

The Aging of State DD Populations

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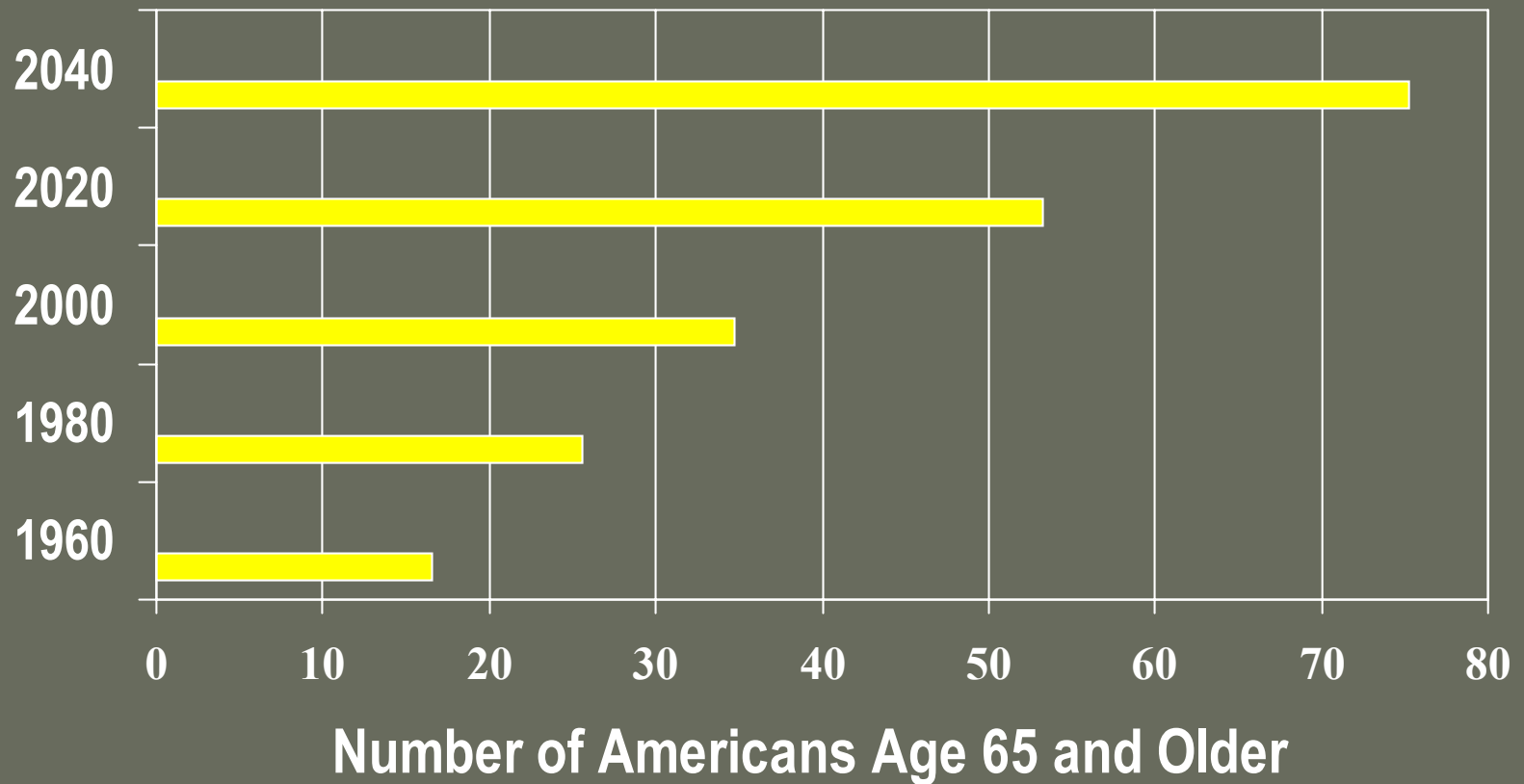
Select Issues

