Medical Care for People with Intellectual and Developmental Disabilities

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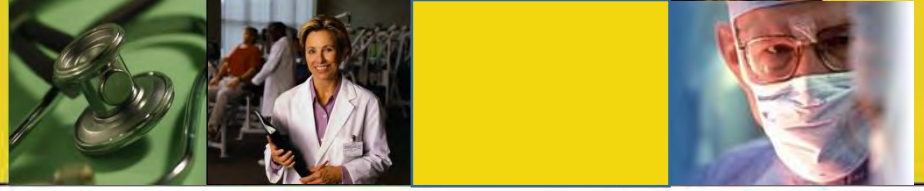
Developmental Pediatric Specialists

Southeast Pediatric Environmental Health Specialty Unit at Emory University



Massachusetts Medical Society

Every physician matters, each patient counts.

Medical Care of Adults with Intellectual and Developmental Disabilities

June 16, 2017

Summary of Disclosure Information

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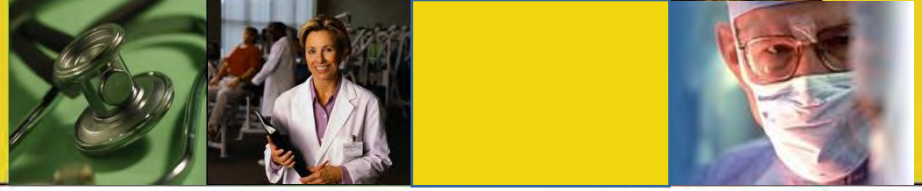

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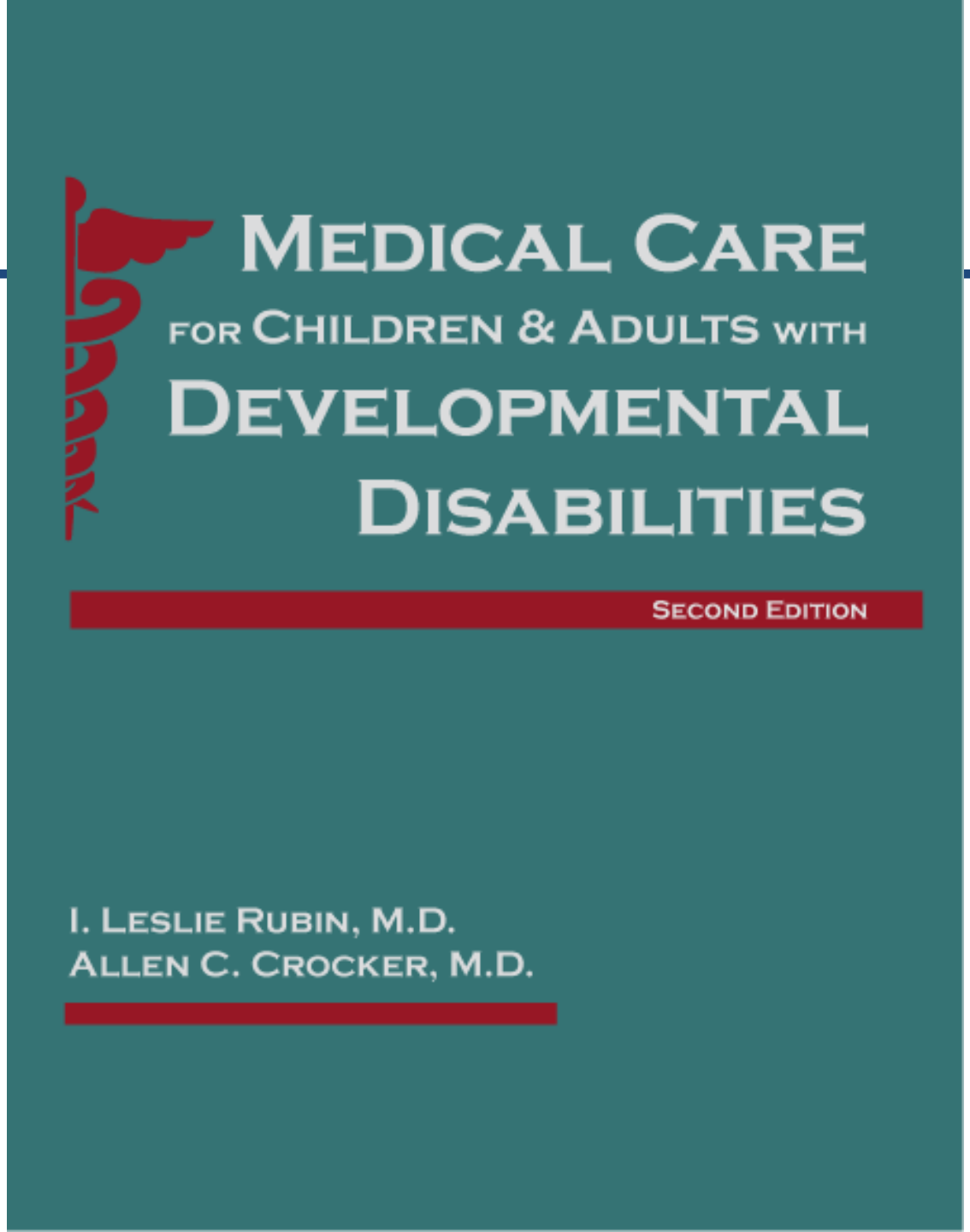
Innovative Solutions for Disadvantage and Disability

