Growing Older: Implications for People with Intellectual & Developmental Disabilities
Module 3: Aging in Place: Developing Appropriate Community Supports

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Aging in Place: Developing Appropriate Community Supports examines current challenges faced by aging individuals and their caregivers. Discussion focuses on developing strengths-based, person-centered approaches to assisting individuals to exercise choice, self-determination, and autonomy in making decisions around future planning and accessing community supports.

Housekeeping & Introductions

Aging in Place: Developing Appropriate Community Supports examines current challenges faced by aging individuals and their caregivers. Discussion focuses on developing strengths-based, person-centered approaches to assisting individuals to exercise choice, self-determination, and autonomy in making decisions around future planning and accessing community supports.

Learning Objectives

- Describe the benefits of aging in place
- Become familiar with principles of self-determination and person-centered planning
- Identify safety concerns and staffing supports necessary in designing a community-based environment for an aging adult with ID/DD, including environmental modifications
- Be familiar with Olmstead, ADA, ACA
Learning Objectives (cont.)

- Identify resources for accessing necessary supports including community agencies, family networks, faith-based communities
- Become familiar with issues caregivers confront as part of providing supports to aging individuals with ID/DD

Demographics of People with ID/DD

- In 2000, 641,000 persons with ID/DD above 60
- Life expectancy for people with ID/DD has increased significantly; common life expectancy for all groups is 66
- For example: In 1930 average life expectancy for a person with Down Syndrome was 9 years; now it is 60
- Life expectancy for people with other etiologies of ID/DD was 20 years, now it is 72


Caregivers Are Also Aging

- 75% of people with ID/DD are living with family members — estimate 480,000 adults
- 78 million “baby boomers” — people born between 1946 & 1964
- Some families are “two-generation” elderly families — both caregiver & care recipient are 60+
- Older caregivers also at risk for dementia or other health issues
- Person may no longer be able to live with family

Source: www.albany.edu/aging/IDD/documents/Aiding_older_caregivers.pdf
Aging & People with ID/DD

- People with mild/moderate ID/DD age at the same rate & in the same ways as people in the general population:
  - Similar longevity
  - Aging affected by lifestyle, genetics, general health habits, historical medication use
  - Age-related changes often include reduced vision & hearing, pain in joints, weight gain, discomfort due to menopause, susceptibility to illness and age-related conditions

People with Down Syndrome & Cerebral Palsy - Increased Risks

- People with Down Syndrome experience “accelerated aging” — increased risk of dementia, hypothyroidism, gastrointestinal issues, atlanto-axial instability
  - 25% will be affected by dementia after age 40
  - 50-70% after age 60
- People with Cerebral Palsy — age-associated complications as the result of chronic immobility — increased contractures, increased risk of fractures, additional mobility challenges

Considerations for Supports

- People with dementia will require special accommodations as loss of cognitive function progresses
- Individuals with cerebral palsy will also require environmental modifications to assure safety and accessibility
- Individuals without these additional risk factors may not need supports immediately but are likely to require them eventually
Enhanced Residential Supports

- Increased needs for hands-on assistance with personal care skills
- Environmental modifications to address ambulation issues, vision and hearing changes, cognitive decline
- Person may need additional caregiver supports, increased residential structure to maintain existing skills as long as possible

Edinburgh Principles

- Developed by Edinburgh Working Group on Dementia Practices at a collaborative meeting called by University of Stirling (Scotland), University of Albany (USA) & University of Illinois at Chicago (USA) in February 2001
- Tasks: define internationally applicable working practices for community supports for people with ID/DD affected with Alzheimer's Disease and/or other dementias
- Focus is on dementia but these are valuable guidelines for working with all individuals with ID/DD who are aging

For more information: [www.albany.edu/aging/DD/edinburgh.htm](http://www.albany.edu/aging/DD/edinburgh.htm)

Edinburgh Principles Based on a Four-Point Approach

1. Adopting a workable philosophy of care
2. Adapting practices at the point of service delivery
3. Working out coordination of diverse systems
4. Promoting relevant research
Edinburgh Principles

- Adopt an operational philosophy that promotes quality of life
- Affirm that individual strengths guide decision-making
- Involve the individual and family in all planning and services
- Ensure availability of appropriate diagnostic and service resources
- Plan and provide supports to optimize remaining in the community

Edinburgh Principles (cont.)