- **“Supporting Aging in Place”** – Addressing the changing nature of client populations in formal and informal situations
- **“Aiding Older Carers”** – Identifying and helping support older parents and other aging carers of people with I/DD to sustain residential situations in the community
- **“Enhancing Clinical Supports”** – Developing clinical consultation resources (MDs, RNs, SWs, Psychologists) to aid community workers, families and people with I/DD remain active and viable in their community settings

“Supporting Aging in Place”

Addressing the changing nature of
client populations in formal and informal
situations

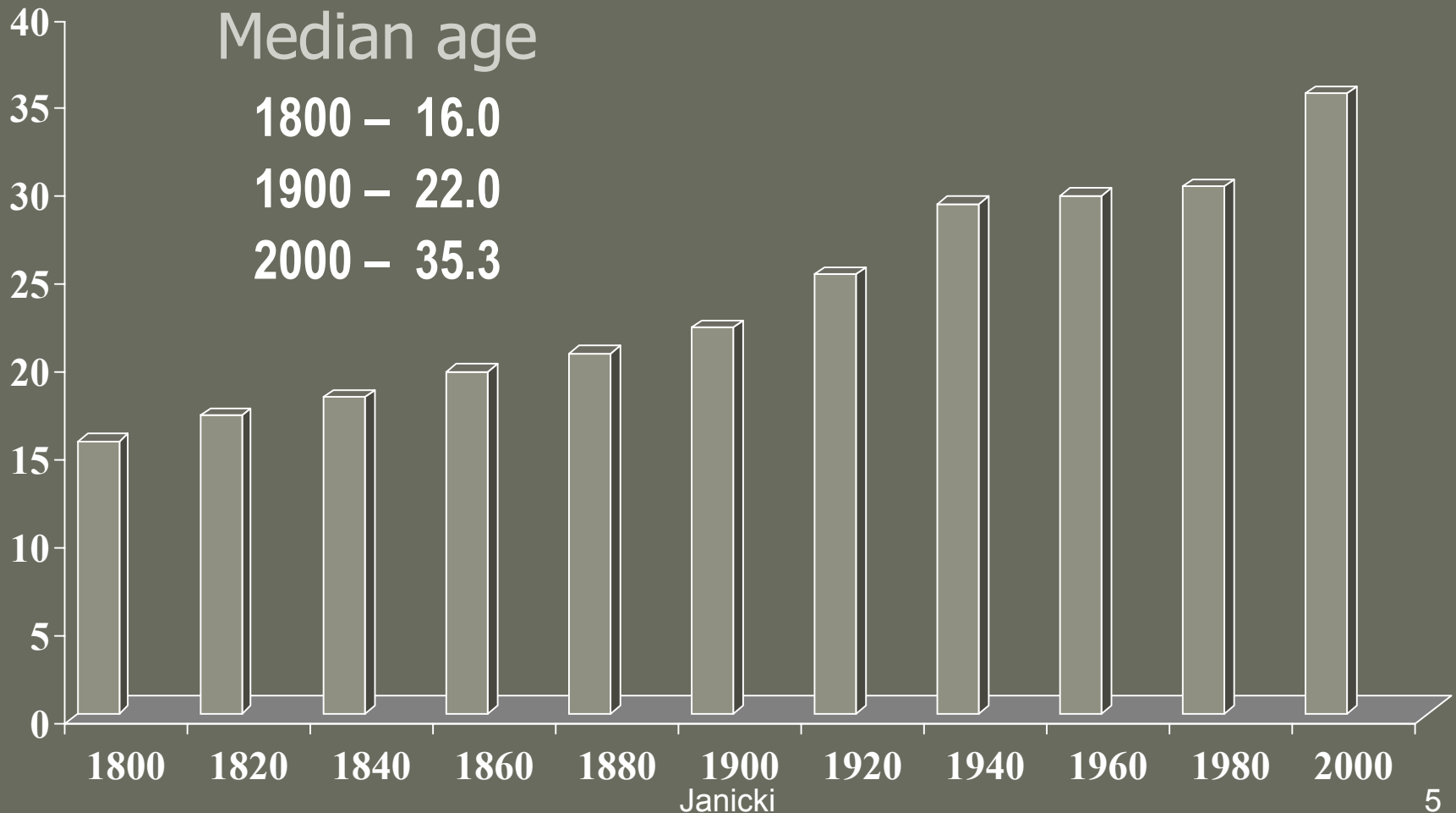
U.S. older population



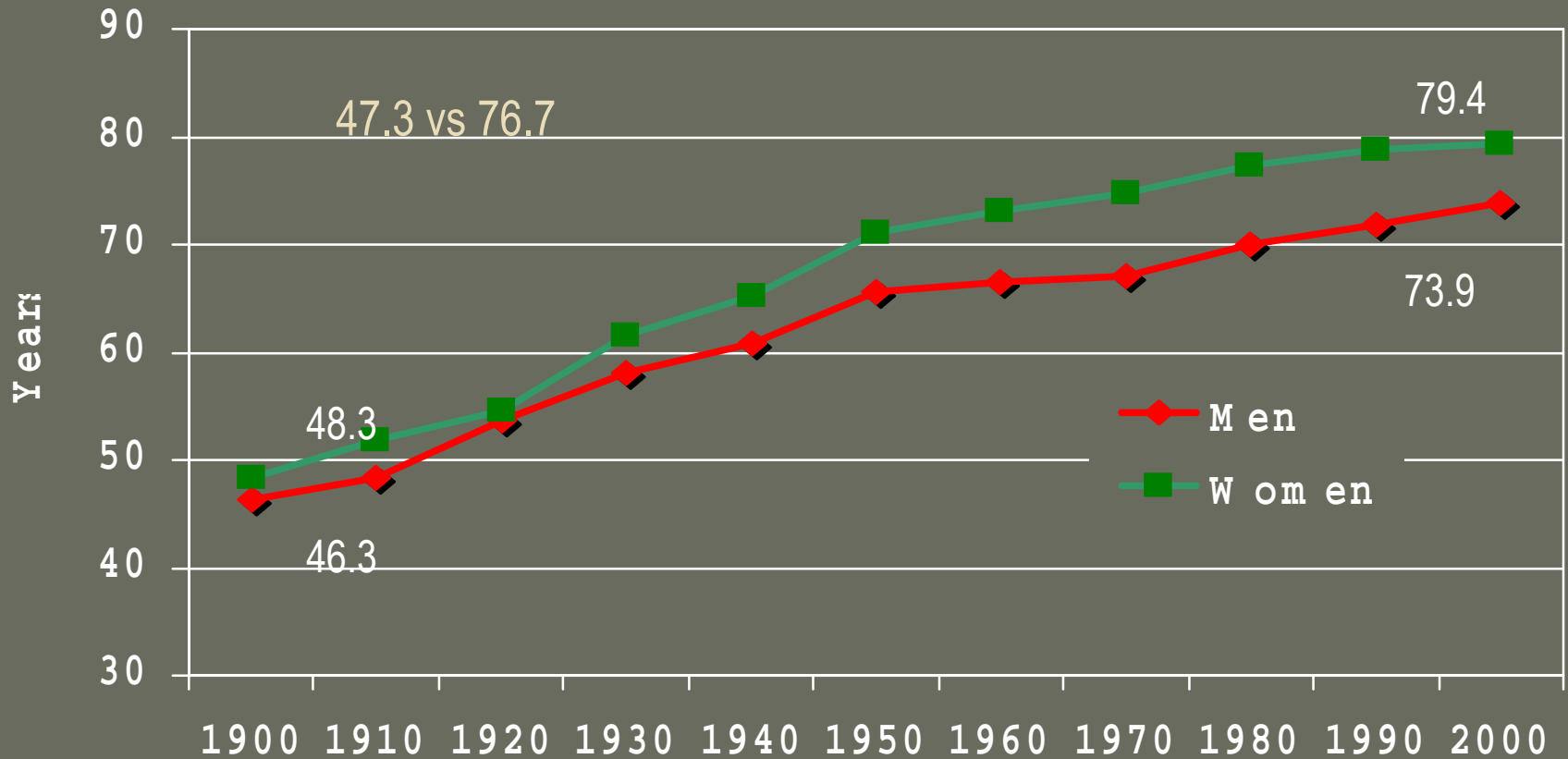
Source: US Census Bureau

Janicki

Changing median age



Life expectancy - USA



Source: National Vital Statistics Report, Vol. 50(6), March 21, 2002

Demographic outcomes

- The general population is changing in its overall composition
- The older-old are gaining in proportion and in absolute numbers
- People with intellectual & developmental disabilities are gaining life years – and growing older in larger numbers