Southeast Pediatric Environmental Health Specialty Unit at Emory University


MOREHOUSE
SCHOOL OF MEDICINE
MEDICAL CARE
FOR CHILDREN & ADULTS WITH
DEVELOPMENTAL
DISABILITIES
SECOND EDITION
I. LESLIE RUBIN, M.D.
ALLEN C. CROCKER, M.D.

WHO Definition of Health

- Not merely freedom from disease but.....

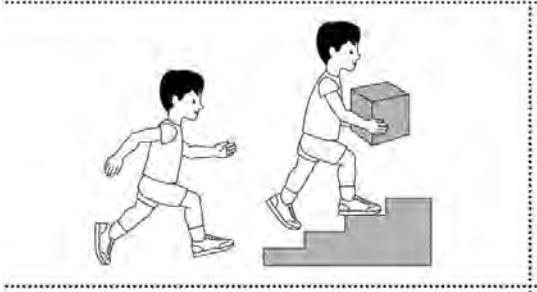
- The promotion of
  Physical
  Emotional &
  Social Well Being

People with IDD Represent a heterogeneous population

- By age group
- By underlying condition
- By degree of severity of disability
- By complexity of health care needs
- By home and community environment
- By society in which the they live

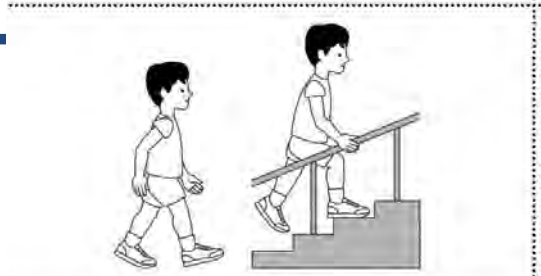
Outline of Presentation: Some Health Care Challenges

- Underlying Neurological Problems
- Associated Medical Conditions
- Syndrome Specific Conditions
- Mental Health
- Access to Quality Health Care



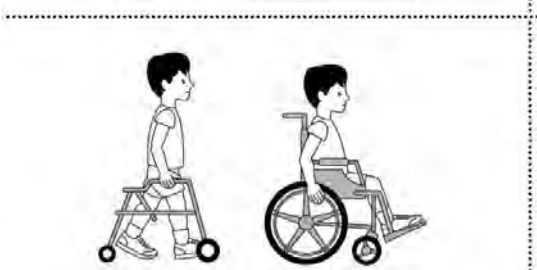
GMFCS Level I

Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited



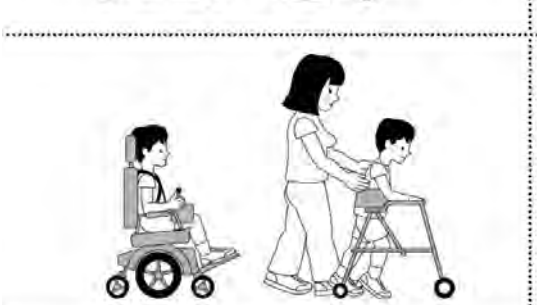
GMFCS Level II

Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.



