DIVISION OF DEVELOPMENTAL DISABILITIES SERVICES

The Learning Curve

"Enhancing the Knowledge of DDDS Professionals"

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AGING WITH A DEVELOPMENTAL DISABILITY …

(*Article adopted from Child Development Institute, LLC).*

Overall projections suggest the disability population will become older, more diverse in race/ethnicity and income, and less educated. The number of individuals with disabilities is growing, while the first of the baby boomers are turning 60, and the numbers of persons who are aging with developmental disabilities are increasing substantially. Further declines in employment status among persons with disabilities will result in reduced income and a greater reliance on federal and state programs for needed support. The most pressing need in accurately projecting long-term care needs is the collection, evaluation, and reporting of meaningful data to track critical population trends and appropriately plan in order to make informed decisions about our future.

How is the growing aging population going to impact the job we do?

During the 20th century, vast changes occurred for older persons with developmental disabilities. While in the first part of the 20th century many persons with a developmental disability were not expected to reach adulthood, their life expectancy now is approximating that of the general population (with the exception of persons with severe disabilities).

The term developmental disability refers to a group of conditions that occur prior to, at birth, or during childhood and affect normal growth and development. These conditions include mental retardation, cerebral palsy, epilepsy, autism and sensory or neurological impairments. By current estimates, there are about 3 million persons with this overall diagnosis in the United States.

It is estimated that four out of every 1,000 older adults have a developmental disability. The total number of elderly persons in the United States who are developmentally disabled is estimated to be as high as one-half million persons. This population is expected to double by 2030. This dramatic increase is due to improved habilitation, better medical care, age-appropriate physical environments, and a change in treatment philosophy. In the past, persons with developmental disabilities were regarded as a burden, a menace or a threat, and were segregated and "warehoused" in large institutions. During the past 30 years a shift has occurred to community based services and integration into community life.

This has presented special challenges as well as special opportunities for the service system, the caregivers as well as for these older persons themselves. The service system has had to adapt to this "new" population, by retraining its workers and designing innovative programs that promote integration between services providing for persons with developmental disabilities with those providing generic services for the elderly. Older caregivers have had to plan for the time when they themselves become too frail to take full responsibility for the care of family members. Older persons with developmental disabilities have had to adapt to their own aging process. In many instances their quality of life has been compromised by long-standing physical or mental impairments as they age. They are in need of adapted housing, day-programs, and other supportive services in order to "age-in-place."

Historical Background

Prior to the middle of the 20th century, it was common practice to place persons with developmental disabilities in large institutions that were overcrowded, under-funded and under-staffed.

In the 1960's a new approach to providing services to persons with disabilities emerged. This approach became known as normalization, with an underlying philosophy that

persons with disabilities should be fully participating members of society. They should have the same rights and responsibilities as all citizens while still needing supportive services. The 1970's saw the beginning of de-institutionalization, aided by advocacy of parents groups, legal intervention by civil rights groups, and politicians needing to cut budgets.

As it became increasingly clear that persons with developmental disabilities were aging, attention began to focus on how to adapt the service system to accommodate their social and health needs. In a number of states, agreements were signed between state units on aging and state developmental disabilities agencies to engage in joint planning, to share technical resources and to provide technical assistance. The joint endeavors resulting from these approaches were meant to benefit older persons with developmental disabilities and their caregivers. This resulted in a number of innovative programs in the country, promoting adapted day and residential services as well as specialized health and mental health services.