- Ensure that people with an intellectual disability have access to same dementia services provided to people who are not disabled others in the population
- Ensure that community dementia services planning also involves a focus on adults with ID/DD
- Ensure generic, cooperative, and proactive strategic planning across relevant policy, provider, and advocacy groups involves consideration of the current and future needs of adults with ID/DD affected by dementia

Questions?
Edinburgh Principles as Guidelines

Quality of Life
Strengths-based Person-Centered Planning
Aging in Place
Developing Community Resources

A Workable Philosophy of Care

Quality of Life

Maintaining Personhood

- Being a person is the fundamental philosophical and sociological position of a human being, with value, intelligence, a history and a present. The challenge in dementia is to continue to seek for and not to dismiss that person. —R.M. Lawrence

Source: Lawrence, R.M. Dementia: A personal legacy beyond words, mental health, religion and culture. 2007.
People Identify Quality of Life as...

- Remaining active – doing the things they enjoy, including work – this also preserves skills and strengths
- Maintaining social relationships with friends and family – sharing their lives with others
- Staying involved in community life
- Living in their own homes – whether a group home, personal residence, or with family

Quality of Life is Impacted by Aging ...

Complications of aging create physical, behavioral, and cognitive challenges & often involve loss

- Close friend or family member may die
- May need to move to another home
- Changes require adjustment to new routines/environment
- Age-related issues often result in a loss of independence
- May no longer be able to work

Additional Challenge: Aging Process Difficult to Understand

- ID/DD often inhibits a person’s ability to understand the changes that occur as part of aging
- Some may have trouble cooperating with rehabilitation and environmental supports—don’t understand the benefit, don’t like the discomfort
- Declining abilities and losses are confusing—person may feel anxious and frustrated without understanding why
New Behaviors May Emerge

Confusion about the aging process, declining abilities, new routines and needs, experience of grief and loss may be expressed in new behaviors:

- Avoiding social contacts, isolating
- Self-injurious behaviors
- Anxiety, agitation
- Angry outbursts
- Aggressiveness
- Loss of interest in activities

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Routines are Reassuring

- External routines provide a tool for orientation
- Familiar environments support the aging individual to feel “at home”
- Telling Time with the News: Jeff’s Story

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Protecting Quality of Life: Support Personhood

- Partner with the person to talk about new challenges he/she is encountering and work together to find ways to manage them
- Support individual’s right to make choices and decisions -- provide information and guidance without giving advice or being judgmental
- Help the person to maintain contact with friends and family and to continue to pursue interests
Charlie’s Story: “It’s Me Again!”

- Charlie lost his eye due to cancer
- Some “old culture” perspectives: “he doesn’t need a new eye - he can wear a patch”
- Charlie couldn’t express how disturbing it was to have no eye!
- “It’s me again!”

Collaboration and Peer Support

- Help people to work together to consider their unique aging experiences
- Provide education about aging, rehabilitation, nutrition, dementia
- Encourage people to talk to each other about their fears and discover of ways to help each other
- Discuss death and dying openly - these are issues everyone confronts

Create Circles of Support

- A network of people who care about the person and honor his or her unique personhood
- May include family members, friends, healthcare professionals, caregivers, community members
- Circle supports the individual’s strengths & abilities, facilitates opportunities, provides advocacy as needed
What Is Person Centered Planning? (PCP)

- PCP is care planning defined and designed by the person—person defines & includes what he/she believes is most important
- Plan evolves from the person’s choices and preferences
- Supports and enhances the person’s individual strengths, talents, personally-defined goals
- Required in developing a plan of care when providing HCBS waiver services
Person Centered Planning Process

- Driven by the individual (person is at the center)
- Strengths-based and outcome-focused
- Includes people the person chooses
- Supports the person to direct the process as much as he/she is able

Person Centered Planning Process

- Health and safety assured through services and supports
- Person chooses how and from whom he/she will receive supports
- Reviewed regularly & at the individual’s convenience
- Sensitive to person’s cultural background and spiritual beliefs
- Uses straightforward language - avoids clinical terms and acronyms

Person Centered Plans ...

