

Adapting Evidence-Based and Informed Caregiver Interventions to Support Caregivers of People with Intellectual and Developmental Disabilities and Dementia

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Family Caregiver

- ▶ The term “family caregiver” means an adult family member, or another individual, who is an informal provider of in-home and community care to an older individual or to an individual of any age with Alzheimer’s disease or a related disorder with neurological and organic brain dysfunction.
- ▶ Older Americans Act (2020)

Who are caregivers of persons with intellectual and developmental disabilities (IDD) and dementia?

- ▶ Parents, siblings, other relatives, friends
- ▶ Great-grandparents and grandparents caring for grandchildren with disabilities
- ▶ Two generation elderly families (older parents or older siblings caring for adults over 60)
- ▶ People caring for old older parents (over 85 years) as well as older son/daughter/sibling with IDD (potentially three generations of caregiving)

Different from other caregivers

- ▶ Caregiving is lifelong duration
- ▶ Mutual caregiving
- ▶ Caregivers may not outlive the family member with IDD
- ▶ Families must plan for the future of the person they are caring for
- ▶ Clash between caregiver and care recipient desires and needs

What's the same and what's different from other caregivers

Common tasks

- ▶ Buying groceries, cooking, cleaning house, doing the laundry
- ▶ Making plans to help someone (making medical appointments., driving to the doctor, re-ordering medications, coordinating care)
- ▶ Helping someone to get dressed, take a shower or give medicines
- ▶ Managing finances

Different Experiences

- ▶ Self-identity as caregiver
- ▶ Lifelong
- ▶ More likely to have to supervise all activities
- ▶ Will not be adult daughter or daughter-in-law
- ▶ More likely to be sibling
- ▶ Person cared for less likely to have had previous independent life
- ▶ Can be devastating that what worked before doesn't work now

Caregivers

- ▶ A 92 year old widow who lives and has lived with her 64 year old son with IDD in a rural community
- ▶ A grandmother in her 90s who is the sole source of support for her grandson aged 48
- ▶ A recently retired 65 year old widower caring for his own mother (aged 89) and who is also the primary caregiver for his 41 year old son with Down syndrome and newly emerging symptoms of dementia
- ▶ A woman 72 who cares for her sister with IDD who is 67. Both have symptoms of dementia

Challenges

- ▶ Reluctance of some elderly families to become associated with the IDD system
- ▶ For those connected to IDD system reluctance to access aging support (concern for potential loss of access to IDD supports)
- ▶ Failure to anticipate that their family member with a disability will outlive them and/or may present with dementia symptoms
- ▶ Strong interdependency between caregivers and their family member with IDD
- ▶ Inability of elderly caregivers to reflect on their own aging and plan for themselves or for the person they care for
- ▶ Lack of coordination between services and needs of families

Needs

- ▶ Assessment, diagnosis and care planning
- ▶ Respite, housekeeping, transportation
- ▶ Financial supports and determination of eligibility
- ▶ Financial planning - entitlements, guardianship, trusts
- ▶ Help with negotiating the service system and advocacy for obtaining services
- ▶ Assistance with obtaining Medicaid and resolving problems with agencies
- ▶ Help with making future life decisions

Why are some families reluctant to seek help?

- ▶ Unnecessary intrusions into their lives
- ▶ Worry that their family member will be taken away from them
- ▶ Don't believe that there are any services that they can rely on
- ▶ Past negative experiences with the disabilities service system
- ▶ Difficulties working with agencies they find complex and impersonal

Why can't we “fit” these caregivers in?



“When my brother was experiencing a precipitous decline, I felt desperate as I searched for others who could relate to our experience.

Without a connection, it was isolating, and I was groping in the dark to make sense of what was happening.

I needed a voice that could relate to me and offer some affirmation.”

Not helpful...

- ▶ When examples and discussion of dementia are about caring for people over 70
- ▶ *“I want a leader who is knowledgeable about dementia issues for people with Down syndrome.”*
- ▶ *“What if there is nobody there who is like me?”*
- ▶ *“Caregiving hasn’t been a surprise for 50 years...” Don’t “educate” me or tell me how to “caregive”.*
- ▶ *“None of the examples and discussion of ways to cope is meaningful for my situation.”*
- ▶ *“Everyone else gets helpful advice and develops relationships in the group.”*

Credibility

“To be mildly hypocritical, when I’m overwhelmed if someone who hasn’t had that experience comes to me and tries to help me, I’d be like you have no idea what you’re talking about.”