Implications of demographics?

Demographers and researchers tells us:

1. The older population will grow dramatically in the next 10 to 20 years
2. There is a low expectation that families will be able to absorb all the older persons with ID/D who want to remain at home
3. Expanded need for community supports for older adults with special needs

“Supporting Aging in Place” – Addressing the changing nature of client populations in formal and informal situations

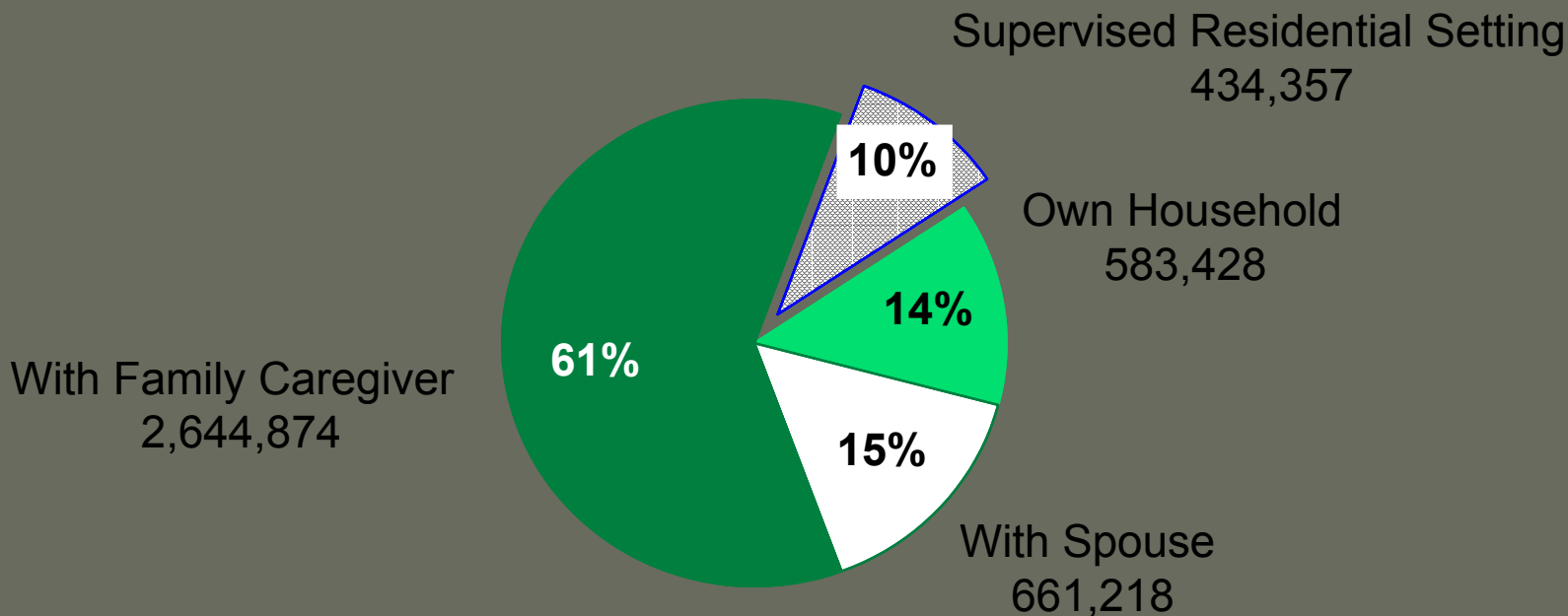
- Discussion points
 - Creating registries or data sets to track adult populations as they age – to ascertain living arrangement needs, supports, and medical/health care services
 - Providing for continuing education for staff and agency personnel on aging-related issues
 - Reviewing laws, regulations, and policies to eliminate barriers to normative supports for aging people