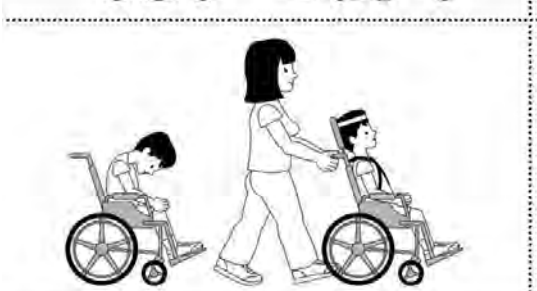
GMFCS Level III

Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.



GMFCS Level IV

Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.



GMFCS Level V

Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

GMFCS descriptors: Palisano et al. (1997) Dev Med Child Neurol 39:214-23

Individuals with Intellectual Disabilities

	IQ 50-70	IQ <50
Epilepsy	12	37
Cerebral Palsy	9	21
Hydrocephalus	2	5
Hearing Impairment	7	8
Visual Impairment	1	15
One or More Condition	24	40

D.K.

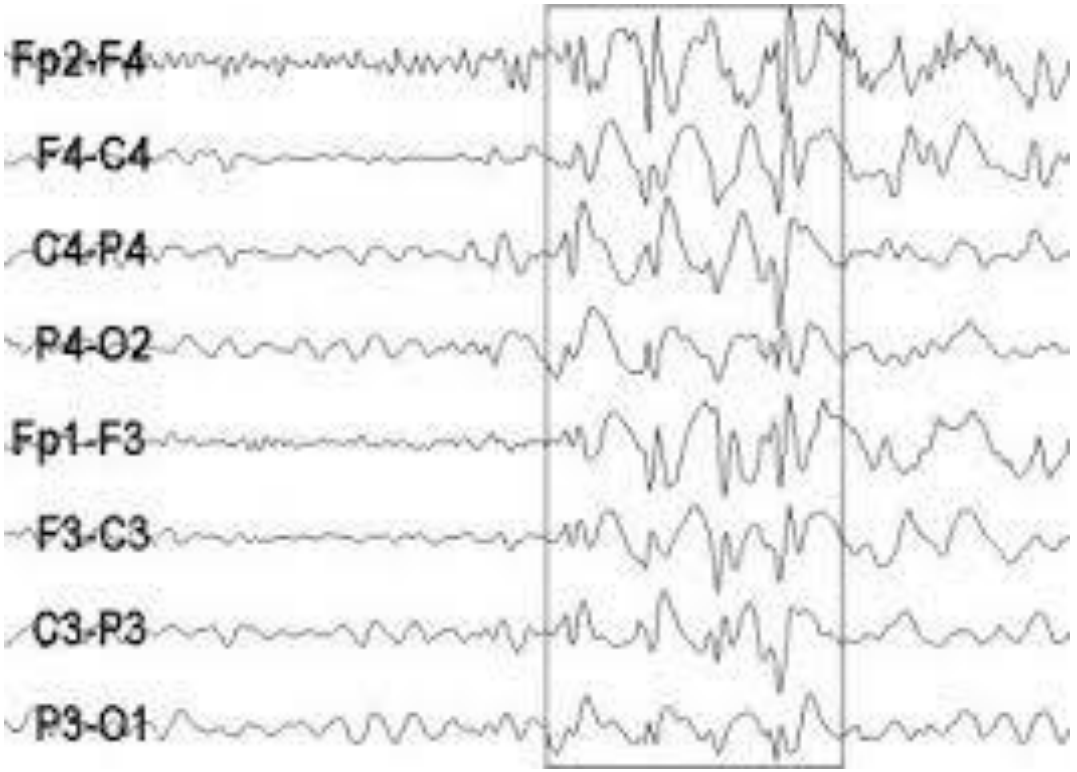
- Born at 36 weeks gestation weighing 2.87 kg. Mother had premature rupture of membranes, and baby was delivered by C-section secondary to **fetal distress** as a result of cephalo-pelvic disproportion. He acquired **Group B Strep meningitis**, and was on a **ventilator for 11 days** with 100% O_2

