

AGING WITH DISABILITIES

Aging and Disability

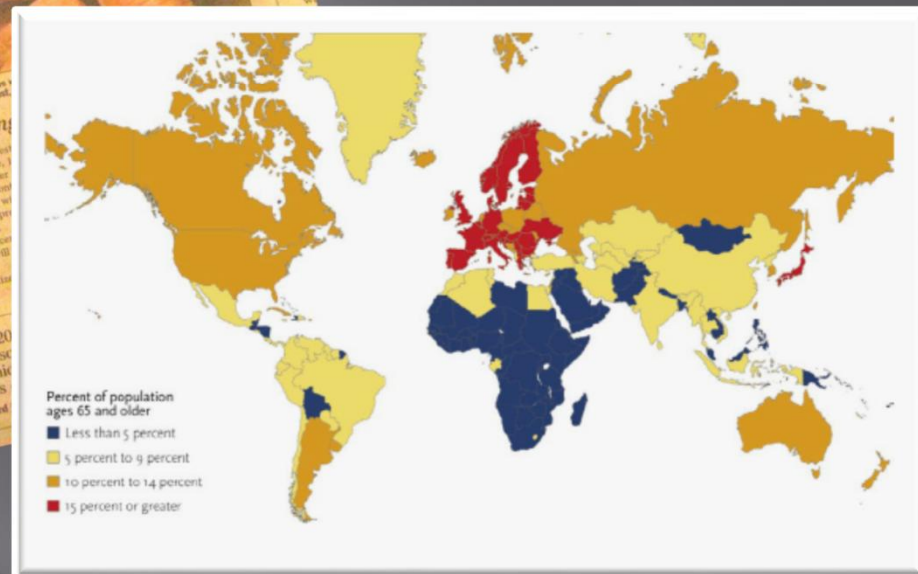
- ▣ Older people with intellectual and developmental disabilities have the same needs as other older people
- ▣ The increasing life expectancy of people with intellectual disability is now an established fact
- ▣ Older people with intellectual disabilities are subject to compound stigmatization for being both *older* and *disabled*
- ▣ Millions of adults with intellectual and other developmental disabilities are still living with their families

Older Adults with Disabilities Have Complex Needs

- ▣ Take individuals with Cerebral Palsy (CP) as an example. Common problems reported by people with CP as they get older include:
 - ✓ Increased pain and discomfort especially in joints resulting in less flexibility
 - ✓ Increased spasms
 - ✓ Increased contractures
 - ✓ Digestive difficulties
 - ✓ Increased incontinence
 - ✓ Fatigue
 - ✓ Weight gain or loss

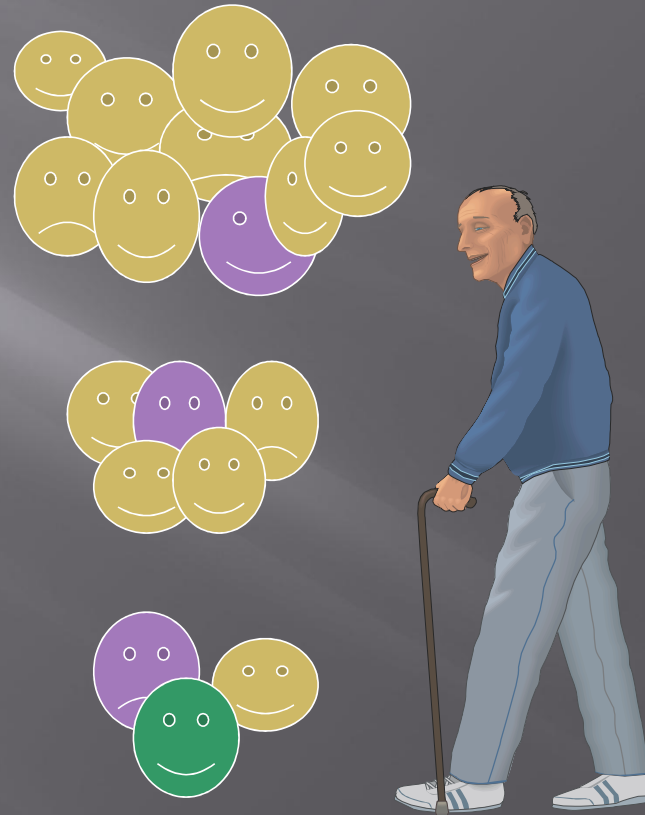
Percent of national populations age 65 and older

By 2018, 65-year-olds will outnumber children age 5 and under...

