



Session 6

Part 1: Role Transitions and Changing Needs

Part 2: Environmental Barriers to Successful Aging

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Outline for Session 6

Part 1: Refocusing Family Support (Parent) Needs

- Facts and Concerns about Parents Caring for an Older ID/DD Adult Child
- Changing Needs for Aging Caregivers
- Support Needs
- Stressors of the Changing Caregiver Role
- Parental Concerns
- Preparing the Older Caregiver for a Changing Role
- Staff Outcomes
- Strategic Plans

Part 2: Environmental Barriers to Successful Aging

- Changes in Senses Resulting in Barriers in the Environment
- Changes in Muscles Resulting in Barriers in the Environment
- Changes in Joints Resulting in Barriers in the Environment
- Staff Outcomes
- Strategic Plans

Part I:

 **Refocusing Family Support
Needs as Parents Age**

Purpose

- Ensure comprehensive care coordination plan accommodates the changing focus of the support needs from the older ID/DD adult child to the needs of the informal caregiver (parents) and of their spouse as they enter the last of the three stages of burden of care

Young caregiver

- focus on needs caring for a young ID/DD child

Middle age caregiver

- transition needs as the ID/DD adult child and caregiver parent become older

Old caregiver

- refocus needs from caring for an older ID/DD adult to their own aging needs and those of their spouse as the caregiving role is ending

Facts about Parents Caring for an Older ID/DD Adult Child

- About 60% of adults with developmental disabilities live at home or with a family caregiver, 15% live with a spouse, and 14% live on their own
- About 25% or more of caregivers are age 60 or older and will be aging beyond their capacity to provide care over the next 10 to 20 years
- Growing evidence indicates that older ID/DD adults are providing caregiver support to aging parent(s), formerly their caregiver(s)

Concerns of Older Families Caring for an Older ID/DD Adult

- Families or households often face problems of increased complexity
- The unreliability or unpredictability of public funds underpins any sustaining supportive services
- Changing household composition and caregiver relationships increases stress
- The type of support families need to face the inevitable end of the caregiving role is complex

Changing Needs of Aging ID/DD Caregivers

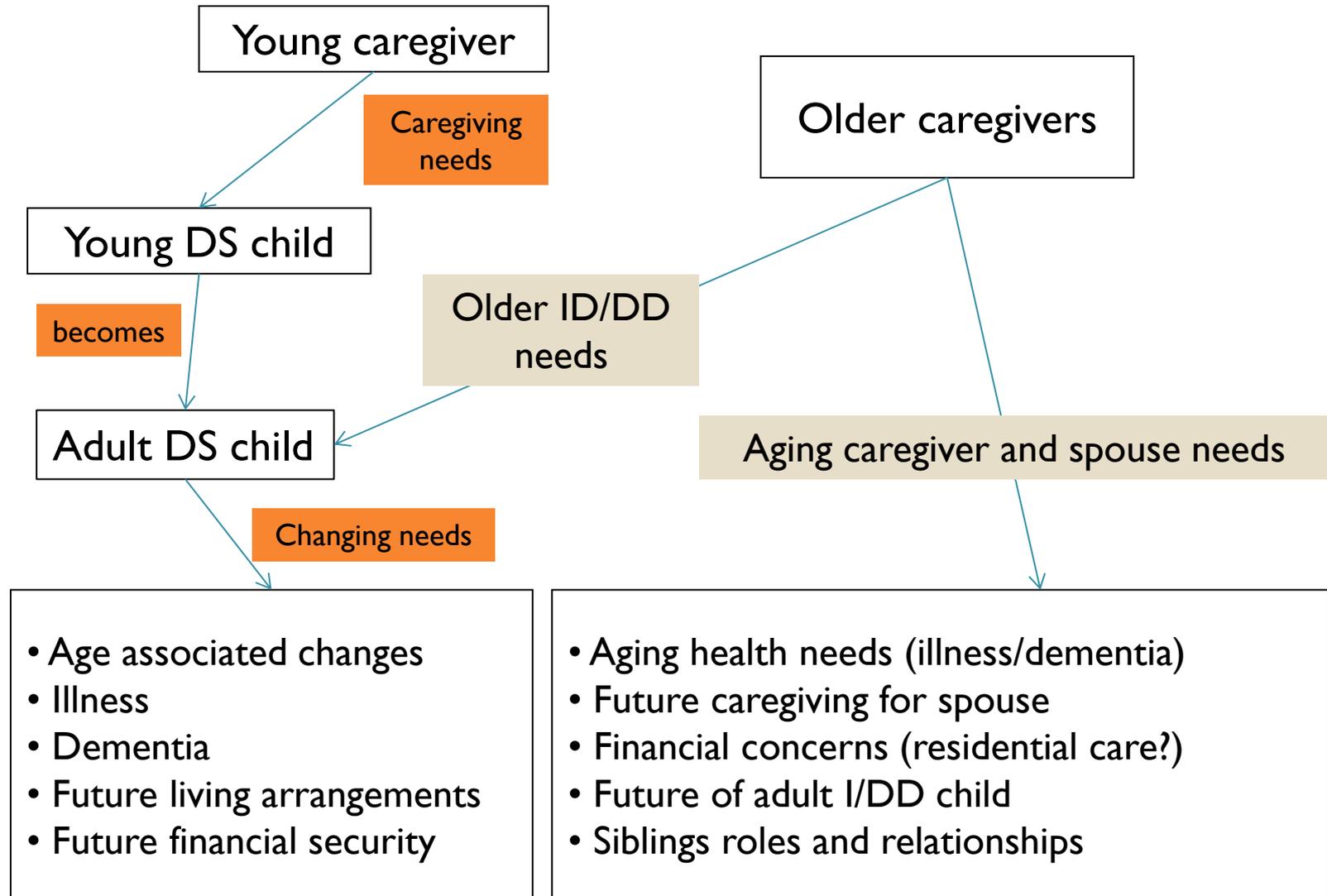
Younger Caregivers (<70)