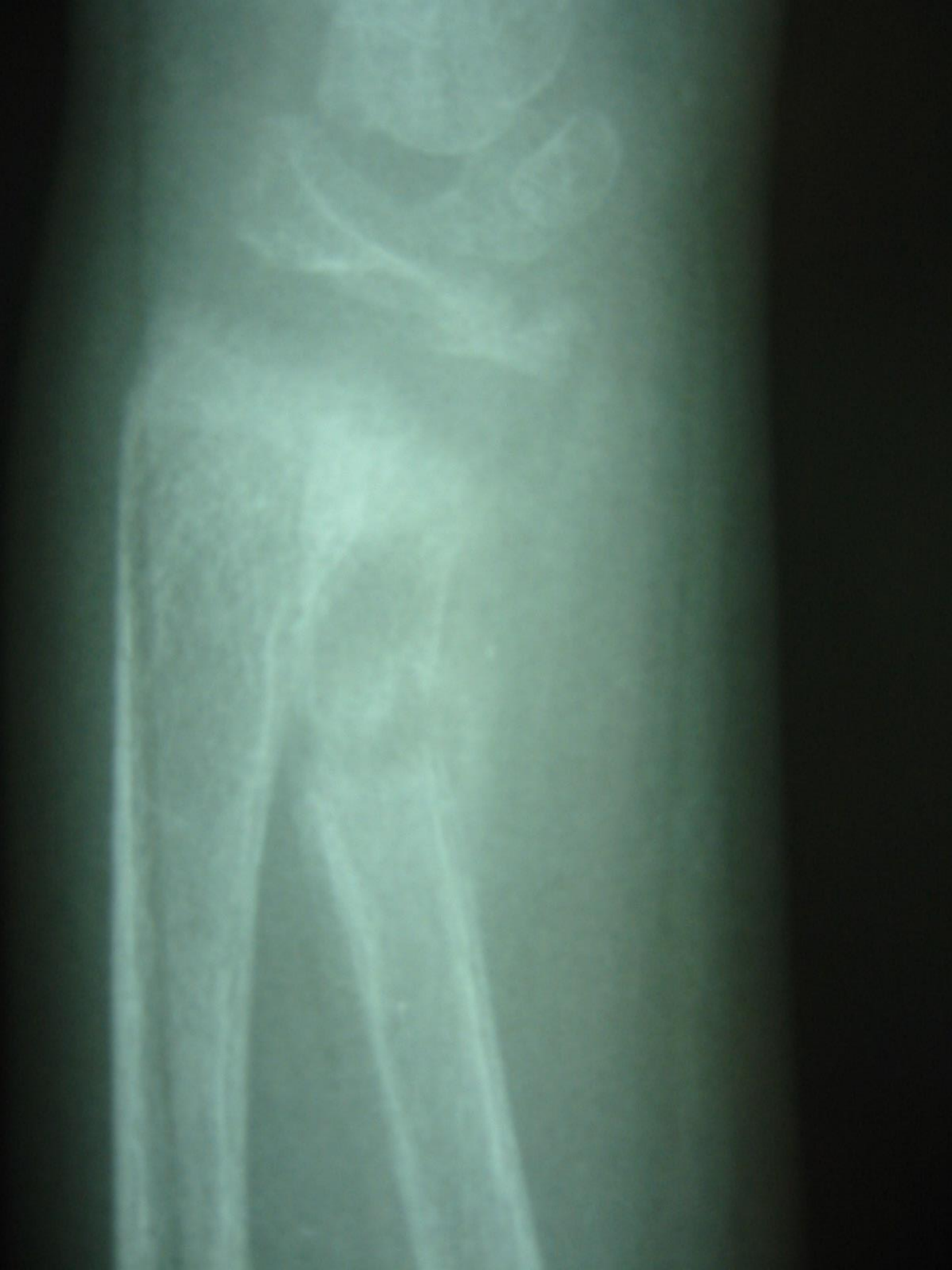
Has neurological consequences with……

- Severe cerebral palsy with quadriplegia
  - GMFCS 5
- Severe intellectual disability
- Multiple and complex medical conditions

Neurological