“Aiding Older Carers”

Identifying and helping support older parents and other aging carers of people with I/DD to sustain residential situations

UNITED STATES

Distribution of Individuals with a Developmental Disability by Living Arrangement, 2000

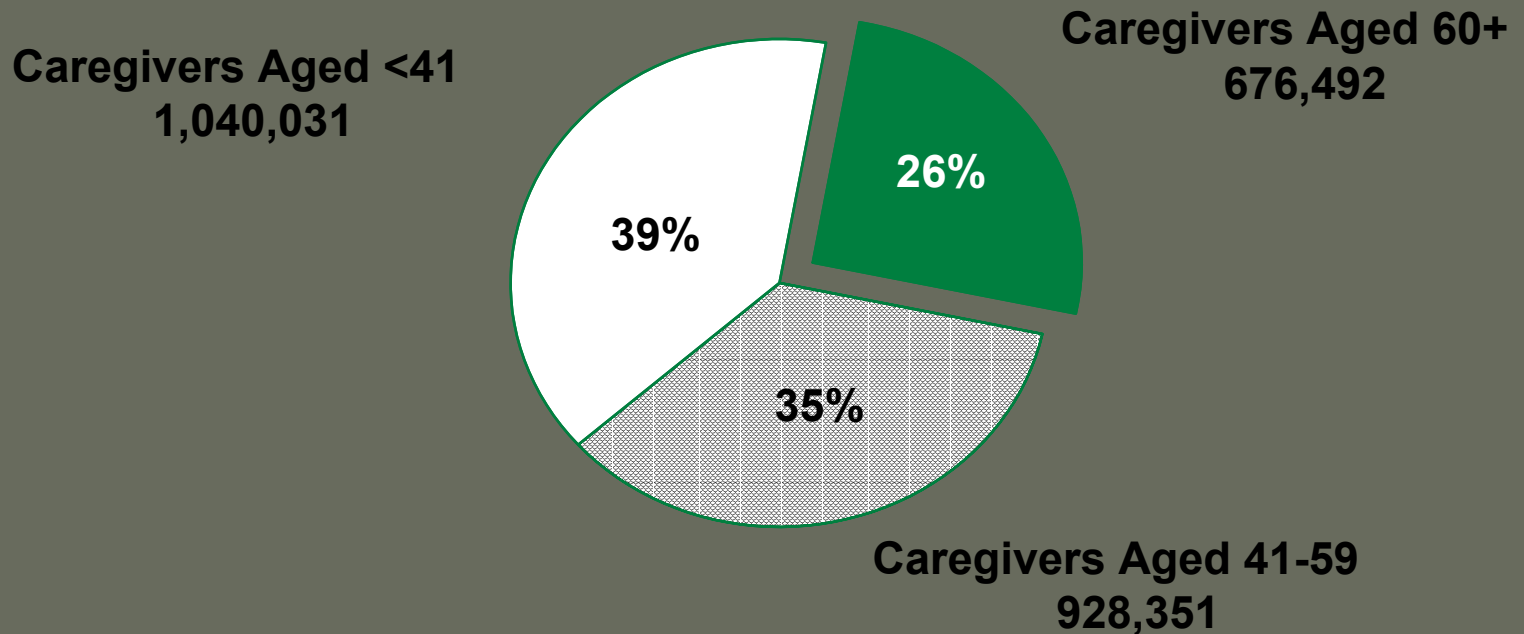


Developmental Disability: 4,323,877

Source : Adapted from Braddock et al. (2001), and Fujiura (1998).

UNITED STATES

Distribution of Individuals with a Developmental Disability Living With Family Caregivers, 2000



Total Estimated Population of Persons with a Developmental Disability Living with Family Caregivers: 2,644,874

Source : Adapted from Braddock, et al. (2001), and Fujiura (1998).

