



Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

Bridging the Networks - Needs of Older Caregivers of Individuals with Developmental Disabilities

Module 4

Based on ADRC training
developed by:

ADRC Training Kathleen M. Bishop, Ph.D.,
and Ron Lucchino, Ph.D.



Purpose of Module 4

- Understand role of caregivers in bridging networks
- Identify caregiver needs, changing focus and challenges
- Understand changing family dynamics of older caregivers



Purpose of Module 4

- Recognize impact of overlapping aging and disability needs on caregivers and the child with developmental disabilities
- Identify vulnerability of older caregivers and what triggers a crisis



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Caregiver Characteristics



Characteristics of Older Caregivers

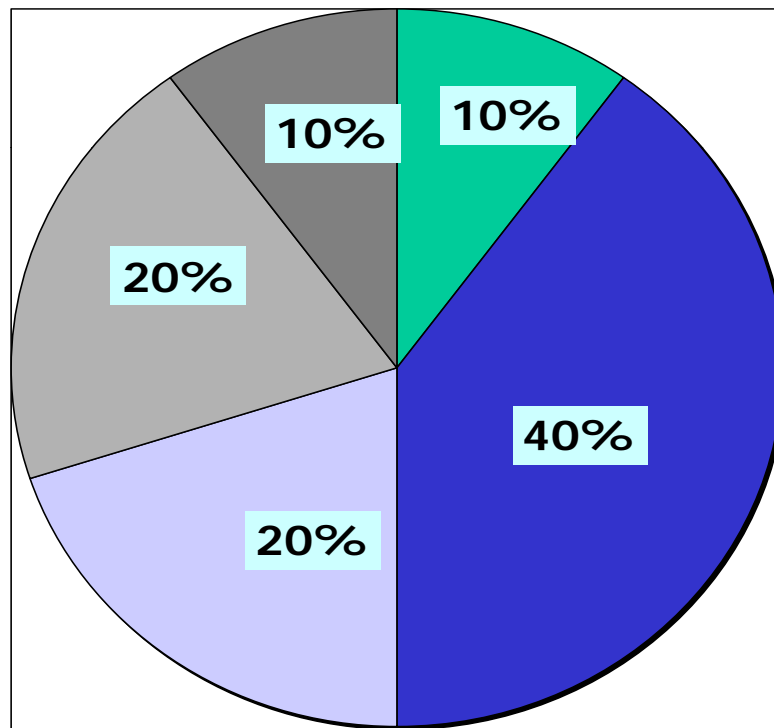
- Large percentage of caregivers 65+
 - Face similar age-related needs and concerns
- Aging of spouse/partner
- Increased multi-caregiving responsibilities
- Limited resources



Characteristics of Older Caregivers

- Increasing health care costs for caregiver and spouse or other family members
- Changing focus of caregivers
- Role reversal of adult child caring for parent

Caregivers as Primary Providers of Care



- 10% Living in residential care
- 40% Living with parents 40-60 years old
- 20% Living with parents over 60
- 20% Living at home without caregiver
- 10% Other living situations

Fujjura, G.T. (1998). Demography of family households. *American Journal on Mental Retardation*, 103, 225-235



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Changing Focus of Caregivers



Focus of Younger Caregivers (Under 60)

- Caring for child or adult with developmental disabilities
 - Education
 - Vocation
 - Independent living
- Caring for parents or grandparents
- Preparing for own retirement



Focus of Aging Caregivers (60)

- Changing focus from son/daughter to other family members in need of assistance
- Begin future planning for transition of care, if not already done
 - Financial
 - Social, vocational, leisure
 - Independence or other family members assuming care



Focus of Older Caregivers (70+)

- Concentration on health of self or spouse
- Maintaining retirement assets
- Current and future housing needs
- Diminished social supports
- Future long-term care needs



Challenges for the Older Caregiver

- Avoiding crisis
- Maintaining independence
 - Caregiver and spouse
 - Child with developmental disabilities
- Maintaining normal routine
- Preparing family unit for change



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Impact of Aging on Caregivers



Impact of Aging on the Caregiver and Family

- Similar aging changes
 - Family members, primary caregiver
 - Adult with developmental disabilities
- Multiple roles of caregiving
 - Older spouse requiring increasing assistance
 - Other family members with multiple diagnoses and needs
 - Adult child with developmental disabilities



Issues Impacting the Older Caregiver and Family

- The adult with developmental disability experiences
 - Frailty
 - Age-associated diseases
 - Need for aging services
 - Reduced independence



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Caregivers of Adults with Down Syndrome



Four Unique Challenges with Down Syndrome

- Early aging changes
- Many aging changes and rate of change similar to the general population
- Early age-associated disorders or diseases
- Increased risk of early onset of Alzheimer's disease

Note: An individual with Down syndrome must also have a diagnosis of retardation to be eligible for APD services.