Did you know that…

- ***Current estimates for adults age 60 and over with intellectual disabilities/mental retardation and other developmental disabilities range between 600,000 and 1.6 million. This population is growing rapidly, and the true number is not known. However, we can expect that by 2030, there will be several million.***

Compared to the General Population…

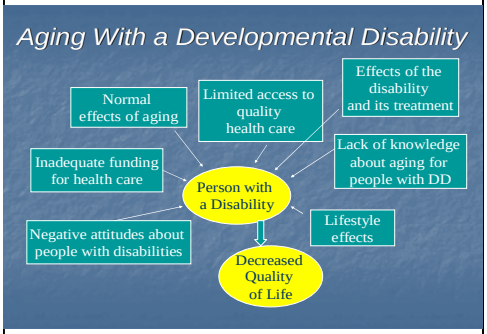
- ***Most individuals with intellectual disabilities/mental retardation will have similar rates of older age-related health conditions. Including heart disease, type 2 diabetes, cancer, osteoarthritis, hearing and vision problems, & dementia.***
- ***Older persons with Down syndrome are at higher risk for developing Alzheimer disease at earlier ages.***
- ***Older persons with cerebral palsy may develop secondary conditions related to or caused by the lifelong consequences of the physical disability, including chronic pain, osteoarthritis, and osteoporosis.***
- ***Older adults with intellectual disabilities/mental retardation have difficulty communicating their symptoms. These difficulties are often aggravated by severe cognitive disability, autism, mental health disorders, early dementia, or cognitive decline.***

- ***The Older Americans Act funds comprehensive support services for adults age 60+ and can also benefit older adults with intellectual disabilities/mental retardation and other developmental disabilities as well as older family caregivers.***

What are the effects of health during the aging process?

The life expectancy for persons with developmental disabilities (with the exception of persons with severe disabilities and those due to organic causes) will continue to increase, and many of them will live as long as their peers in the general population. Older persons with developmental disabilities manifest the same age-related changes and age-related diseases as their non-disabled peers; it is not known whether the onset of age-related diseases occurs earlier in the life cycle.

The health of persons aging with a developmental disability is also affected by lifestyle choices, family genetics and environment.



What are the differences and similarities for aging persons with a Developmental Disability?

Studies have shown that the causes of death for older persons with developmental disabilities are similar to those of the general population: cardiovascular disease, respiratory disease and cancer (Janicki, Dalton, Henderson, & Davidson, 1999). However, older persons with a developmental disability are at greater risk for age-related chronic diseases and health related functional impairments than persons in the general population. Preliminary studies indicate that older persons with developmental disabilities may exhibit relatively high rates of mobility impairments, fractures and osteoporosis (Evenhuis, Beange, Chicione & Henderson, 1999), visual and hearing impairments (Evenhuis, 1995) and mental health conditions (Day & Jancar, 1994), as well as psychotropic drug polypharmacy. Medications started in childhood may have serious adverse effects after prolonged use (Anderson & Polister, 1993). Some of these impairments may have been the result of life long conditions; others may have been a combination of early onset and later life problems.

A large proportion of persons with mental retardation have Down's syndrome. Older persons with Down's syndrome have an increased risk for the early development of age-related visual and hearing disorders, seizure disorders and Alzheimer's disease (Burt, Loveland, Chen, Chaung, Lewis, & Cherry, 1995, Evenhuis, 1995, Janicki, Heller, Seltzer & Hogg, 1996). They are also at risk for specific endocrine, infectious and skin disorders (Evenhuis, 1995).

A significant number of persons with developmental disabilities have associated conditions, resulting from central nervous system abnormalities. Two examples are persons with cerebral palsy and epilepsy. Persons with cerebral palsy are at risk for osteoporosis, arthritis, chronic pain and skeletal deformities. In some cases their gastrointestinal disorders may lead to bowel and bladder problems. Swallowing disorders can result in a poor nutritional status and recurrent pulmonary infections (Overeynder & Turk, 1998, Turk, Overeynder & Janicki, 1995). Persons with epilepsy are at risk for falls and injuries, aspiration episodes and the specific short and long-term adverse effects of specific anticonvulsant medications (Evenhuis et. al.).

What supports to consider during the aging process?

- Need to carefully document the current level of function.
- Consider Palliative Care for Advanced Disease (PCAD) assessment
- Recognition of changes that need special attention, especially in non-verbal residents. e.g., dementia vs. more treatable problems
- Develop an agency plan for aging in place or alternative care.
- End-of-life planning.
- End-of-life care.