- Empower the individual to be autonomous in making life choices, including end of life plans
- Ensure the person’s rights to privacy, dignity, respect, and freedom from coercion & restraint
- Support and facilitate the individual’s choices around services, service providers, caregivers
PCP is based on the Principles of Self Determination

- Freedom - to plan a real life: exercise the same rights as all citizens
- Authority - over resources
- Support - to build a life in the community of choice, to choose caregivers who will offer support
- Responsibility - to be fiscally responsible & to contribute to one’s community in a meaningful way

www.independentliving.org

What is self-determination?

“Self-determination refers to a characteristic of a person that leads them to make choices and decisions based on their own preferences and interests, to monitor and regulate their own actions, and to be goal-oriented and self-directing. A person acting in a self-determined way has a voice in the decisions that affect them and is causing things to happen in his or her own life.”

Source: Advising through Self Determination, retrieved from http://www.aucd.org/docs/Advising_Through_SD.pdf

Person identifies what is important
Aging Creates Challenges

- Empowerment to make decisions may be compromised by health and cognition issues associated with aging
- Initiate collaborative conversations with the person to acknowledge and cope with losses, health issues, and planning

Use Person-Centered Language

<table>
<thead>
<tr>
<th>Clinical</th>
<th>Person-Centered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive impairment</td>
<td>Often confused</td>
</tr>
<tr>
<td>Impaired ambulation</td>
<td>Difficulty walking</td>
</tr>
<tr>
<td>Depression</td>
<td>Feeling sad</td>
</tr>
<tr>
<td>Increased agitation</td>
<td>Get upset easily</td>
</tr>
<tr>
<td>Decline in skills</td>
<td>Harder to take care of myself</td>
</tr>
<tr>
<td>Visual impairment</td>
<td>Don’t see as well</td>
</tr>
<tr>
<td>Isolates self</td>
<td>Spends more time alone</td>
</tr>
</tbody>
</table>
Planning Ahead

NYSARC provides information on guardianship & advanced directives – documents are designed for use by people with ID/DD and their caregivers and families:

- Five Wishes: step-by-step manual to develop advanced directive
- Advance Health Care Directives: An Informational booklet on Health Care Decisions

Retrieve from: www.nysarc.org

Preserving Personhood: Remember Who the Person Is

- Personal identity - expressed through sentences using “I”
- Personality traits often define the person in our minds
- The way a person presents himself socially usually defines his “self” to others
- Illness and dementia can obscure the person’s self-hood


Keep the Person at the Center of Aging Supports

- Aging and dementia do not define who the person is— they are what happen to the person
- Develop advance directives and plans with the person while he or she is still able to participate actively
- New behaviors may be efforts to express pain, fear, anxiety—new territory for the person and the practitioner
- Continue to communicate with the person even when it becomes difficult
Begin Conversations Now

Demystify the aging process through straightforward conversations with the person and his/her caregivers:
- Talk about how aging is affecting the person -- changes in appearance, health, stamina, thought processes
- Initiate discussions around the person’s wishes for new supports/living arrangements to manage age-related needs
- Encourage caregivers to discuss their own aging issues & abilities to continue to provide care

Where to Begin...

- Where do you want to live?
- What things are most important for you where you live?
- Who are your closest friends?
- What other things do you like?
- What do you want to do during the day?