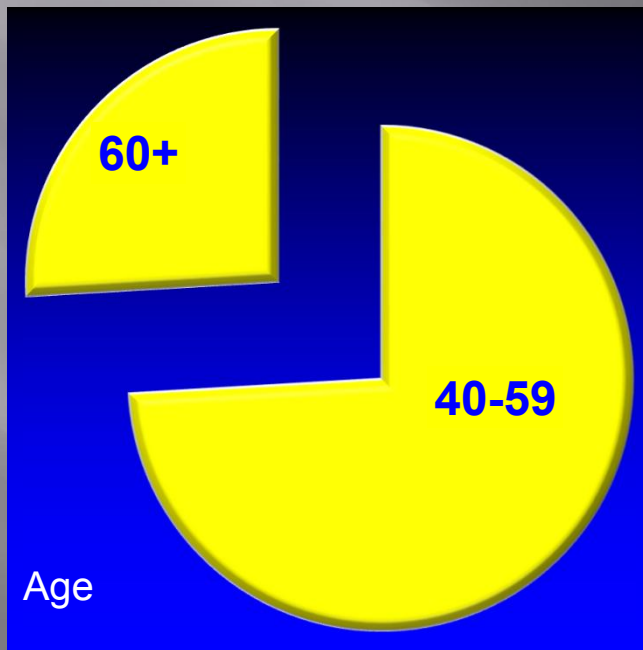


Changing Older Population

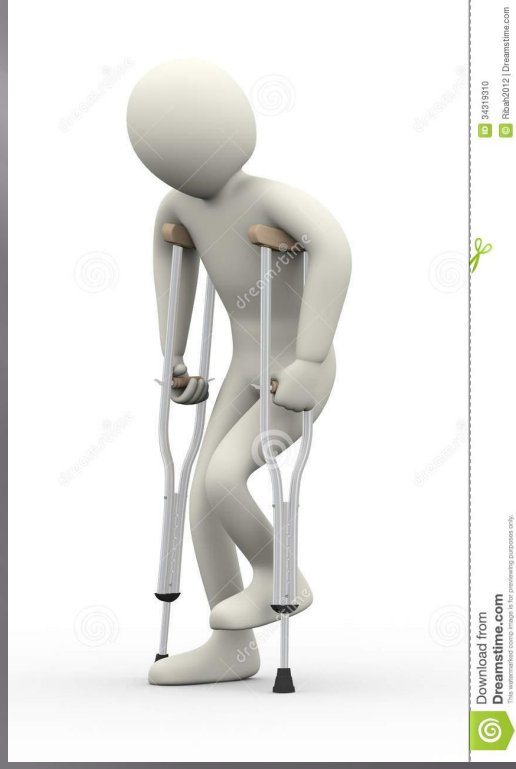
- ▣ **2000** - 1 of every 10 persons was 60+
- ▣ **2050** - 1 of 5 will be 60+
- ▣ **2150** - 1 of 3 will be 60+



Proportion of older population of adults w/intellectual disabilities



- Currently about 75% of all older adults with intellectual disabilities are in the 40-to-60 age group
- Expectations are that the 60+ age group will increase threefold over the next 20 years



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Never Too Old or Disabled to Exercise!