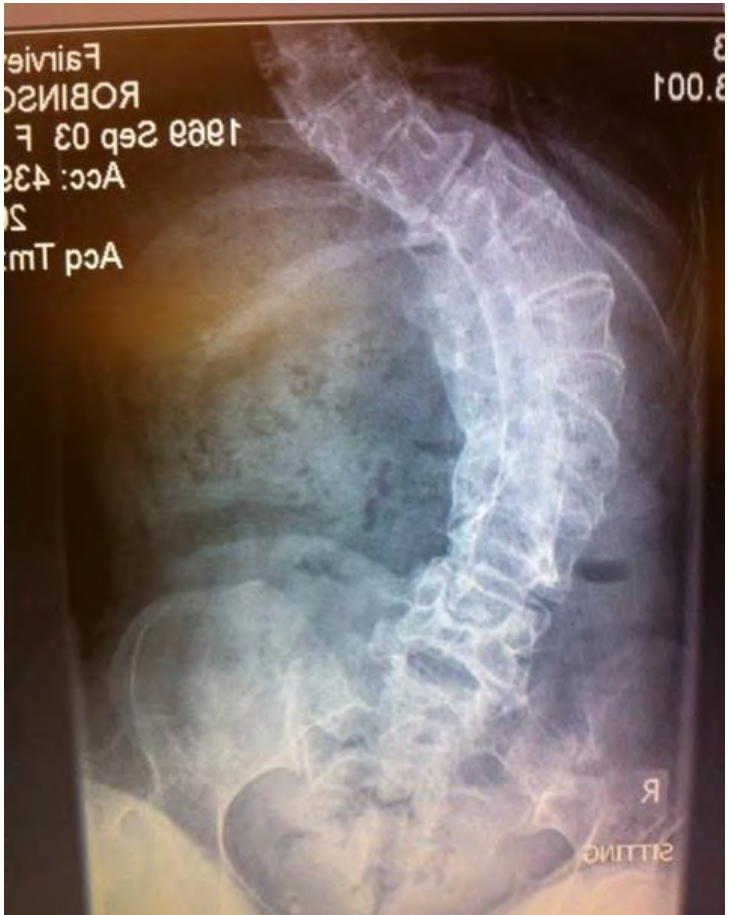
- He is followed by Dr. P. Nerve for his seizure disorder. Antiepileptic medications include
  - Phenobarbital,
  - Valproic Acid,
  - Tegretol,
  - Dilantin and
  - Valium, prn.