Create a Time Capsule

- A personal legacy from the person and to the person, prepared early in dementia
- Individual’s experiences, pictures, memories
- Cultural and religious beliefs, attitudes about death, dying
- Wishes around end of life care, advanced directives
- Humanistic inspiration - ideals, art, nature

Adapted from Lawrence, R.M. & Head, Julia H. A Time Capsule for Patients with Dementia. Journal of the Royal Society of Medicine, 2005.
Teddy's Story

- Record the person’s likes, dislikes, preferred activities, fears, capabilities, interests as part of advance planning
- Teddy and the White Food

Advance Health Care Directives (NYSARC)

- Provides information in easy to read format about
  - Choosing a health care agent
  - Life support treatments
  - Health care choices for end of life
  - Signing & witnessing the document
  - Changing the information, updating choices
  - Sharing the Advanced Directive

Retrieve PDF from www.nysarc.org

Five Wishes (NYSARC)

1) The Person I Want to Make Care Decisions for Me When I Can't
2) The Kind of Medical Treatment I Want or Don’t Want
3) How Comfortable I Want to Be
4) How I Want People to Treat Me
5) What I Want My Loved Ones to Know

Retrieve PDF from www.nysarc.org
Hospice is a Choice

■ Difficulties with making decisions does not preclude participation in advance care planning
■ Hospice maximizes autonomy in decisions for better end of life care
■ Be proactive around policy barriers to Do Not Resuscitate (DNR) orders or right to refuse life sustaining care
■ Promote collaboration of care between person, hospice staff and caregiver

Fannie’s Story Choosing Quality of Life

■ Fannie: a woman in her mid-70s, diagnosed with cancer
■ Chemotherapy offered to extend life by several months
■ Fannie chose hospice -- she did not want to use chemotherapy and experience the side effects
■ Fannie was clear that she wanted to say farewell to friends, make funeral arrangements, enjoy her remaining days

Questions?
Aging in Place: Adapting Practices at the Point of Service Delivery

Aging in Place

The ability to live in one's own home and community safely, independently, and comfortably regardless of age, income, or ability level.


Aging in Place Principles

- Individual planning
- Continuity of personal relationships
- Continuity of community
- Integration with generic supports

Aging in Place: Safety First

- Safe home: rehabilitation and environmental supports to meet the progressive & changing needs of people as they age
- Safe community: day programs with e-mods and sufficient protective oversight
- Safe relationships: caregivers and family who understand implications, process, and necessary supports associated with aging and dementia

Meeting Environmental Needs

- Accessible sites: ramps, wider doorways, raised toilet seats, tub rails
- Lighting for people with dementia & visual impairments
- Areas for quiet & calm moments
- Safe space to wander - inside and outside areas
- Room dividers to create spaces for privacy & one on one activities


Keep the Home Understandable

- Avoid confusing layouts, provide cues to navigate
- Use adequate lighting, and limit disruptive noises
- Select sturdy simple and versatile furniture
- Secure lightweight objects such as lamps
- Use red or yellow – more accurately perceived
- Use large-print signs to label familiar items
Home Safety: Address Clutter & Trip Hazards

- Install railings and hand grips at top of steps or stairway
- Use reflective tape to call attention to steps
- Replace steps with ramps if possible
- Replace raised doorsills with flat plates
- Keep areas free of clutter

Be Alert to Fall Risks

- Among older adults leading cause of fatal and non-fatal injuries
- Falls are preventable
- Most fractures in older adults are caused by falls
- Most common fractures are spine, hip, leg, arm, pelvis
- See Centers for Disease Control (www.cdc.gov) for more information

Why do fall risks increase?

- Vision changes (glaucoma, cataracts, diabetic retinopathy, not wearing glasses)
- Medications (sedatives, diuretics, blood pressure meds, muscle relaxers)
- Lack of exercise leads to muscle weakness
- Not using assistive devices like walkers or canes; not wearing appropriate shoes
Minimize Fall Risks
- Proper lighting
- Avoid cluttered spaces
- Provide handrails and grab bars
- Secure area rugs
- Secure electrical cords
- Keep eyeglasses, assistive devices close to person & encourage use

Assess Fall Risks Regularly
(www.cdc.gov)
Identify at-risk people:
- Fell in past year
- Feels unsteady when walking or standing
- Worries about falling

Evaluate gait, strength & balance

Educate the Person & Refer to:
- Community exercise programs
- Balance
- Fitness
- Fall Prevention Programs

Respond to gait or balance problems
(www.cdc.gov)
- Conduct Risk Assessment
  - Falls history
  - Physical exam
  - Postural hypotension
  - Postural dizziness
  - Cognitive screen
  - Med review
  - Feet/footwear
  - Mobility aids
  - Visual acuity