- ▣ Exercise is a great way to improve health, physical functioning and well-being
- ▣ Exercise can improve strength and mobility
- ▣ Exercise can improve balance and help prevent falls
- ▣ Exercise can improve mood, decrease fatigue, lower blood pressure and cholesterol
- ▣ Exercise can improve self-esteem and increase clarity of thinking
- ▣ Physical Activity can improve sleep, prevent weight gain and improve bowel and bladder function

Keeping up with exercise

- ▣ Keep a positive attitude
- ▣ Find physical activity that you enjoy
- ▣ Find an exercise environment that is comfortable for you – some people like to take classes, other do not feel comfortable in a gym
- ▣ Add a social component by having a friend to walk with, a walking club or join a bowling team
- ▣ Make exercise a habit. Some form of physical activity should be part of a daily routine

Sleep



Sleep and Aging with Disability

- ▣ Not sleeping well can negatively impact upon your sense of well-being and can worsen other conditions such as Depression, Anxiety, Pain, Fatigue and Irritability
- ▣ Common sleep problems include:
 - Insomnia
 - Sleep apnea
 - Excessive daytime sleepiness/extreme drowsiness
 - Restless Leg Syndrome
 - Bruxism

How does age affect sleep?

- ▣ Brain injury may cause the brain to be less efficient in “telling” the body to sleep or awaken; it may affect that chemicals within our bodies that help us start to sleep, remain sleeping or stop sleeping
- ▣ The body’s ability to regulate breathing may change resulting in sleep apnea
- ▣ Inactivity, lack of exercise, or daytime napping can interfere with sleep
- ▣ Chronic pain or discomfort may affect sleep
- ▣ Difficulties with sleep are a common symptom of depression, anxiety and mood problems

Medications that can cause sleep problems

- ❑ Most over-the-counter sleep aids contain antihistamines and are not recommended for people with brain-related disabilities because they can cause a disturbance of memory and new learning
- ❑ Many prescription “sleep meds” are only recommended for short-term use and should not be used for longer than 2 weeks without a doctor’s management and can actually worsen sleep problems
- ❑ Some sleep medications can be addictive and the body builds a tolerance to them
- ❑ Need for medical supervision in tapering medication; never stop medication abruptly

What can be done during the day to improve sleep?

- ▣ Set an alarm to wake up at about the same time every day
- ▣ Include meaningful activities in your daily schedule
- ▣ Get off the couch and limit TV watching
- ▣ Exercise every day
- ▣ Get outdoors for some sunlight during the day
- ▣ Limit napping to no more than 20 minutes during the day

What can be done at night to help sleep?

- ❑ Go to bed at about the same time every night
- ❑ Follow a bedtime routine
- ❑ Avoid caffeine, nicotine, alcohol and sugar for at least five hours before bedtime
- ❑ Avoid eating prior to sleep to allow time to digest but do not go to bed hungry
- ❑ Do not exercise within 2 hours of bedtime but stretching, meditation or a warm bath before bed may help with sleep
- ❑ Do not eat or watch TV while in bed
- ❑ Try not to have a computer in the bedroom or shut it off prior to bedtime
- ❑ If you do not fall asleep within 20 minutes, get out of bed and do something relaxing or boring until you feel sleepy

Maintaining Health



Fatigue and Aging with Disability

- ▣ Fatigue is a feeling of exhaustion, tiredness, weariness or lack of energy that significantly interferes with what you want to do:
 - ✓ Physical: feeling like you are tired and need rest
 - ✓ Psychological/emotional: lack of motivation to do anything, feeling “spent”
 - ✓ Mental: difficulty concentrating or staying focused

Can be addressed via nutrition, rest (naps), being more efficient, looking at medication side-effects, exercise, managing stress

Fall Prevention for Older Adults with Physical Disability

- ▣ There are both physical and emotional consequences from falling
- ▣ Physical consequences may include cuts, scrapes, bruises, sprains, broken bones, TBI
- ▣ Emotional consequences may include fear of falling which leads the older adults to decrease outings and social activities, greater anxiety, depression, lack of physical activity, reduction in overall health and independence
- ▣ Risk factors include poor balance, coordination or walking problems, poor vision, muscle weakness caused by physical disability or inactivity

Depression and Aging with a Disability

- ▣ Older adults are at higher risk for depression. Depression is a treatable medical condition that often goes untreated because:
 - ✓ People think depression is a normal part of aging (it is not!)
 - ✓ Some people are ashamed to admit they are depressed because they see it as a sign of weakness or a character flaw
 - ✓ Older people report more physical symptoms of depression such as difficulty sleeping and loss of appetite than younger adults
 - ✓ The loss of social supports and potential isolation can worsen depression in older adults

What are the symptoms of Depression?

