

Parallel Issues, Behavioral Issues and Care Provider Struggles



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An Aging Population



- The number of adults with I/DD aged 60 and older is projected to nearly double from 641,860 in 2000 to 1.2 million by 2030.
- Adults with I/DD are more likely to develop chronic health conditions at younger ages than other adults because of biological factors related to syndromes and associated developmental disabilities, limited access to adequate health care, and lifestyle and environmental issues.
- I/DD adults experience higher rates of obesity, sedentary behaviors, and poor nutritional habits compared with the general population.

An Aging Population



- Adults with I/DD can have a shorter life span compared with other older adults, which is thought to be caused by an accelerated aging process, manifest in their increased rates of cataracts, hearing loss, osteopenia, and hypothyroidism and a genetically elevated risk of developing Alzheimer's disease.

An Aging Population



- **A higher incidence of:**
 - Dental disease
 - Functional decline
 - Mental illness
 - Bowel obstruction
 - Gastrointestinal cancer
 - Vision Loss
 - Hearing impairment

Downs Syndrome and Alzheimer's



- Individuals with Down syndrome have an increased risk of developing a type of dementia that's either the same as or very similar to Alzheimer's disease.
- Studies suggest that more than 75 percent of those with Down syndrome aged 65 and older have Alzheimer's disease, nearly 6 times the percentage of people in this age group who do not have Down syndrome.

Downs Syndrome and Alzheimer's



- Individuals with Down syndrome live, on average, 55 to 60 years, they are more likely to develop younger-onset Alzheimer's (Alzheimer's occurring before age 65) than older-onset Alzheimer's (Alzheimer's occurring at age 65 or older).

Downs Syndrome and Alzheimer's



- Autopsy studies show that by age 40, the brains of almost all individuals with Down syndrome have significant levels of plaques and tangles, abnormal protein deposits considered Alzheimer's hallmarks.
- But despite the presence of these brain changes, not everyone with the syndrome develops Alzheimer's symptoms.

Difficulty Identifying Dementia



- Due to pre-existing communication issues, cognitive deficits and mental illness it can be hard for caregivers to identify dementia
- Caregivers who specialize in caring for I/DD population often have less education regarding issues commonly associated with aging such as dementia

Mental Illness and I/DD



- Individuals with I/DD are at a significantly higher risk of mental illness. Estimated that between 30-35% have a dual diagnosis.
- Standard clinical graduate programs and medical schools do not include dual diagnosis in their training curriculum. When a clinician sees such a case in a practice, there is often a tendency to recognize only the developmental delay and attribute any odd behaviors to that condition.

Mental Illness and I/DD



- **Common mental illnesses:**
 - Mood Disorders
 - Anxiety Disorders
 - Psychotic Disorders
 - Personality Disorders
 - Adjustment Disorders
- **Treatment of mental illness can be hampered by lack of resources/access, communication issues, cognitive deficits and physical limitations**

Challenges with Health Care



- Lack of access to primary care providers who are knowledgeable and experienced with the I/DD population.
- Behavioral issues that could negatively impact the individual's cooperation for tests, injections, etc.
- Communication issues that make interaction among the provider, caregiver, and patient difficult.
- Physical challenges that make it physically difficult to access a health care facility.

Challenges with Health Care



- Environmental issues that may involve sensory challenges (i.e. lighting, sound, smells) that interfere with a patient's ability to effectively participate in the visit.
- A shortage of time for providers to accommodate adults with I/DD who may have communication and behavioral difficulties that create challenges to patient assessment and treatment.

Challenges for Care Providers



- **Behavioral Issues can be common**
 - Difficulty transitioning from home to a care setting
 - Resistive to care
 - Poor social skills make group living difficult
 - Anger Outbursts
 - Sleep issues
 - Identifying pain or another health issue vs behavioral issue

Challenges for Care Providers



- Lack of education regarding behavioral interventions
- Lack of knowledge regarding dementia and how to best care for individuals with dementia
- Caregiver burnout when there are multiple behavioral issues present
- Lack of knowledge regarding community resources for respite, MH support and crisis care or difficulty setting up

Challenges for Care Providers



- Lower rates for care due to higher physical function than the general aging population
- No reimbursement for caregiver time allotted to behavioral issues
- Fewer community living resources due to lower reimbursement rates (supported living, adult family homes, etc.) making finding appropriate care settings challenging

Advocacy



- Increased research into Alzheimer's and other dementias, with the inclusion of individuals with I/DD
- Increased education and resources for caregivers regarding the needs of an older individual with I/DD
- Increased education regarding how to care for someone with behavioral challenges
- Increased education regarding dual diagnosis mental illness and I/DD

Any Questions?