- Key Interventions
  - Education person
  - Enhance strength & balance
  - Improve functional mobility
  - Manage meds
  - Address foot problem
  - Vitamin D: calcium
  - Optimize vision
  - Optimize home safety

- Patient Follow-up
  - Review patient education
  - Assess & encourage adherence to recommendations
  - Discuss & address barriers to adherence
**Home Safety: Bathrooms**

- Safety rails
- Raised toilet seats
- Walk-in showers
- Shower chair
- Adjustable shower hoses/nozzles
- Scald-protection devices

**Safety in the Bedroom**

- Remove wheels to prevent bed from rolling
- Adjustable height hospital bed if needed
- Install bedside light and remote control switches for TV, radio
- Intercom, or bedside phone
- Urinal or commode if needed at bedside
Home Safety: Kitchen
- Meals on wheels—reduce use of stove & assure nutrition
- Auto shut off for electronic appliances
- Place commonly used items in easy reach
- Increase number of lights
- Contrasting colors in china or placemats
- Bright colored handles on utensils

Safety in the Living Room
- Automatic seat lift chair
- Good armrests to push up on
- Firm back and seat cushions
- Avoid rocking chairs
- Relocate furniture so pathways are not obstructed
- Touch sensitive light switches, contrast color for light switch plates

Managing Stairs
- Stair lift, ramps if needed
- Provide handrails
- If unable to climb stairs, keep second walker available at top or bottom of stairs
- Remove loose rugs
- Mark edge of each step with bright colored tape
Assuring Fire Safety

■ If unable to hear alarms or smoke detector, have blinking lights or vibrating surfaces
■ Have alternative exit in case of emergency/ practice fire drill plan
■ Adequate lighting on stairs and hallways
■ Night lights, change bulbs when dim
■ Lever door handles instead of doorknobs

Managing Wandering

■ Medical alert programs in community settings
■ Wanderguard or bed/chair alarms in hospital or rehab facilities
■ Provide supervision and/or secure areas to walk indoor and outdoors
■ Keep the person involved in activities
■ Redirect pacing or restless behavior
■ Use calming techniques, quiet areas, music

Habilitation Focus Changes

■ Needs increase, skills decline
■ Sustainable programs accommodate changing needs
■ “Memory appropriate” activities vs. “age-appropriate” activities
■ Maintain skills rather than teach new skills
■ Enjoyable activities vs. activities requiring active participation
**Additional Age-Related Challenges When Taking Meds**

- Skills may affect a person’s ability to self-medicate: provide supports
  - Memory loss: difficulty remembering to take meds (use pillboxes or reminder calls)
  - Impaired vision: difficulty reading labels
  - Dexterity: difficulty opening bottles, inability to break tablets, difficulty handling inhalers
  - Difficulty swallowing large tablets or capsules

**Demographics of Caregivers**

- 65.7 million or 29% of U.S. population are caregivers of ill or disabled person
- Many caregivers of older adults are age 63+ and facing their own health issues
- 641,000 age 60+ adults with ID/DD and number expected to double by 2030
- 49% of aging caregivers report that they must use assistance programs to continue providing care

**Sources**: National Alliance of Caregiving & AARP 2012

**Aging Caregiver Fears**

- Reduced ability to provide care
- Meeting increased needs of person in their care
- Dealing with their own health needs
- Emotional and physical exhaustion
- Inadequate community supports or access to programs for assistance
Help Caregivers Understand the Person's Experiences

Teach strategies to support and preserve the person’s strengths:
- Individualize activities based on the person’s changing abilities & interests
- Use a multi-sensory approach - provide activities that are both calming & stimulating
- Simple exercises often most effective --music, art, aromatherapy

Help Aging Caregivers Plan for Alternatives

- Can siblings takeover?
- Availability of alternate caregivers
- Placement plan in event of illness or death of a caregiver
- Community supports to continue current placement

