



Successful Later Lives

Environmental and Social Supports for Older Individuals With
Intellectual and Developmental Disabilities

Institute of Medicine Task Force

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"If I had known I was going to live this long, I would have taken better care of myself...."

- Eubie Blake on his 100th birthday

Changes in Life Expectancy

- ◊The number of persons age 65–74 will grow by 107% by 2030
- ◊By 2020, 7 million persons will be 85+ and this number will double by 2040
- ◊Life span for people with I/DD is increasing, also.
- ◊In 1930, a person with mental retardation lived to an average age of 20 years.
- ◊A person with Down Syndrome lived to an average age of 9 years.
- ◊The average life expectancy of people with DD is now the same as the general population – early 70s.
- ◊People with Down Syndrome have an average life expectancy of early to mid-sixties.

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- ◊ There are 526,000 people with DD over the age of 60 in the United States
 - ◊ This number will double by 2030
 - ◊ There are 479,000 aging people with DD living at home with parents who are over 60
 - ◊ Fewer than 50% of parents have made plans with/for their aging son or daughter with DD
 - ◊ There are more than 83,000 people with DD on waiting lists for living arrangements in the United States



Age Related Change

- ◇ *There is a pattern of typical age related changes.*
- ◇ *Age related changes occur at different rates and impact individuals in different ways.*
- ◇ *There are unique patterns of aging in people with Down Syndrome and cerebral palsy.*

Aspects of Usual Aging

- Modest increase in blood pressure
- Modest increase in blood sugar
- Modest increase in body weight
- Lowered bone density and muscle mass
- Losses in immune system, cardiac, kidney, and lung functions

All promote the risk of disease and all can be modified.



Health Complications as We Age

- Arthritis – 50%
- Hypertension and Heart Disease – 33%
- Diabetes 11%
- Communication and Hearing – 32%
- Cataracts – 17%
- Visual Impairments – 9%



I/DD and Age Related Change

- ◇ People with I/DD may experience some aspect of aging earlier than typical.
- ◇ Research suggests that early signs of the aging process in people with I/DD is seen around the ages of 45 - 55.
- ◇ People with Down Syndrome experience premature aging, as much as 20 years earlier than expected in normal aging.



Special Concerns for People With Down Syndrome

- ◇ Early onset/hearing and vision impairments
- ◇ Age related eye disorders
- ◇ Premature aging of immune system
- ◇ Susceptibility to airway obstructions
- ◇ Hypothyroidism (20-30%)
- ◇ Joint problems
- ◇ Development of seizures
- ◇ Risk of osteoporosis linked to anti-convulsant use
- ◇ Tumors
- ◇ Periodontal disease
- ◇ Heart disease (40% have congenital problems that may worsen)
- ◇ Susceptibility to hypertension
- ◇ Dry skin, fungal infections of skin and nails
- ◇ Premature intellectual and adaptive decline



Special Concerns for People with Cerebral Palsy

- ◇ Decreased mobility due to joint or muscle weakness/pain
- ◇ Difficulty with eating/swallowing due to decreased oral motor control
- ◇ Problems with breathing and muscle control resulting in speech problems
- ◇ Upper respiratory infections
- ◇ Bowel and bladder problems
- ◇ Risk for osteoporosis
- ◇ Risk for pressure sores

Complications of Aging With DD

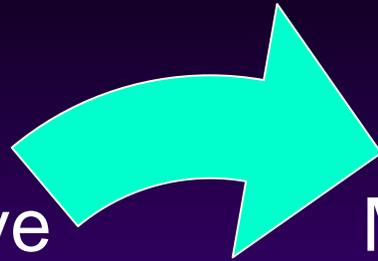
- ◊ Sedentary lifestyles combined with poor nutrition, excessive use of tobacco and caffeine
- ◊ Lack of awareness of typical aging process and health changes
- ◊ Difficulty in expressing changes in health status, presence of discomfort or pain
- ◊ Absence of emphasis on healthy aging
- ◊ The risk for dementia