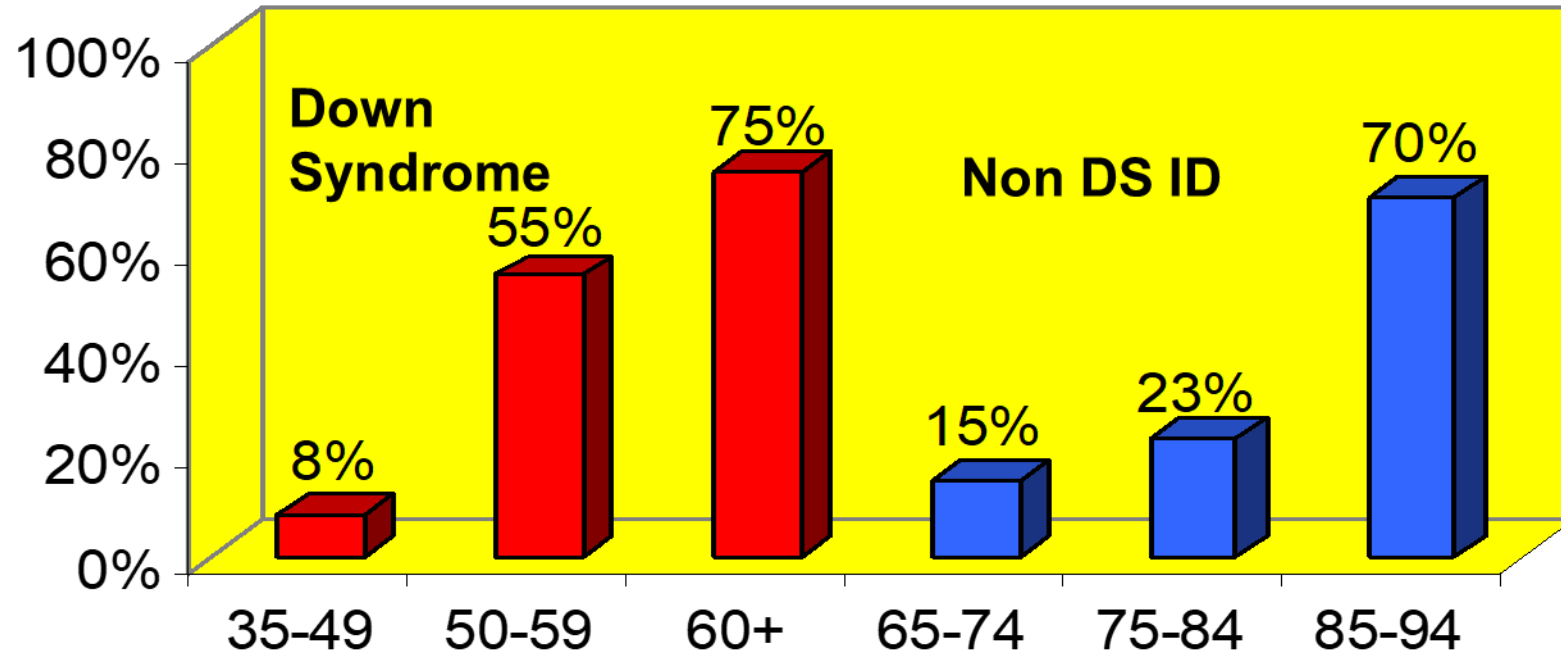
First steps in adapting interventions

- ▶ Understanding IDD and dementia
- ▶ Language
- ▶ Is there content that speaks to my issues?
- ▶ Will examples used be meaningful?

Understanding Dementia in People with IDD

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Prevalence of dementia in people with Down syndrome & people with intellectual disability



Lai, F. Williams, R. 1989 Archives of Neurology; Cooper, SA. 1997 JIDR

Disease presentation

- ▶ Earlier onset
- ▶ Initial more rapid decline but extended late stage
- ▶ Co-occurring epilepsy for people with Down syndrome
- ▶ Minor changes will exacerbate existing disabilities
- ▶ The promise is broken - next year you will be more independent than last year

Quality of life in IDD and Alzheimer's disease

- ▶ Absence of pain
- ▶ Maintenance of health
- ▶ Psychosocial well-being
- ▶ Skills maintenance and support
- ▶ Absence of and supportive responses to problem behaviors
- ▶ Leisure and community participation
- ▶ Family and friends
- ▶ Dementia–focused programming
- ▶ Supportive environments
- ▶ Alleviation of caregiver burden

(McCallion & McCarron, 2003)

Language

Know the terms

- ▶ People first language
- ▶ Least restrictive environment
- ▶ Normalization
- ▶ Self-determination
- ▶ Person centered planning
- ▶ Aging in place

Know the services

- ▶ Residential/group home/independent living
 - ▶ Day habilitation
 - ▶ Supported employment
 - ▶ Respite
 - ▶ Adaptive and communication devices
 - ▶ Environmental modifications
 - ▶ Family education and training
- ... and who can provide them...*

Understand the dilemma: Protection versus self-determination

Federal and state law are clear that the appropriate response of society and systems responsible for protecting citizens with disabilities must not unduly suppress choice and self-direction. 42 U.S.C. § 15002(23); Welf. & Inst. Code §§ 4646.7 (a)(1) & 4646.5(a)(2).