Talk with Caregivers

- Aging caregivers may no longer be able to provide a previous level of support
- Encourage family caregivers to identify their personal goals for retirement and health care
- Discuss plans for their family member’s care - who will care for this person in their absence?
- Develop a “wish list” for their family member and help them to prioritize and actualize these wishes
- Collaborate to identify community resources to make their plans and wishes reality

Aiding Older Caregivers; retrieved from www.albany.edu/aging/DD
Louise's Story: A Party with Cake and Yellow Icing

- Louise was diagnosed with multiple issues - right-sided heart failure, pulmonary edema, physical anomalies
- Louise wanted to die at home but her caregiver of many years was afraid
- Grief & loss associated with change of home
- Supporting dignity and choices

QUESTIONS?

Person-Centered Approaches
Managing Specific Issues
Bereavement

Managing Grief and Loss

What is Grief?
- A complex response to loss (or the threatened loss) of a loved one
- Person may also grieve the loss of a thing or a place to which he/she is attached -- change of home, inability to participate in an activity or work
- Grief and grieving can be prolonged and complicated

Grief Issues for People with ID/DD
- People with ID/DD are as vulnerable to grief over loss as anyone else -- it’s a myth that people with ID/DD don’t grieve
- Person’s ability to work through the experience of loss and bereavement is prolonged and complicated if it is ignored
- Avoid misunderstanding & confusion: discuss death and grieving with the person frankly
Experiencing Grief and Loss

- Persons with DD/ID may struggle to make sense of the loss – “how could this happen?”
- They need help to understand what has happened & why they feel as they do
- Common experience of bereavement: the world is no longer viewed as a safe and predictable place

Bereavement May Include Multiple Losses

- Death of a caregiver may mean a change in living arrangements, day services, community
- Leaving old friends & needing to develop new relationships
- Give the person time to adapt to life changes -- talk about what has happened, discuss feelings

Common Grief Responses

- Physical: fatigue, sleep & appetite disturbances
- Emotional: anger, anxiety, sadness
- Cognitive: confusion, disorientation
- Social: withdrawal from friends, isolation
Supporting the Person
- Help the person to understand the loss
- Encourage the person to take part in ceremonies & rituals to honor the deceased
- Be aware that expressions of grief can be delayed -- the person may need time to understand the permanence of loss
- Therapy can help -- see a professional grief counselor trained in helping people with ID/DD

Managing Challenging Behaviors
New Behaviors Emerge in Response to Aging & Dementia

Behaviors and Communication
- Challenging behaviors are common for people with dementia
- People with ID/DD may not know how to communicate discomfort associated with common aging issues
- Behavior may be a response to pain, depression, confusion or other issue
- The person is often struggling to communicate a need or an attempt to change something in his/her environment
Coping with Difficult Behaviors

- Work as a team with other caregivers - provide mutual support to each other as well as to the person
- Try to understand the meaning of the behavior
- Does the behavior create a problem? Consider managing the problem rather than the behavior


Meaning of Some Behaviors

- Hostility/Aggression: attempt to isolate, expresses frustration
- Agitated/Attention-Seeking: person may need companionship, may be frightened, anxious, or in pain
- Property Destruction: Often an attempt to self-soothe (tearing paper)
- Disrupting others’ activities: often a response to noise and confusion in the environment


Behavior as Communication

- Resistance to Care: lack of cooperation or response to caregiver’s attempt to help - may indicate pain, discomfort
- Wandering: may be a side effect of medication (restlessness), may indicate boredom with current environment
- Hoarding, rummaging: common behavior, may indicate anxiety, fear of loss
- Loss of interest in activities, isolation: may signal depression, evaluation necessary
- Delusions: common in people with dementia; respond with reassurance and re-direction; psychotropic meds may help

Coordination of Diverse Systems

Accessing Resources

The 4 C's: Tools For Providing Supports

- Collaboration: partner with community groups, faith-based resources, local universities, provider agencies
- Communication: develop networks and circles of support; identify healthcare providers and professionals who are good listeners, advocates, and use a person-centered approach; teach them about who the person is
- Creativity: explore new ways to maintain the person's quality of life and person-hood; advocate strongly and purposefully
- Commitment: be proactive in researching, developing and accessing supports