Improve
Cognitive
Functioning

Maintain
Physical
Activity

Improve
General
Health





Health and Wellness in Later Life – Central Concerns

- **Preservation of function**
- **Enhancement of independence**
- **Disability prevention and postponement**
- **Chronic disease prevention and management**



Alzheimer's Disease

- ◇ A progressive disease resulting in the loss of brain cells
- ◇ Not a mental illness
- ◇ Not a normal part of aging
- ◇ No treatment to cure, stop, or reverse the process
- ◇ Medications to slow the process
- ◇ Effective care and support can improve life quality
- ◇ Early intervention results in the most effective treatment

Alzheimer's Disease

- ◇ Down Syndrome is a significant risk factor for Alzheimer's
- ◇ Ages 40 - 60 - 22% affected
- ◇ Age 60 and older - 56% affected (Janicki, 1997)
- ◇ Age is the greatest risk factor for Alzheimer's Disease
- ◇ Traumatic Brain Injury is a significant risk factor for dementia



Universal Goals for Aging

- ◊ Optimum Health and Independence
- ◊ Psychological/Emotional Stability
- ◊ Personal/Social Control
- ◊ Continued Engagement With Life

–The MacArthur Foundation Study

(Rowe and Kahn, 1998)



Aging Well Means...

- Being well
- Being active
- Having social connections
- Having financial security
- Retaining personal and social control



People age most successfully if they continue to engage with life and maintain close relationships.



Person Centered Approaches for Later Life

- ◇ Support older adults in learning about aging, knowing their options, and choice making
- ◇ Provide training to staff, families, community resources about supporting later life choices
- ◇ Identify community resources to meet later life needs – use the aging network
- ◇ Recognize changing functional abilities and health status and plan accordingly – know that maintaining skills is an appropriate focus

Essentials of PCP in Later Life

- ◊ Continued opportunities for growth and active participation in community – “raison d’être”
- ◊ More than ever, do what you want to do (each person defines his or her “good later life”)
- ◊ Co-planners **MUST** know the person well (know the person’s past and HONOR it)
- ◊ Listen, really listen... to the person and those who know him
- ◊ All the little things matter
- ◊ Respect the importance of rituals



Areas of Special Need for People Who Are Aging with Developmental Disabilities:

- ◇ Medical (health care concerns related to aging and specific disabilities)
- ◇ Functional (maintenance of independence in activities of daily living)
- ◇ Living arrangements and primary support system
- ◇ Social and leisure (general lifestyle choices)
- ◇ Legal and financial (retirement income planning, guardianship, advance health care directives)



Challenges to Aging in Place with DD

- ◇ Significant support needs of individuals with functional decline and/or dementia
- ◇ Two generation elderly families
- ◇ Decreasing capabilities of caregivers coinciding with increasing needs of individual
- ◇ "Services" or "programs" vs. life planning



Aging in Place: The New American Dream

- ◊ Growing older in a familiar environment
- ◊ Own your own home, purchase needed supports, rely on circle of friends
- ◊ CCRCs , Long Term Care Insurance, a successful investment strategy...☺
- ◊ Ongoing residential services – remaining in group home, AFL, or family home

Is it the "Impossible Dream?"



“Make or Break” Elements for Aging in Place in Residential Programs

- ◊ Philosophical Belief in Aging in Place
- ◊ Sound Management
- ◊ Capable and Dedicated Staff
- ◊ Commitment to Training and Clinical Support
- ◊ Adequate Fiscal Investment for necessary staff, environmental changes, and special equipment



End of Life Issues

- ◊The right and opportunity to acknowledge the end of life
- ◊Making deliberate choices and plans
- ◊Receiving the same array of services and supports as everyone else
- ◊Affirming the value of each life
- ◊Grieving the end of each life, the loss of each friend



North Carolina's Challenges:

- **Identifying unserved and underserved individuals**
- **Changing our approach to services; creating later life supports**
- **Improving health care, educating health care providers, empowering consumers**
- **Identifying dementia, creating demential capable services**
- **Identifying gaps in legal/financial arrangements; educating providers and consumers**



*People with intellectual
and developmental
disabilities are living
longer... will they live
well?*