Case: Cerebral Palsy

A.W. is a 48 y.o. AA female with diplegic Cerebral Palsy (CP)

- Dysphagia, coughing, with solid foods X 3 mo.
- Vague generalized abdominal pain intermittently, 3 lb wt loss
- Seizure disorder
- Foot pain
- Moved in with sister one year ago after father died.
- Sister is legal guardian.
- Post-menopausal
Cerebral Palsy: Physical Exam

New findings:
Generalized abdominal tenderness, 8 pound loss

- Severe dysarthria but near normal cognition
- Ambulates with cane, unsteady gait, clumsy hand movements
- Dental caries
- Scoliosis, Flat feet
- Left hand contracture
Cerebral Palsy Case

- D/Dx: GERD, strictures, web, Schatzki’s ring, PUD, aspiration

**Evaluation and Treatment:**
- EGD: mild esophagitis
- Swallowing study: mild aspiration
- BMD: osteoporosis
- Vitamin D deficiency noted
- Referred to speech therapy
- Podiatry for foot inserts
- Walker obtained
- Orthopedics for scoliosis
Cerebral Palsy

- Second to ID as the most frequent cause of DD in children
- 30% of children with CP have ID
- Non-progressive, motor impairment syndromes secondary to lesions of the brain arising in the early development
- CP itself is not progressive but many age-related changes occur earlier in persons with CP
Common Medical Problems in Adults with Cerebral Palsy

- **Dysphagia/Aspiration**: Increased in quadraparesis & gastrostomy
- **Gastroesophageal Reflux Disease**
- **Constipation**
- **Osteopenia**: noted in childhood
- **Osteoporosis**: risk increases with age, earlier than general population
- **Vitamin D deficiency**
- **Obesity**
Adults with Cerebral Palsy

- **DJD** and resulting chronic pain
- **Spasticity and weakness** may lead to contractures
- **Scoliosis**: 25-64% of institutionalized patients
- **Decubitus ulcers**
- **Seizures**: 30% of all individuals with CP
- **UTIs, incontinence**
Adults with Cerebral Palsy

Intellectual Disability (ID) variable in predicting survival

Strauss et. al
• Mobility and feeding skills were strong predictors to survival
• Most common cause of death: Aspiration pneumonia
• ID contributed little to predicting survival

Blair, et. al 2001
• ID strongest predictor of survival
• Immediate cause of death in 59 % respiratory problems
Common Medical Problems in Adults with Down Syndrome

**Cardiovascular:**
- MVP and AR higher prevalence
- Echocardiogram at baseline then follow clinically

**Endocrine:**
- 40% have thyroid dysfunction; screen annually

**Hearing Loss**
- Overall 40 – 50% ; screening every 2 years

**Atlanto-Axial Instability**
- Increased mobility at C1 & C2: 15 % of patients
- C-spine films prior to special Olympics or intubation.
Common Medical Problems in Adults with Down Syndrome

- Overweight/Obesity
- Mobility restrictions:
  - Foot deformities, scoliosis, early DJD
- Constipation: overall 30%
- Obstructive sleep apnea due to upper airway obstruction
- Seizures: Lifetime incidence 5%
- Intellectual decline/Alzheimer’s dementia
Common Medical Conditions in Adults with Developmental Disabilities

- Overweight/Obesity
- Mobility Issues
- Premature Aging
- Constipation
- Visual and Hearing impairments
- Cardiac abnormalities in genetic disorders
- Seizure disorder
- Mental health disorders
- Need for multi-disciplinary care
Evaluation of Adults with Developmental Disabilities

• ADLs/functional capacity
• Day program/workshop
• Home setting: family, group home, independent
• Homecare services
• Need for respite care for family members
• Guardianship
Multidisciplinary Evaluation of Adults with Developmental Disabilities

- Durable medical equipment needs: wheelchair, walker, cane
- Occupational/Physical Therapy services
- Coordinated care with subspecialists:
  - Mental health: psychiatry
  - Neurology: seizure disorder
  - Orthopedics: contractures, DJD
- Vision/Dental evaluation
Case: C.B.

Mr. C.B. is a 52 y.o. African American male with CP

- Using a wheelchair since early childhood, has hand contractures, neurogenic bladder, rare UTIs.

- Severe dysarthria, contractures of both hands, no decubiti

- He is obese (BMI 35), has hypertension, diabetes, and hypercholesterolemia

- He is accompanied by his brother for routine follow-up. His brother asks about colonoscopy.
A woman with Cerebral Palsy who died of inoperable cervical cancer after never having had a pap smear or pelvic exam despite annual physicals recorded by her assigned primary physician.

Doostan & Wilkes 1999
Quality of Life and Disabilities (QOL)

Individuals with disabilities can accurately assess their QOL.

Key to self report of QOL among people with disabilities:

Accurate modified instrumentation:

- Self-Rated Quality of Life Scales for People with an Intellectual Disability: A review (R. Cummins, 1997)
- Methodological Issues in Interviewing and Using Self-Report Questionnaires with People with Mental Retardation (Finlay & Lyons 2001)
Quality of Life and Disabilities

Public Opinion
“Non-disabled people believe that the QOL of people who live with disabilities is extremely low…When disabled people report about their own QOL, they rate it as only slightly lower than when non-disabled people self-report their own QOL” (Amundson 2010, pp374-375)

Professional Opinion
Healthcare professionals judge QOL of people with disabilities to be even lower (Albrecht & Devlieger 1999)