Build Your Own Circle of Support

- Learn about federal and state initiatives
  - Visit websites for federal, state, & local agencies -- information abounds!
  - Resources from other states are often helpful in developing solutions for the people you work with
  - Initiate contacts with people who do what you do in another state - sharing information keeps you informed and excited about your work
Person-directed Dementia Care Assessment tool
- See tool on evaluating environment to determine strengths and improvement areas
- Retrieve from: www.dhs.wisconsin.gov
  (Enter aging and Person-Dementia Care Assessment Tool into search option)
- Not intended for diagnosis—Discuss results of dementia assessments with healthcare professionals as part of routine wellness visits and if results indicate significant changes

Learn about Local Options
- Explore residential settings that offer "progressive supports" for aging individuals
- Develop & access caregiver support networks in your local community

Develop Relationships with Healthcare Professionals
- Network with healthcare professionals who have a person-centered focus
- Encourage them to participate in circles of support for individuals they serve
- Build a team of person-centered care providers:
  - Occupational Therapists
  - Social Workers, Therapists
  - Nurse
  - Physical Therapists
  - Hospice
D.J’s Story

- D.J: a man with cerebral palsy; non-verbal, non-ambulatory, ADL dependent
- Communicates well using a chatterboard & computer-assisted technology
- Developed scoliosis & was hospitalized during hospitalization hospital staff reported he couldn’t communicate
- Chatterboard was in a corner of the room -- not accessible to D.J.

Stay Informed about Federal Initiatives

- Affordable Care Act (ACA)
- Olmstead
- Changes to requirements/guidelines for Medicaid/HCBS Waivers

Affordable Care Act (ACA)

- Extends Money Follows the Person to 2016: funding for supporting individuals with disabilities in their communities; special focus on the elderly
- Explicitly provides coverage for ID/DD and mental health disabilities
- Covers habilitative & rehabilitative services
- Covers devices including durable medical equipment, prosthetics, orthotics
- Supports evidenced-based and community-based prevention & wellness services
Olmstead Litigation & Plans

- 1999 litigation in Georgia: Tommy Olmstead, Commissioner v. plaintiffs L.C. & E.W.
- L.C. & E.W.'s continued stay in an institution was viewed as discrimination according to the Americans with Disabilities Act - identified mental illness & developmental disabilities as covered by the ADA
- "Integration mandate" - state & local governments must provide services "in the most integrated setting appropriate to the needs of qualified individuals with disabilities" – must develop an "Olmstead Plan"

Olmstead is enforced throughout the country

http://www.hhs.gov/ocr/civilrights/understanding/disability/serviceolmstead/

Aging & Disability Resource Centers (ADRC)

- Collaborative effort of the Administration on Aging & Centers for Medicare & Medicaid
- Local centers provide information about aging resources and benefits
- Provide assistance in finding appropriate services
- Information on Benefits Management
- Connections to wellness programs
- Search on web for local ADRCs
1. Most individuals (75%) with ID/DD live with family members.
2. Person-centered planning is not appropriate for aging individuals.
3. The Edinburgh Principles define practices for community supports for people with ID/DD affected with Alzheimer’s Disease and/or other dementias but are useful in designing supports for all individuals with ID/DD who are aging.
4. Individuals with ID/DD should be excluded from participating in rituals and ceremonies associated with a loved one’s death because they don’t understand.

Post-Test: True or False?
5. Mobility risks can be addressed through environmental modifications including hand-rails and ramps.
6. People with cerebral palsy are more likely to develop dementia than people with Down Syndrome.
7. Hoarding and rummaging may be a common behavior for someone experiencing dementia.
8. Individuals with ID/DD should not be included in developing an advanced directive because it is too upsetting.
9. ADRCs provide information and assistance about local resources for aging individuals.
10. The Olmstead decision includes an integration mandate for all states.
Answers

1. True   6. False
2. False  7. True
3. True   8. False
4. False  9. True
5. True   10. True

Discussion

Thank You!!!

Please Contact Lisa Zimmerman with any questions:
lisa@nyrehab.org