Challenges for Caregivers of Adults with Down Syndrome

- Age-related changes occur 20 years earlier
- Older than other caregivers
 - Own medical concerns
 - Lifetime of not caring for own needs
 - Increased risk for disease
- Changed expectation of outliving adult child with Down syndrome



Challenges for Caregivers of Adults with Down Syndrome

- Complicated diagnosis and treatment of adult child
- Increased risk of Alzheimer's disease
 - Assumption of Alzheimer's disease by health care providers
 - Other underlying diseases not treated

Challenges for Caregivers of Adults with Down Syndrome



- Reluctance to seek services from disability network
- Lack of knowledge by practitioners concerning aging adults with Down syndrome
- Increased need for support
 - Activities of daily living (ADLs)
 - Lifting and moving



What Does Earlier Aging Mean for Adults with Down Syndrome?

- Shorter longevity
- Reduced cognitive and physical function
- Increased communication challenges
 - Often exhibited as inappropriate behavior
- Early aging may mask or mimic Alzheimer's disease



What Does Earlier Aging Mean for Adults with Down Syndrome?

- Increased risk at an earlier age for
 - Sensory impairments (vision and hearing)
 - Onset of symptoms of Alzheimer's disease
 - Acute dementia
 - Cardiovascular disease
 - Seizures

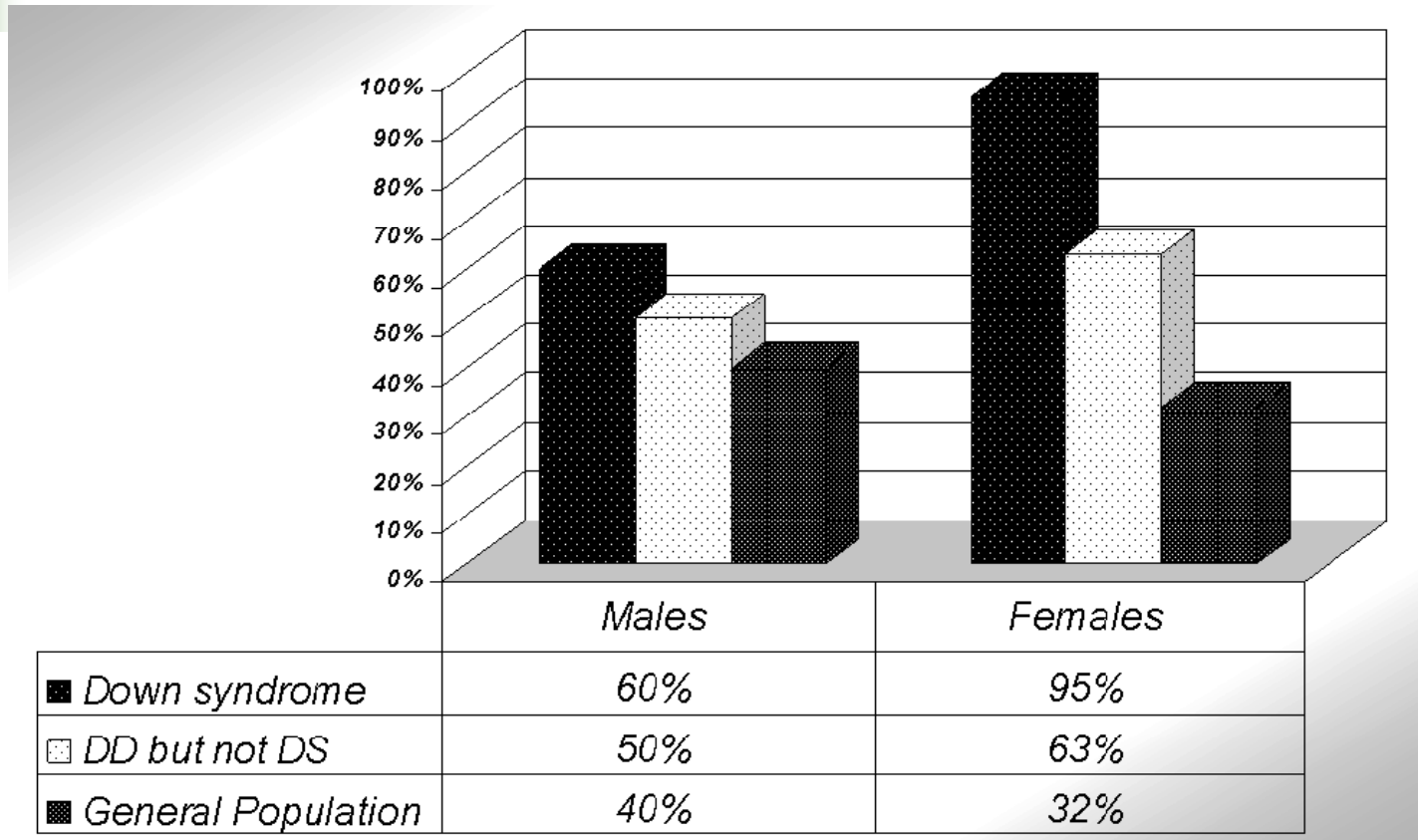
Note: An individual with Down syndrome must also have a diagnosis of retardation to be eligible for APD services.