- Parents or grandparents in 60s *Third age issues (retirement)
- Primary focus on the ID/DD child
 - financial & transition social-vocational programs, housing
- Challenge: supports for planned transition

Older Caregivers (70+)

- Parents or grandparents in 70s-90s *Fourth age issues (health issues)
- Primary focus on caregivers and spouses
 - health, housing, & social support issues
- Secondary focus on adult child
- Challenge: Avoiding precipitous housing for adult child

Complexity of the Changing Role of the Older Caregiver



Support Needs of Older Caregivers

Young caregivers also have the same needs, but older caregivers are vulnerable to exhaustion and burn out, increasing their risk for illness, hospitalization or residential care resulting in the collapse of informal caregiving role

- Day care/respice care
- Transportation
- Recreation opportunities
- Meals
- Trained providers
- Counseling
- Home-care services
- Alternative living arrangements
- Supportive social and health services

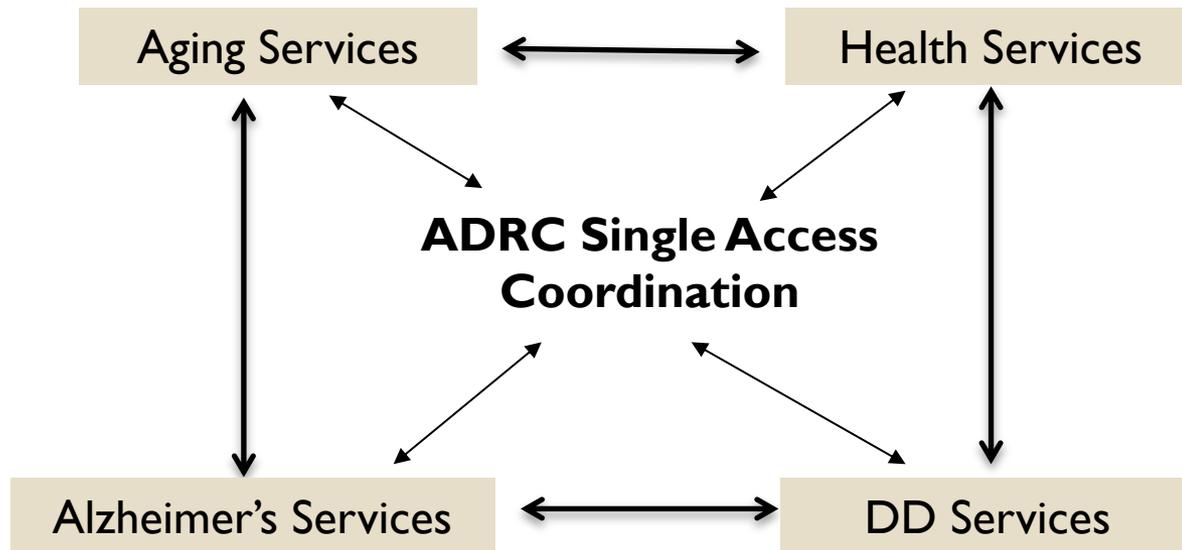
Stressors of the Changing Caregiver Role

- Changing family interrelationships among aging primary caregiver, their spouse, older ID/DD adult child, and siblings
- High probability that caregiver (spouse) may have additional caregiver role
- Reduced or lost ability to care for adult child due to poor health or emotional/physical exhaustion
- Siblings' response to possible caregiver role after parents are gone
- Future of adult ID/DD child after parents are gone
 - Financial support
 - Housing/future living situation
 - Caregiver
 - Independence

Older Parents . . .