- Feeling down or change in mood with increase in irritability
- Loss of interest in activities or not enjoying activities that you formerly enjoyed
- Changes in appetite
- Changes in sleep
- Lack of energy/ feeling fatigues
- Cognitive changes such as difficulty concentrating, making decisions, memory problems
- Feeling worthless, hopeless and guilty
- Thought of death or suicide

What can the older adult do to address depression?

- ▣ Depression can affect your ability to function on a daily basis
- ▣ Depression can worsen pain, take away enjoyment and make it more difficult to be as independent as possible
- ▣ Regular exercise is known to improve mood
- ▣ Eating a balanced diet
- ▣ Getting enough sleep
- ▣ Doing activities you enjoy including social activities
- ▣ Meditation or mindfulness-based practice or faith based practice
- ▣ Being outside exposed to natural light

Behavioral Aspects of Aging with Disabilities

- ▣ There is nothing about aging in itself that should lead to a significant change in behavior
- ▣ However, some individuals experience changes in their ability to control their impulses due to cognitive changes over and above the cognitive challenges due to their developmental disorder
- ▣ Individuals may develop a condition known as BPSD- Behavioral and Psychiatric/Psychological Symptoms of Dementia

What is BPSD?

- ▣ As individuals age, they may experience changes in thinking, memory, judgment and behavior associated with dementia
- ▣ These are changes that are in addition to challenges the person experiences by virtue of their intellectual or developmental disability and cause *excess disability*
- ▣ **BPSD**= Behavioral and Psychiatric Symptoms of Dementia
- ▣ A key is that individuals who develop these problems did not have behavioral or psychiatric problems (to this extent) prior to the onset of dementia

BPSD-psychiatric symptoms

- ▣ Sometimes people develop psychiatric symptoms within dementia
- ▣ Individuals may develop moodiness and may experience hallucinations
- ▣ This is not a psychiatric illness in the usual sense that we think about it — it is related to the brain changes associated with dementia
- ▣ Sometimes medications can help but often the main strategy is environmental management of triggers

Cognitive Aspects of Aging with Disabilities

- ❑ Memory problems that interfere with everyday functioning
- ❑ Problems in orientation to time, place or person (presuming that the person was previously oriented in these spheres)
- ❑ Slowing down in movement, thinking and processing information
- ❑ A coarsening of social behavior
- ❑ Increased impulsivity
- ❑ Difficulty with new learning
- ❑ Change in ability to communicate (impoverishment of communication)
- ❑ Problem pursuing well-learned routines and activities
- ❑ Confusion in familiar places

Social and Emotional Aspects of Aging with Disabilities

- ▣ Loss of family members
- ▣ Loss of friends and peers
- ▣ Loss of work
- ▣ Loss of abilities

- ▣ Higher likelihood of depression, self-isolation
- ▣ Encourage individuals to remain active and pursue mental and social stimulation

Successful Aging with Disabilities

- ▣ Involves the same recipe as does successful aging without disabilities!
- ▣ Exercise
- ▣ Sleep
- ▣ Nutrition
- ▣ Mental Stimulation
- ▣ Social Stimulation
- ▣ Limit use of caffeine, alcohol, nicotine

Communication

Only 10% of communication
is verbal.

90% of communication is
non-verbal.



