



## Florida Statewide Quality Assurance Program

# Healthy Aging for Persons with Developmental Disabilities

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## Aging

- **There are between 600,000 and 1.6 million people with intellectual/developmental disabilities (I/DD) that are over the age of 60**
- **By the year 2030 that number will rise to more than 2 million**



## Extended Life Expectancy

- Average age at death is 66 years
- Individuals with I/DD have similar life expectancy as compared to the general population unless:
  - Cerebral Palsy
  - Down Syndrome
  - Multiple Disabilities
  - Cognitive impairment is severe



# Obstacles to Optimum Health

- Access to care
- Lack of health insurance
- Health care providers attitudes
- Lack of education/training of healthcare providers
- Difficulty communicating
- Difficulty cooperating with examinations
- Physical capacities/mental capacities



# Down Syndrome

- Alzheimer Disease
- Menopause
- New onset of seizures
- Increased incidence of sleep apnea
- Early onset of visual and hearing loss
- Obesity
- Increased risk of heart disease

# Cerebral Palsy

- Decreased muscle tone
- Increase of fractures
- Increased dysphagia
- Increased pain threshold
- Increased incidence of constipation/bowel obstruction
- Increased nutritional needs
- Breathing problems



## Prader – Willi Syndrome

- Increase in cardiovascular disease
- Increase in diabetes
- Low hormone levels
- Hypogonadism



# Autism Spectrum Disorders

- Seizures
- Accidental Death (drowning, suffocation)
- Cardiovascular Disease
- Cancer
- Respiratory Disorders (mostly pneumonia)



# Autism Spectrum Disorders

- Restricted interests
- Stereotypical movements
- Need for rituals/sameness
- Compulsive disorders
- Self-injurious behaviors

These have been shown to be less severe and more infrequent with increasing age



# Spina Bifida

- Renal failure
- Increasing UTI's
- Increasing skin break down
- Increasing sensitivity to Latex
- Constipation
- Osteoporosis



# Spina Bifida

- Obesity
- Increasing episodes of depression
- No access to multidisciplinary spina bifida clinics

## Fragile X Syndrome

- Increased rate of heart problems
- Increased rate of musculoskeletal disorders
- Early menopause
- Increased visual impairments
- Increased rate of epilepsy
- Increased risk of osteoporosis



## Seizure Disorders

- Increased risk of seizure frequency
- Increased risk of osteoporosis
- Increased risk of fractures
- Effects of long term use of antiepileptic medications



# Dementia

- Decreased brain function
- Decreased memory
- Increase in confusion
- Difficulty with ADL's
- Increase sleep disorders
- Decreased appetite and weight loss



## Behavioral Issues

- Medication side effects
- Medical problems – anemia, high blood pressure
- Metabolic problems – diabetes, thyroid dysfunction
- Hearing and vision problems



## Common Problems

- Cardiovascular Disease
- Obesity
- Osteoporosis
- Aspiration Pneumonia
- Hypertension
- Diabetes





## Common Problems

- Diabetes
- Visual Impairments
- Thyroid Abnormalities

These range anywhere from 10% to 70% higher than the average population



## Aging Caregivers in Florida

- In Florida there are approximately 60,663 caregivers aged 60+ who co-reside with a son or daughter that has I/DD.
- Only California has more aging caregivers!



## Costs

- Adults with I/DD account for 17% of the total US population; however
- 47% of all medical expenditures are for individuals with I/DD.



# What Health Information Does Delmarva Gather?

- 4 processes
  - NCI: This tool captures information about basic health. Height, weight, diagnoses, male/female preventive health care and physical activity.



# What Health Information Does Delmarva Gather?

- III

This tool gathers information about adaptive equipment needs, dietary needs, medication concerns, neurologist and psychiatric needs. Specialist medical needs and Baker Acts.



# What Health Information Does Delmarva Gather?

- HBA

Therapies (OT,PT,ST,Nutrition), environmental factors, safe habits, types of insurance, medication names, types of physicians, dental needs, behavioral health needs are all captured here.

# What Health Information Does Delmarva Gather?

- MPR (Medical Peer Review)

This process looks at Medicaid Claims data to ensure that all medical appointments, hospitalizations (inpatient and outpatient) and medications are captured



# What can we do to support people as they age?

- Life Style Changes
  - Exercise
  - Proper diet
  - Weight control
  - Preventive health screenings





# What can we do to support people as they age?

- Living Situations
  - With Family
  - Independently
  - Group Homes
  - Assisted Living Facilities
  - Intermediate Care Facilities



## What Can We Do?

- Futures Planning
  - Residential
  - Legal
  - Financial
  - Respite
  - Retirement



## Reference Material

- Future Care Planning: A Roadmap for Family Caregivers @ <https://sonoranucedd/fcm/arizona.edu>
- The Future is Now: A Future Planning Training Curriculum for Families and Their Adult Relatives with Developmental Disabilities @ <http://www.rrtcadd.org>



## Reference Material

- Physical Changes and Aging: A Guide for the Helping Professions (5<sup>th</sup> Edition)
- Delmarva Foundation @ [www.dfmc-florida.org](http://www.dfmc-florida.org)
- Linda Tupper @ [tupperl@dfmc.org](mailto:tupperl@dfmc.org) or 866-254-2075



# Questions?



Thank you!