- Want to maintain independence
 - To ask for help when need is felt
 - Help for self – then help for son or daughter
 - Help define caregiving and future on their own terms
- Have reluctance to be drawn into disability system – fear of re-institutionalization
- Want reduced frustration by having a single number to access services

Reducing Stress: Single Access Point to Service Networks for Support Needs



Many ADRCs provide a single access into the network of supportive services, allowing each agency, in turn, to coordinate their services with others to meet the needs of aging parents and their older ID/DD adult child.

Comprehensive Coordinated Care Plan to Reduce Risk of ACSC for Parent and Child

- Sharing resources among the provider networks reduces cost (staff, funds, equipment, buildings, etc.)
- Coordinated approach to helping individuals and families by reducing duplication of effort, services, and cost
- Reducing barriers causing disparities in accessing health care by:
 - Targeted training and shared information/referral
 - Coordinated approach to helping individuals and families

Preparing Aging Parent for a Changing Role

- Explain the physical and behavioral aging changes they and their aging ID/DD older child will experience
- Help them understand dementia and changes they need to notice and document
- Help them understand their role as a aging caregiver will change with increased stress levels as the caregiving role is reduced

Preparing Aging Parent for a Changing Role

- Help them understand the need for planning for their future health care needs and those of their older ID/DD adult child
- Explain they must be an advocate and be involved in the health care planning or transitional care planning with the health care network for their ID/DD adult child

Staff Outcomes

1. Recognize that comprehensive coordinated care planning must accommodate the changing role and the service needs of the elderly informal (parent) caregiver and their aging ID/DD adult child
2. Understand the types of stress on the aging informal caregiver as their role changes from caring for a younger ID/DD child to an aging adult child
3. Recognize that the older informal caregiver should be asked what they want/need and involved in any comprehensive coordinated or transitional care plan

Strategic Planning

1. Implement an educational program for older informal caregivers and their older ID/DD adult child on what to expect from the aging process (supplemental session in this series is for caregivers)
2. Implement an educational program for staff on the changing role of the older adult informal caregiver and what stresses will be encountered
3. Develop a training program for the informal caregivers on how to document changes (see handout) and how to advocate for their older ID/DD adult child with health care professionals

Part 2

° **Environmental Barriers
to Successful Aging**

Purpose

- To be aware that changes in both the aging caregivers and the older ID/DD adults do not create barriers to independence but increase the risk that the environment may become a barriers to independence



Age related/associated changes in three areas increase the risk of the environment becoming a barrier

1. Changes in the senses
2. Muscular changes
3. Changes in the joints

Changes in Senses – Vision

Aging Changes in Vision

- Central vision Impairments
 - Difficulty with seeing in front affects ability to read, see signage, recognize people
- Reduced ability to see in dark or dim lighted areas
- Increased glare from bright light or reflective surfaces
- Difficulty with busy patterns, increased background interference

Environmental Barriers that Lessen Independence

- Unable to adjust to changing environment increasing risk for:
 - Confusion and dementia like symptoms
 - Increased risk for falls and broken bones
 - Increased withdrawal, isolation, and reduced interest
 - Changes in behavior

Environmental Modifications for Vision Changes

- Increase lighting at night between bed and bathroom; use motion detectors
 - Decrease light bulb glare (use fluorescent bulbs)
 - Direct light away from eyes on to objects or area; use hats with visors
 - Use low gloss waxes and paints to decrease shiny surfaces, uniform lighting in area to reduce shadows, use sunglasses
 - Reduce confusing patterns (rugs, wall, furniture)
 - Use contrasting colors between furniture, floors and walls, and edge of steps, textured wallpaper
 - Carpeting on matted floor surfaces
- Remember – You cannot judge the amount of light needed, you have to adapt to their visual environment and ask them.**