Speaking to the older adults

- ▣ Sensory considerations:
 - ✓ Visual and hearing loss may affect ability to understand others or effectively communicate
 - ✓ Since non-verbal aspects of communication are essential, how can we help people who have diminished vision?
 - ✓ What are environmental factors to be considered in order to increase our effectiveness in communicating with others

Speaking with older adults

- ▣ Tone and attitude:
 - ✓ Address the consumer in the way he/she wants to be addressed; when in doubt, ask...
 - ✓ Allow for extra time in communicating with an older person
 - ✓ Communicate interest and respect
 - ✓ Do not use terms of endearment “honey, sweetie, etc.” unless this is something you know is preferred by the consumer
 - ✓ Give the older speaker your full attention

Communicating with Older Adults with Disabilities

- ▣ Try to avoid:
 - Talking down or infantilizing the older adults
 - Raising your voice to someone who cannot hear (yelling does not help, it distorts the message)
 - Be aware of how you approach someone who is seated in a wheelchair or is seated; try not to approach from behind

Communication Strategies

- ▣ Always be aware of your body language, facial expression, tone of voice, and behavior: “What you give is what you get.”
- ▣ It's not the words we speak, it's the way we say it.
- ▣ Most people with dementia have difficulty understanding spoken language
- ▣ They can easily pick up on the FEELINGS being expressed.
- ▣ It is not what you say, but how you say it – when frustration, anger creep into your voice the dementia person feels it.
- ▣ Offer encouragement and positive feedback.

Communication Tips

- ▣ Do: Back off and ask permission; use calm, positive statements; reassure; slow down; add light; offer guided choices between two options; focus on pleasant events; offer simple exercise options, try to limit stimulation.
- ▣ Say: May I help you? Do you have time to help me? You're safe here. Everything is under control. I apologize. I'm sorry you are upset. I know it's hard. I will stay with you until you feel better.
- ▣ Do not: raise voice; show alarm or offense; corner, crowd, restrain, demand, force or confront; rush or criticize; ignore; argue, reason, or explain; shame or condescend; or make sudden movements out of the person's view.

Agree
or
Disagree:

All Behavior is a form of communication.



ABC's

- ▣ Our goal is to become good observers of behavior in order to alter or at least decrease the frequency of the behavior.
- ▣ Record the behavior for one week.
- ▣ Look for patterns
 - Time of day
 - Staff
 - Blood sugar levels, med changes
 - activity



Investigate

- ▣ Learning to identify triggers that cause the behaviors will enable us to intervene before a problem begins.



Strategies to Manage Problem Behaviors

- ▣ Maintain a calm, patient, positive and flexible approach
- ▣ Tailor your approach to the individual based on his or her history, likes, dislikes, and personality
- ▣ Offer choices
- ▣ Allow the resident to do what she can for herself
- ▣ Avoid becoming defensive if the consumer reacts with anger, yells out, name calls, or swears

Unmet Needs

- ▣ If I have physical discomfort due to arthritis pain in my hips and lower back but cannot use words to describe it due to language impairment. How can I tell you I am in pain when you try to get me out of my chair? I may show you by resisting, withdrawing, shouting, striking out.
- ▣ I am trying to tell you that I have an unmet need: **I am in pain; I need comfort.**

Strategies to Manage Behaviors

- ▣ Speak to resident in short, simple sentences
- ▣ Break tasks into small steps
- ▣ Do not rush – give resident time to respond
- ▣ Always explain step-by-step what you are going to do before assisting with personal-care/intrusive procedures.
- ▣ Use gestures, body language, and facial expressions to facilitate communication.
 - Gently direct and cue as needed:
 - ▣ Mrs. Brown may begin to brush her hair when you hand her a toothbrush.
 - ▣ If you stick the toothbrush in her mouth and rapidly brush her teeth, you may get spitting, biting, and clamping of the jaw because it's an intrusive, foreign object.
 - ▣ Instead, model the behavior.

