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:

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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


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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


<table>
<thead>
<tr>
<th></th>
<th>Males</th>
<th>Females</th>
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</thead>
<tbody>
<tr>
<td>Down syndrome</td>
<td>60%</td>
<td>95%</td>
</tr>
<tr>
<td>DD but not DS</td>
<td>50%</td>
<td>63%</td>
</tr>
<tr>
<td>General Population</td>
<td>40%</td>
<td>32%</td>
</tr>
</tbody>
</table>
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
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