What are the physical changes that occur with aging? How do these changes impact functioning and what are the support strategies?

Physical decline accompanying advanced age and an increased frequency of dementia and chronic illness of older persons with developmental disabilities will have a significant impact in the health care system (Janicki et al, 1999). Health care providers will see increasing numbers of persons with developmental disabilities in their practices. Extensive research, training and dissemination about possible risk factors, the particular ways in which age-related diseases manifest themselves in this population and best treatment practices is an ongoing task.

What are the specific concerns related to aging for persons with: Down Syndrome; Cerebral Palsy; Prader-Willi; and Fragile X Syndrome?

Down Syndrome (DS)

- ➲ Longer lifespan than in the past
- ➲ More rapid aging at the cellular level-affects all body systems
- ➲ Normal aging processes occur earlier than in persons without Down syndrome
- ➲ Poor function of immune system
- ➲ Increased incidence of Alzheimer's Dementia (AD)
  - Early onset type of AD
  - Begins at earlier age than gen. population.
  - First noticed in daily function rather than memory loss.
  - Progresses more rapidly.
  - Affects about 25% of DS population.
  - May have new onset of seizure disorder.
- ➲ Dry skin, more fungal infections of nails.
- ➲ Increased incidence lifelong risk of thyroid dysfunction, usually hypothyroid.
- ➲ Earlier onset of visual and hearing problems.
- ➲ Increased incidence of sleep apnea.
- ➲ Obesity, especially those living with family.
- ➲ Joint problems of neck, knee, and hip and more likely to develop bunions.
- ➲ Lower peak bone density and earlier risk for osteoporosis.
- ➲ Many born with heart abnormalities.
- ➲ Increased risk of heart valve disease.
- ➲ Decreased risk of atherosclerosis.
- ➲ Atlanto-axial Instability
  - Spinal column instability-about 14%.
  - May compress cord leading to neck pain, poor posture and gait, loss of upper body strength, abnormal neurological reflexes and changes in bowel & bladder emptying.
  - Treatment - ask health care provider.

Cerebral Palsy

- ➲ Amount of decrease in life expectancy related to degree of severity of condition.
- ➲ Abnormal muscle tone
  - Muscular and joint pain
  - Hip and back deformities
  - Worsening bowel and bladder function
  - Orthopedic surgeries
- ➲ Abnormal movement of food through the throat and stomach:
  - Dysphagia (abnormal swallowing)
  - Reflux of stomach acid into throat (GERD gastro-esophageal reflux disease)
  - Delayed emptying of the stomach.
  - All contribute to dental erosion, irritation of the esophagus, anemia, feeding problems, aspiration and pneumonia.
- ➲ Abnormal movement of food and waste through the small and large intestine.
  - High incidence constipation, fecal impaction
  - Increased risk of death from bowel obstruction and intestinal perforation
- ➲ Feeding and digestion problems worsen.
- ➲ Joint pain and deterioration worsens.
- ➲ Breathing difficulties worsened by above problems. Speaking more difficult.
- ➲ More susceptible to pressure sores due to decreased mobility and thinning of skin.
- ➲ Nutritional deficits, limited movement and medication usage increase risk of osteoporosis.

Prader-Willi Syndrome

- Hypogonadism- low hormonal levels.
- Problems related to uncontrolled obesity
  - Cardiovascular
  - Diabetes

Fragile X Syndrome

- Increased rates of mitral valve prolapse
- Musculo-skeletal disorders
- Early menopause
- Epilepsy
- Visual impairments.
- Earlier osteoporosis

How does aging affect persons with seizure disorders?

Seizure Disorders

- Change in seizure frequency, increase or decrease
- Cumulative effects of long term use of seizure medications
- Decreased bone density and increased trauma and falls due to seizures may lead to fractures

What are some service delivery models or recommendations available to assist persons with Developmental Disabilities who are aging?