Changes in Senses - Hearing

Aging Changes

- Increased hearing threshold - especially high frequency sounds such as children or females voices
- Increased background noise interference
- Wax build-up in ear
- Increased tinnitus – ringing in the ears

Environmental Barriers that Lessen Independence

- Confusion and dementia like symptoms due to inability to hear well
- Reduction in answering or giving wrong answers
- Increasingly withdrawn, isolation, and reduced interest
- Changes in behavior

Environmental Modifications for Hearing Changes

- Addition of soft materials, such as rugs, into the environment to absorb loud noises
- Reduction of hard surfaces which echo sounds
- Reduction of background noises from appliances, conversation, street noise which compete with listening
- Talk slowly, at eye level, so lips can be seen. (mustaches and beards interfere with ability to see lips)

Changes in Senses – Touch

Aging Changes

- Decreased sensitivity to touch
- Reduced fine motor control of muscles – reduced skill in doing fine muscle tasks
- Reduced ability to feel pain or sense something is happening to their body

Environmental Barriers that Lessen Independence

- Frustration with limited ability to do former tasks due to reduced fine muscle coordination
- Visually impaired users of braille, may have difficulty reading

Environmental Modifications for Reduced Touch

- Use different tasks that do not require fine muscle skills
- Increase roughness of textiles or surfaces

Changes in Senses – Taste and Smell

Aging Changes

- Reduced ability to taste and smell
- Increased sensitivity to noxious or dangerous odors
- Reduced appetite

Environmental Barriers that Lessen Independence

- Poor nutrition – symptoms of dementia
- Behavior – argumentative, refusal to eat, disruptive during meals, complain food does not taste right

Environmental Modifications for Smell and Taste Changes

- Reduce noxious odors in environment
- Awareness that inappropriate behaviors may be related to noxious odors or hunger
- Bake before meals to stimulate appetite
- Many small snacks throughout the day
- Increase food seasoning
- Improve the appearance of food

Changes in Proprioceptor (Balance) and Vestibular (Orientation) Senses

Aging Changes

- Proprioceptors – reduced ability to identify relative position of parts of the body and strength in movement (balance)/equilibrium)
- Vestibular senses – reduced ability for self orientation in environment (vertigo)

Environmental Barriers that Lessen Independence

- Isolation – does not want to go out due to disorientation when environment has multiple sensory inputs (shopping mall)
- Fear – increased problems with balance increases anxiety

Environmental Modifications for Mobility

- Increased cueing in the environment to reduce falls
- Marking of personal space and objects
- Use chairs with arms and instruction to stand up slowly while holding on to a stationary object
- Decrease accessibility barriers that may lead to disorientation
- Adaptive equipment for ease of movement and independence
- Removal of throw rugs

Changes in Muscle

Aging Changes

- Moderate (15%) loss of muscle mass but if no exercise, then 30% loss
- Increased upper body weakness reducing ability to support body

Environmental Barriers

- Difficulty opening doors, turning handles
- Reduced ability to complete tasks that require strength
- Increased risk for falls due to lack of strength

Environmental Modifications for Mobility

- Performing upper body muscle strengthening exercises
- When standing or turning hold onto something solid
- Stand up slowly or with help
- Change doors and handles for ease of opening
- Have appropriate height chairs for ease of standing up from sitting position (should not be soft that one sinks into cushion)
- Reduce weight of objects (including clothing, tools, and utensils)

Changes in Joints – Arthritis

Aging Changes

- Deterioration of shoulder, knee, hip joints
- Reduced range of motion of arms limiting activities

Environmental Barriers that Lessen Independence

- Difficulty in standing up, moving
- Behavior changes due to pain of movement
- Reduced activity due to pain when moving
- Reduced ability to turn knobs or faucets, etc.

Environmental Modifications

- Change handles, knobs etc. for ease of gripping and turning
- Make modifications to chairs, etc. for ease of standing up or sitting down
- Place all utensils, etc. at a level for easy access
- Make clothes easy to put on (reduce buttons, zippers, hooks etc.)

Staff Outcomes

- Observe changes in behavior or ability that may be limited by the environment being a barrier to changes in senses, muscles or joints
- Consult health care professionals (PT/OT) for possible changes in the environment that limit ability
- Help older parents and older ID/DD adult understand the changes in senses, muscle and joints and how it may limit activities without them being aware of the changes

Strategic Planning

- Develop a check list of possible environmental barriers (home and facilities) that can be modified
- Develop a training program for staff on the change in senses, muscles and joints
- Develop a training program for parents on the change in senses, muscles and joints they and their adult child may experience