Supporting families

- Identifying older families – both known and unknown – to help plan for eventual needs
 - Registries can help agencies prepare for eventualities, i.e., helping parents and housing offspring
- Financing family support services
 - Respite, home aide supports, environmental modifications, day services, etc.
- Specialty units for casework and brokering

Partnering with the “Aging Network”

- National Family Caregiver Support Program initiatives
- Cooperative endeavors with AAAs and local or regional I/DD agencies
- Sharing resources to provide supports for families
- Joint regional planning (registries, funding, referrals, hot-lines)

“Aiding Older Carers” – Identifying and helping support older parents and other aging carers of people with I/DD to sustain residential situations

- Discussion points
 - Sustaining continued care-at-home and special attention to help families financially and with special supports
 - Helping families with transition planning – the “who, when, where” of making decisions
 - Partnering with aging network to target older families with special needs

“Enhanced Clinical Supports”

Developing clinical consultation resources (MDs, RNs, SWs, Psychologists) to aid community workers, families and people with I/DD remain active and viable in their community settings

Rationale

- Many providers see the general age of their clientele increasing and are raising concerns about how to deal with physical decline and age-associated pathologies, such as Alzheimer's disease and related dementias
- Dementia affects an abnormal number of adults with Down syndrome and a normal number of adults with other etiologies of intellectual disability
- Many at-risk adults live on their own or with friends, and many affected adults live in small community group homes or with their families
- The challenge for agencies faced with an increasing number of such affected adults is how to provide sound and responsive community care

Aging related changes

- Concerns related to physical aging include:
 - Interaction of lifelong disability and the aging process (e.g., among adults with CP & DS)
 - Decline in cognitive and physical abilities is normal – however, such decline varies by individuals
 - Age-associated pathologies – like Alzheimer’s disease, cardiovascular disease, and diseases related to being overweight/obese

Alzheimer's and age-associated decline

- High prevalence among adults with Down syndrome
- **Early onset among adults with Down syndrome**
- Adults with Down syndrome living with families
- **Organizations need to adapt services to accommodate dementia**
- Training for clinicians for assessment and consultation

Prevalence of dementia

Dementia found in adults with ID

- 3% > 40 years
- 6% > 60 years
- 12% > 80 years

Dementia found in adults with DS

- 25% > 40 years
- 66% > 60 years

Except for DS, the 60+ data correspond with the data reported for the population in general 60+

Sources: Janicki, M.P. & Dalton, A.J. (2000). Prevalence of dementia and impact on intellectual disability services. *Mental Retardation*, 38, 277-289; Zigman, W.B., Schupf, N., Devenny, D., et al. (2004). Incidence and prevalence of dementia in elderly adults with MR without DS. *AJMR*, 109, 126-141.

We need to be aware of

- when “onset” of dementia occurs
- **having readily available assessment and diagnostic services**
- special needs in early stage – mostly early memory loss and frustration due to noticed changes
- **training for creating “dementia-capable” environments, whether at home or in programs**
- preparing for eventual loss of capabilities (e.g., advance directives, housing, financial instruments, etc)
- **accommodating late stage care**

“Enhanced Clinical Supports” – Developing clinical consultation resources (MDs, RNs, SWs, Psychologists) to aid community workers, families and people with I/DD remain active and viable in their community settings

- Discussion points
 - Developing close links between clinicians/diagnosticians and care provision staff
 - Stimulate agency administrators to operate “dementia-capable” and aging-associated decline services
 - Consider home modifications and gleaning advice from specialists on what to modify



Concluding points

- Being “enablers”
 - Educating - stimulating awareness of aging, its physical, social, and mental components among providers
 - Planning – understanding the demographics of the I/DD population in state and projecting the trajectories of health status, housing needs, and other supports
 - Financing – ensuring that budgets reflect resources for supporting retirement, aging in place, and dealing with pathological aging issues

Anything you want to know about aging and developmental disabilities . . .


Rehabilitation Research and Training Center on **UIC University of Illinois at Chicago**
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