What Does Earlier Aging Mean for Adults with Down Syndrome?

- Thyroid changes
 - Increased fatigue
 - Feeling cold, lethargic
 - Increased short-term memory loss
 - Change in sleep patterns
 - Confusion

Age-associated Obesity in Adults with Down Syndrome



Bell AJ, Bhate MS. J Intellect Disabil Res. 1992 Aug;36 (Pt 4):359-64.



Health Problems in Adults with Down Syndrome

- Increased risk due to obesity
 - High blood pressure
 - Diabetes
 - Heart problems
 - Alzheimer's disease

Note: An individual with Down syndrome must also have a diagnosis of retardation to be eligible for APD services.



Age-associated Diseases in Adults with Down Syndrome

- Decreased immune system with resulting infections, illness, and diseases
- Gastrointestinal problems
- Sleep apnea
- Leukemia



Alzheimer's Disease in Adults

- No cure or prevention
- Medications (Aricept, Namenda)
 - Treatment for short-term memory loss
 - Does not work for every one; significant behavioral changes in some people
- Value of social interaction may slow decline
- Increasing dependence on caregiver



Increased Risk for Dementia in Adults with Down Syndrome

- Acute dementia – reversible
 - Remove underlying causes to reduce or eliminate symptoms
 - Symptoms of sudden changes in memory, behavior, or cognitive functioning
- Vascular dementia (stroke/heart disease)
- Higher risk for Alzheimer's disease

Alzheimer's Disease in Adults with Down Syndrome



- Typical timeline
 - Early onset of symptoms by 40s
 - 60% exhibit symptoms of Alzheimer's disease by age 60
 - Fewer than 10% exhibit symptoms after age 60
 - Short duration (4 – 7 years)

Note: An individual with Down syndrome must also have a diagnosis of retardation to be eligible for APD services.



Alzheimer's Disease in Adults with Down Syndrome

- Not every adult with Down syndrome will exhibit symptoms
- Must rule out all possible underlying causes to diagnose Alzheimer's disease
- Most common type of dementia
- Symptoms are slow, progressive loss
- Depression common as a secondary condition



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Caregivers of Adults with Cerebral Palsy



Three Unique Challenges with Cerebral Palsy

- Early aging changes
- Many aging changes and rate of change similar to the general population
- Early age-associated disorders or diseases



Challenges for Caregivers of Adults with Cerebral Palsy

- Earlier onset of age-related conditions
 - Decreased muscle strength after many years of no changes
 - Sensory impairments
 - Urinary tract disorders
 - Swallowing disorders
 - Significant reduction in stamina
 - Increased fatigue



Challenges for Caregivers of Adults with Cerebral Palsy

- Earlier onset of age-associated diseases
 - Osteoporosis
 - Osteoarthritis
 - Increased risk for seizures
 - Respiratory infections, pneumonia
 - Difficulty moving joints



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Increased Caregiver Stress



Caregiver Stresses

- Changing status
 - End of caregiving role
 - Becoming the care receiver rather than giver
 - Reduced ability to provide care to others (spouse, children)
 - Increased frailty, losses, and death within support system



Caregiver Stresses

- Relationships within family at end of caregiving
 - Who will care for the spouse or child with developmental disabilities?
- Unreliability and unpredictability of
 - Earned assets and benefits
 - Services and supports



Caregiver Stresses

- Lack of long-range planning
- Increased anxiety of future for spouse and child
- Own medical problems
- Possible dementia of self, spouse, child
- Multiple caregiving roles for two or more generations of family members



Caregiver Response to Stress

- Decline in mental health due to fatigue
- Increased depression
- Reduction in own social activities
- Increased anxiety
- Increased cognitive impairment
- Inability to provide care as in past



Caregiver Response to Stress

- Decline in physical health
- Disengagement or re-entrenchment in caregiving role
- Seeking services from the aging or disability network for the first time



Summary of Module 4

- Caregivers are the bridging point for the aging and disability networks collaboration
- Aging brings increased stress to the caregiver



Summary of Module 4

- Multi-caregiving responsibilities result in the collapse of the caregiver and the supporting system
- Some adults with developmental disabilities will experience earlier aging
 - Adults with Down syndrome
 - Adults with cerebral palsy
 - Adults with very severe disabilities



Summary of Module 4

- Caregivers and providers can
 - Minimize disease through early prevention
 - Work together to reduce stresses
- Importance of Planning Ahead



Exercise

- Scenarios
 - See handouts for scenarios and questions
- Group Discussion
 - Questions