Service Delivery Models

- Aging in place- adaptation as client needs, abilities and behaviors change.
- Dementia-specific environment-specialized staff and setting.
- Referral out, usually to long-term care facility or other generic community programs.

Programs and Services

"Dual aging," the aging of persons with developmental disabilities as well as that of their caregivers (family members and paid staff members) will continue to put more demands on the service system. The need for services and the length of time these services need to be provided can be expected to increase.

Thus far, increased flexibility in funding has not always been followed by increased flexibility in services. For example, retirement options have been designed for this population in senior centers and social adult day care. However, retiring also means being able to stay at home and take it easy from time to time. The latter is not possible under the current system. Also, many current staffing patterns are not designed to provide coverage in an agency residence during daytime hours.

Activities in day programs for persons with developmental disabilities are still not always age-appropriate for an older clientele. Many people continue to be exposed to the same curriculum that they followed when they were younger. This does not do justice to the concept of treating older persons with developmental disabilities with the dignity they deserve.

There is a need for increased flexibility in service delivery as well as a continued emphasis on creative design of these services. Continued training needs to be provided to alleviate the effects of staff turnover and to bring the latest information from gerontology and geriatrics to the field of developmental disabilities. Cross-training to aging services providers about developmental disabilities also needs to continue.

Caregiver Issues

There will be more families who are caring for an older person with a developmental disability. These families will provide this care for a longer period of time. There will be an increase in multigenerational caring (grandparents caring for adult grandchildren with a developmental disability). More families from different cultures will be identified who will present a challenge to the mainstream service systems. There will be more aging caregivers who are becoming too frail to provide care for their adult sons or daughters. More families will age who have had positive experiences with the service system and who will expect that service system to meet their needs as they age. Long term planning efforts need to be responsive to these families and work with them in ways that meet their specific needs. Specialized outreach training needs to continue, using caregivers' day-to-day expertise as a resource.

Family support programs need to be expanded that are individualized and can be tailored to the individual situation of each family that provides care for an older adult with a developmental disability.

In some situations, the older person with a developmental disability may be providing care for the "caregiver" and this needs to be taken into consideration when planning for family assistance.

- Caregivers need to be able to request the specific services they need for the particular problem they are facing.
- Agency personnel need to include older caregivers in their planning process.
- Families need to receive services allowing them to remain functioning with their developmentally disabled son or daughter at home.
- Residential placements designed for older parents (i.e., nursing homes, assisted living homes, etc.) should make provisions to accept placement for their adult sons or daughters if needed.
- Agencies providing services need to be culturally sensitive and be able to work with local cultural provider agencies.

References and Resources

An excellent source for books, journals, and fact sheets on older adults with mental retardation and other developmental disabilities is:

Clearinghouse on Aging and Developmental Disabilities
Dept. of Disability and Human Development
Univ. of Illinois at Chicago, 1640 W. Roosevelt Road, Chicago, IL 60608-6904
(800) 966-8845

http://www.uic.edu/orgs/rrtcamr/

Other Selected References

Davidson, P. W., Prasher, V. P, & Janicki, M. P. (2003). Mental health, intellectual disabilities and the aging process. Oxford, UK: Blackwell.
Davis, S. (2003).

Family Handbook on Future Planning. Washington, DC:The Arc.Janicki, M.P. & Dalton, A.J. (Eds.) (1999).

Dementia, Aging, and Intellectual Disabilities: A Handbook. Philadelphia: Brunner-Mazel.
Prasher, V. P., & Janicki, M. P. (2002).

Physical health of adults with intellectual disabilities. Oxford, UK: Blackwell.
Seltzer, M. M. (Guest Ed.). (2004).

Websites for National Disability Organizations

American Association on Mental Retardation
Home page for AAMR, the national organization for professionals and others interested in the field of mental retardation.

National Association of Developmental Disabilities Councils

The Arc of the United States The national organization of and for people with mental retardation and related disabilities and their families. Arc's official publications and video resource web site.

National Down Syndrome Society Home page for this national organization on Down syndrome. Includes information on inclusion.