acquired post age 22.



CAREGIVERS

- Approximately **2.9 million family caregivers** of persons with I/DD in the U.S.
- Most of these family caregivers provide more than **40 hours of care per week**
 - including 40% who provide more than 80 hours of care per week.
- More than **25% of family care providers are over the age of 60 years** and another 38% are between 41-59 years (Braddock, Hemp, & Rizzolo, 2008)

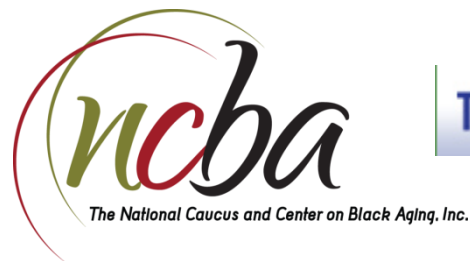
Quality Domains

- Health Status / Medical Care
- Community-Based
- Employment / Other Day Activities
- Living Independently / Choice
- Decision-Making
- Service Coordination



Adjusting to changing circumstances associated with aging is linked to quality improvements in these domains.

National Advisory Board Members



Texas Parent to Parent



NATIONAL ALLIANCE for CAREGIVING
Advancing Family Caregiving Through Research, Innovation, and Advocacy



Donna Meltzer
Executive Director
National Association of Councils on
Developmental Disabilities

National Association of Councils on Developmental Disabilities



Our Mission:

To provide national leadership promoting the interests of people with developmental disabilities and their families, and serve as the united voice representing Councils on Developmental Disabilities

Our Vision:

People with developmental disabilities are fully included as valued members of their communities and have equal opportunities to achieve their potential, make their own decisions, and exercise their civil rights

What NACDD Does



- Federal Advocacy
- Technical Assistance for our 56 member DD Councils
- Address key trending issues and work to develop projects/workgroups/solutions to address these issues

Some Examples of Trending Issues



- Supporting/Training Self Advocates (Partners in Policymaking, Close Up, Art of Impact)
- Civic Engagement (community projects/inclusion/voting rights)
- Financial Literacy
- Aging with I/DD

How Are We Addressing the Issue of Aging?



- Study and discuss key concerns
- Survey Councils and design ways to respond to the concerns
- Work with key partners in aging at federal and state levels (e.g, NASUAD, NCOA, HHS/ACL, ADRCs, White House)
- Independent Living Centers/Statewide Independent Living Councils
- National Task Group on DD and Dementia

Changing Attitudes



- NACDD is working with member Councils to Change Attitudes which opens up Community
- Community of Practice on Supporting Families Across the Life Course
- TN, District of Columbia, WA, OK, CT, MO and now 12 more states coming on board
- Defining the “Good Life” for individuals and families – person centered planning and futures planning work

How Are We Addressing the Issue?

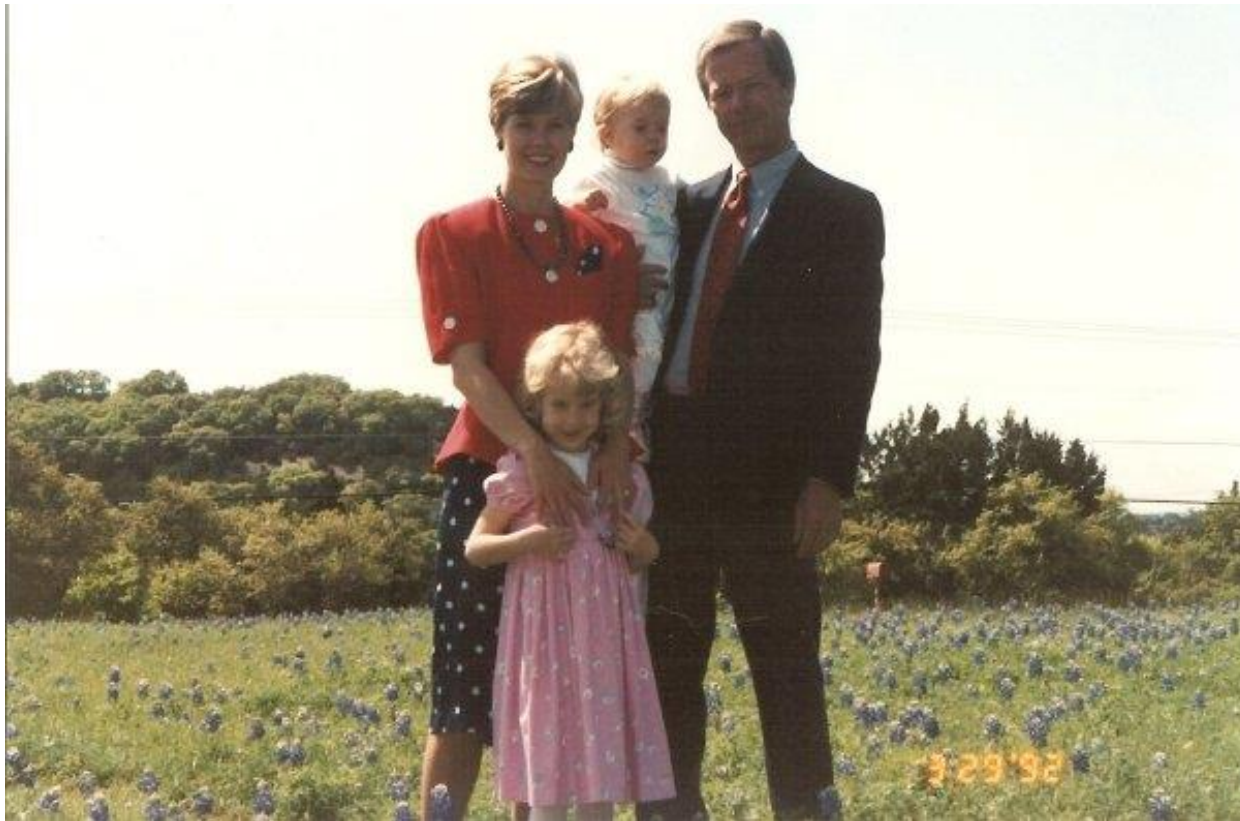


- Policy work at state and federal levels
- HCBS Rule Implementation
- ABLE Act Implementation
- Supporting Families including Siblings and Parents who have disabilities and addressing their unique needs for raising families and aging

Karen Yeaman

Family Caregiver & Texas Advocate

Our Family



Lathom and Father



Brother and Sister



Lathom Working

Work



Office Work



Hampton Inn



Hampton



Food Bank



Goodwill



Home Depot



Burlington



YMCA

Robert Kennedy

Advocate, Washington D.C.

Meet Robert Kennedy



**People Planning
Together Trainer
Candidate**

Employee

Advocate

Volunteer

**Board
Member**



Robert's Story

Lived with his mother until graduation from high school

Moved in with his mother and was her caregiver

Purchased and lives in his family home with drop in supports

What advice would you give younger people with disabilities who want their own lives?



Questions?

Discussion...

Ideas...