



Adults with Intellectual or Developmental Disability

Intellectual/Developmental Disability and Complex Care Needs

Individuals with IDD and co-occurring mental illness, medical illness and/or challenging behavior

12/11/2025- Dawn Graber
“Guardian/Caregiver Wellbeing”

This program is supported by Molina Cares.



Dawn Graber, BA

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- Mother of four adult children; son with severe Autism Spectrum Disorder and daughter with Cerebral Palsy, Epilepsy, and Intellectual Disability
- Family members with acquired disabilities living in rural Iowa
- First person in family to attend college
- Matches families with future healthcare professionals in Parents as Mentors program

Learning Objectives

- Build curiosity and compassion for caregivers
- Identify unique stressors and systemic challenges impacting the well-being of guardians/caregivers of children and adults with IDD and complex care needs
- Identify barriers to and tools for caregiver well-being



Building Curiosity and Compassion through Storytelling



Unique Stressors and Challenges for Caregivers

- Medical Responsibilities: Managing treatments, medications, and devices
- Behavioral & Communication Challenges: Self-injurious or aggressive behavior, finding successful ways to communicate
- Emotional Strain: Chronic stress, anxiety, grief
- Physical Demands: Lifting/bathing, sleep deprivation, lack of exercise
- Financial Pressure: Ability to maintain a job
- Social Isolation: Limited social life, stigma
- System Navigation: Coordinating healthcare, education, and services
- Lack of Respite: Lack of funding and trained staff
- Physical and Mental Health Neglect: Lack of time, money, access
- Individual strengths and weaknesses

Common Tools for Caregiver Well-being

Take Care of Yourself as a Caregiver



Activities like these can lower your stress, boost your mood, and help make you a better caregiver, too.

Learn more about caregiving at www.nia.nih.gov/caregiving.



Accessible Tools for Caregiver Well-being in the Moment of Need

Grounding techniques: Help reconnect with the present moment and reduce feelings of anxiety, stress, racing thoughts, and rumination

- **Sensory:** Drink something cold or hot, smell essential oils or citrus fruits, eat a crunchy or spicy snack, listen to music, look at a photo or piece of art that is calming or brings joy, get sunlight on face or skin, go for a drive with windows down
- **Physical:** Progressive muscle relaxation, jump up and down 50 times, 30 second dance party, singing with full voice in the car for deeper breathing
- **Cognitive:** Do a problem-solving game, watch something that pulls you into another person's life story for inspiration or perspective, write down thoughts and feelings without editing
- **Environmental:** Arrange your environment in small ways that are soothing, lights up or down, sorting objects, clearing surfaces, soft furnishings or clothing

Accessible Tools for Caregiver Well-being that Create Connection with Others

- Don't run away from hard conversations, run toward them.
- Seek to understand before seeking to be understood.
- Words of affirmation
- Telling their story: creates social connection, reduces loneliness, creates opportunities for problem-solving and resource sharing, offers a way to understand/process/integrate life experiences and find meaning in them

Opportunities for Caregivers' Stories to be Told

- Project ECHO!
- Iowa Health Care Family Trainings
 - Iowa Family Leadership Training Institute: combination of virtual and in-person
 - Storytelling for Families: virtual training
 - Digital Storytelling: in-person training
 - LEND Program: Leadership Education in Neurodevelopmental and related Disabilities: in-person
- Facebook support groups
- Autism Society of Iowa support group
- National support groups: Profound Autism Alliance

Parting Thoughts



- Things are not always as they seem.
- Direct support providers need well-being support too.
- Every story is unique and valuable; work to maintain your curiosity and compassion.

Resources and References

- Iowa Family Leadership Training Institute – YouTube—Digital Stories
- How the 5-4-3-2-1 Grounding Technique Can Help You Calm Down
- Family Training | Stead Family Children's Hospital
- Iowa LEND | Center for Disabilities and Development - University of Iowa Health Care
- Caregivers Connected - Profound Autism Alliance
- Support Groups – Autism Society of Iowa
- Caregiving | National Institute on Aging
- Writing about emotions may ease stress and trauma - Harvard Health