Environmental Strategies

- ▣ Ensure consumer has necessary adaptive devices in use (hearing aide, eyeglasses, cane, etc)
- ▣ Keep environment calm and relaxed
- ▣ Avoid overcrowding in dining, activity, and lounge areas
- ▣ Maintain consistent staffing assignments as much as possible
- ▣ Adjust daily schedules and routines according to the needs of consumers

G-R-A-Y

- ▣ G=get others away from consumer
- ▣ R=reduce stimulation
- ▣ A=alternative to be offered (food, snack, activities, etc.)
- ▣ Y= your own room for music and relaxation

Strategies to Manage Repetitive Actions

- ▣ Respond to the emotion, not the behavior.
 - Rather than focus on what he is doing, think about how he is feeling.
- ▣ Turn the action or behavior into an activity.
 - If the person is rubbing his hand across the table, give him a cloth and ask him to help with dusting.
- ▣ Stay calm and be patient.
 - Reassure the person with a calm voice and gentle touch.
- ▣ Engage the person in an activity.
 - The person may be bored and need something to do. Provide structure.
- ▣ Use memory aids.
 - If the person asks the same questions over and over, remind people with notes, clocks, calendars or photographs.

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Aggressive Behaviors

- ▣ Aggressive behaviors may occur suddenly without apparent reason or result from a frustrating situation:
 - ▣ Verbal
 - Shouting
 - Name calling
 - ▣ Physical
 - Hitting
 - Pushing

Aggressive Behavior Responses

- ▣ Try to identify the immediate cause.
 - What may have triggered this behavior?
- ▣ Focus on feelings, not facts.
 - Try not to concentrate on specific details, rather consider his emotions. Look for feelings behind words.
- ▣ Don't get angry and upset.
 - Be positive and reassuring and speak slowly and softly.
- ▣ Limit distractions.
 - Examine the environment and make adaptations.
- ▣ Try a relaying activity.
 - Use music, massage or exercise to help soothe the person.
- ▣ Change focus to another activity.

Anxious or Agitated Feelings

- ▣ Sometimes people become restless and need to move around or pace.
- ▣ Pain, discomfort (being too hot, too cold, hungry, needing to use the bathroom, etc.), frustration, and overstimulation are all common triggers of agitation.
 - Listen to the person's frustration
 - Reassure the person
 - Involve them in activities
 - Modify the environment
 - Find outlets for the person's energy

Strategies to Manage Misidentifications

- ▣ False fixed beliefs based on something real or that is misinterpreted.
 - Thinking staff or family members are imposters or part of the mafia
 - Not recognizing themselves in a mirror and telling others a stranger is in their room
- ▣ Do not argue with or challenge the consumer's belief.
- ▣ Take steps to reduce opportunities for misidentifications to occur.
- ▣ Reassure, redirect, and validate as needed.

Strategies to Manage Catastrophic Reactions

- ▣ Excessive emotional response to something in the environment; being pushed to perform beyond abilities
- ▣ Appears suddenly: yelling-out, screaming, crying, physical aggression
- ▣ Common during personal care
- ▣ Focus on prevention; your approach with the consumer can make a significant difference. Explain before doing. Talk to the person while performing task. Use a gentle, calm approach. Offer to assist as needed. Offer positive encouragement.

Inappropriate Sexual Behaviors

- ▣ Pattern – can occur anytime but can be associated with a memory.
- ▣ Common triggers - to satisfy physical needs for companionship and intimacy
- ▣ To continue a life-long pattern
- ▣ In response to “perceived” relationship

Resistance to Care

- ▣ Usually occurs in moderate stage of dementia
- ▣ Frequency, duration, intensity important
- ▣ Look for triggers to behavior (cold room, tone of caregiver's voice, recent environmental changes)
- ▣ May need to come back later
- ▣ Remind the person you will be taking them to get a shower/bath
 - dry erase board
- ▣ Explain step by step – something sudden is not good
- ▣ Have them hold/use item (comb/washcloth)

Refusal to Eat

- ▣ Use clock – Many cannot see the center of the plate
- ▣ Use ear plugs
- ▣ Avoid distractions
- ▣ Soft background music
- ▣ Small amounts

Simple Pleasures

- ▣ Using comforting objects and meaningful activities to decrease agitation.
 - Cost effective = no fancy gadgets needed
 - Soft, plush objects
 - Colorful things that catch the eye
- ▣ Gardening is a meaningful activity
 - It gives residents a job that works that activates large muscle mass activity that otherwise would be expressed in wandering