Relevant Content

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Transitions

- ▶ Respite and other services
- ▶ Environmental modifications to support aging in place
- ▶ Legal and guardianship issues
- ▶ Financial plan
- ▶ Medicaid and IDD services eligibility established
- ▶ On a waiting list
- ▶ Day program attendance
- ▶ Moving into out of home placement

Planning

- ▶ The future life of the person with IDD
- ▶ The future life of the caregiver
- ▶ Health, health promotion, health care
- ▶ Accessing aging services
- ▶ Engagement of siblings
- ▶ Guardianship/legal/financial

Finding Meaningful Participation

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Building the relationship

- ▶ Suspend judgment
- ▶ Listen to the story/history
- ▶ Acknowledge the service system failures
- ▶ Avoid jargon
- ▶ Appreciate a lifetime of caregiving
- ▶ Avoid person first “corrections”

Group offers practical advice

- ▶ Finding **new** ways to address caregiving and behavioral challenges
- ▶ Managing epilepsy
- ▶ Self-care for the caregiver
- ▶ Not overstepping role but understanding that recommending caregivers consult with physician/healthcare professional means they are being left with no advice

Engaging siblings in care

- ▶ Practicing conversations and family meetings
- ▶ Offering support when conversations are not helpful
- ▶ Exploring specific help needed versus assuming care responsibilities

Finding competent professionals support

- ▶ Preparing for health professional visits
- ▶ Understanding what will be paid for (usually by Medicaid)
- ▶ Obtaining differential assessment and diagnosis

Preparing for advanced disease

- ▶ Advance directives issues are different
- ▶ Challenges in transfer to hospital and to out of home placements
- ▶ Palliative care decision-making

Planning for the future

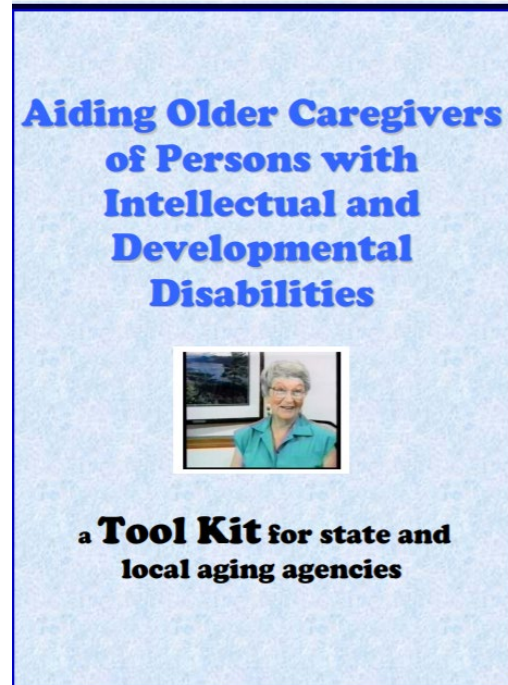
- ▶ Identify services that benefit both
- ▶ Discuss future plans
- ▶ Encourage and support involvement of other family members
- ▶ Discuss options
- ▶ Identify and problem solve barriers to planning
- ▶ Develop and implement a plan
- ▶ Celebrate

Resources

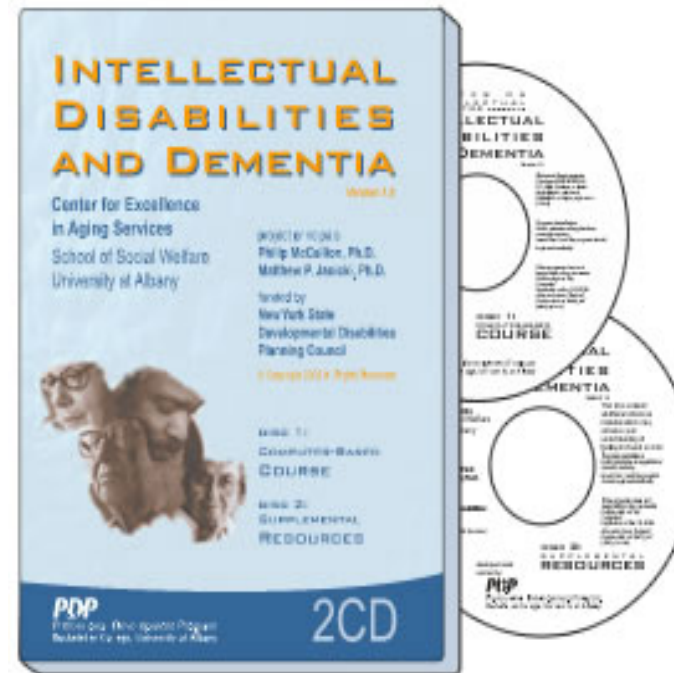
Intellectual and Developmental Disabilities and Dementia: Practical Strategies for Professionals



<https://nadrc.acl.gov/node/169>



https://www.alz.org/national/documents/aoagrants_tools_disabilities.pdf



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