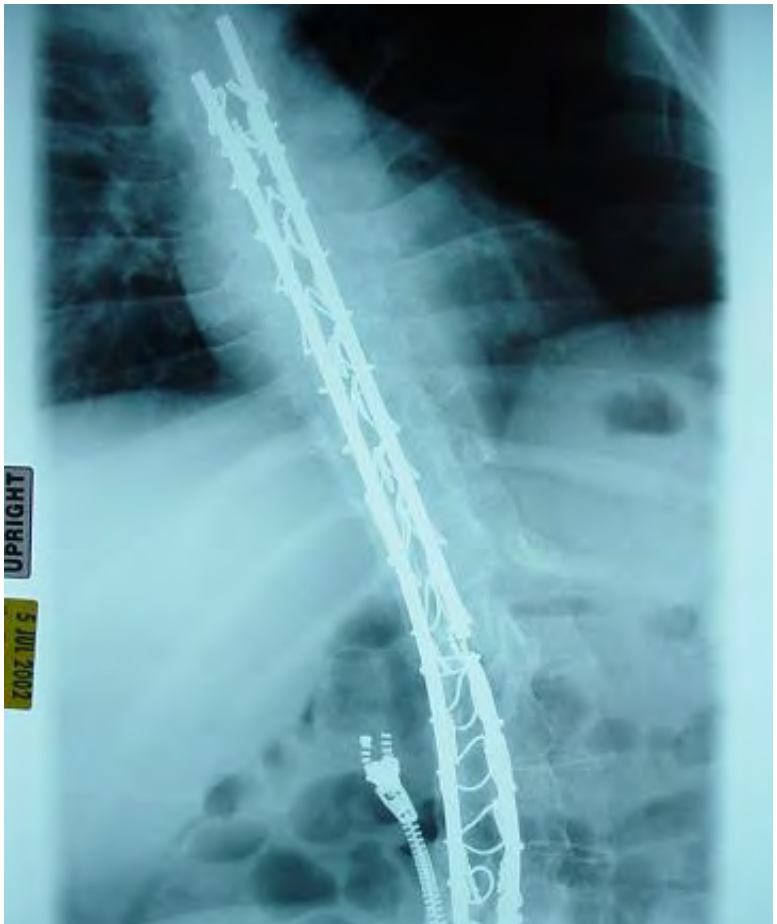




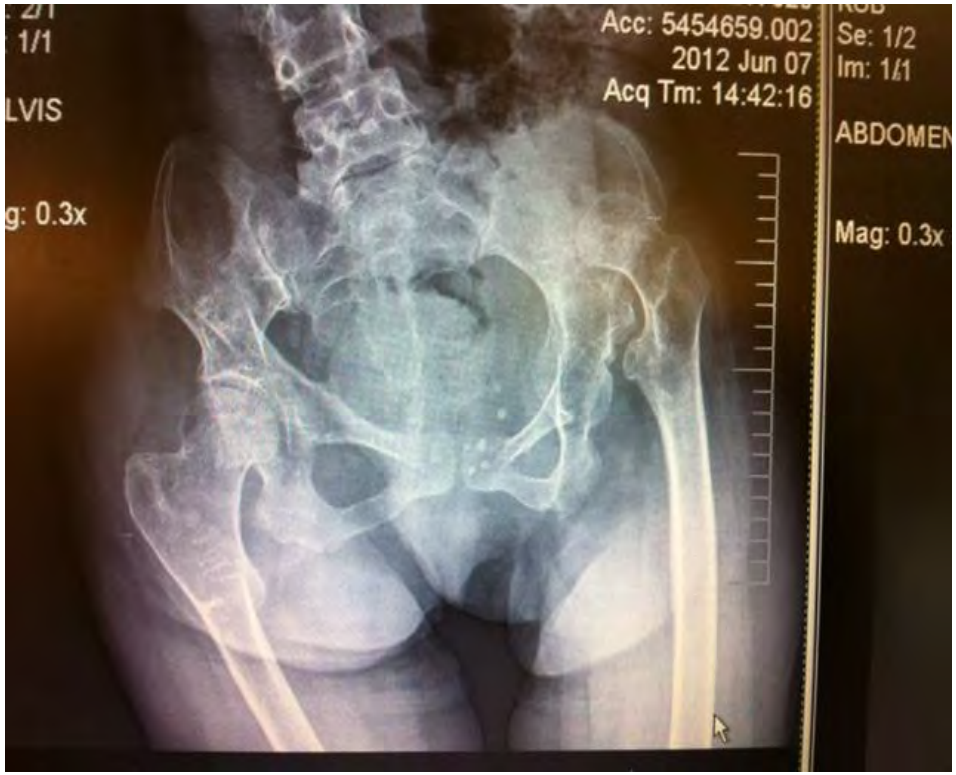
Orthopedic

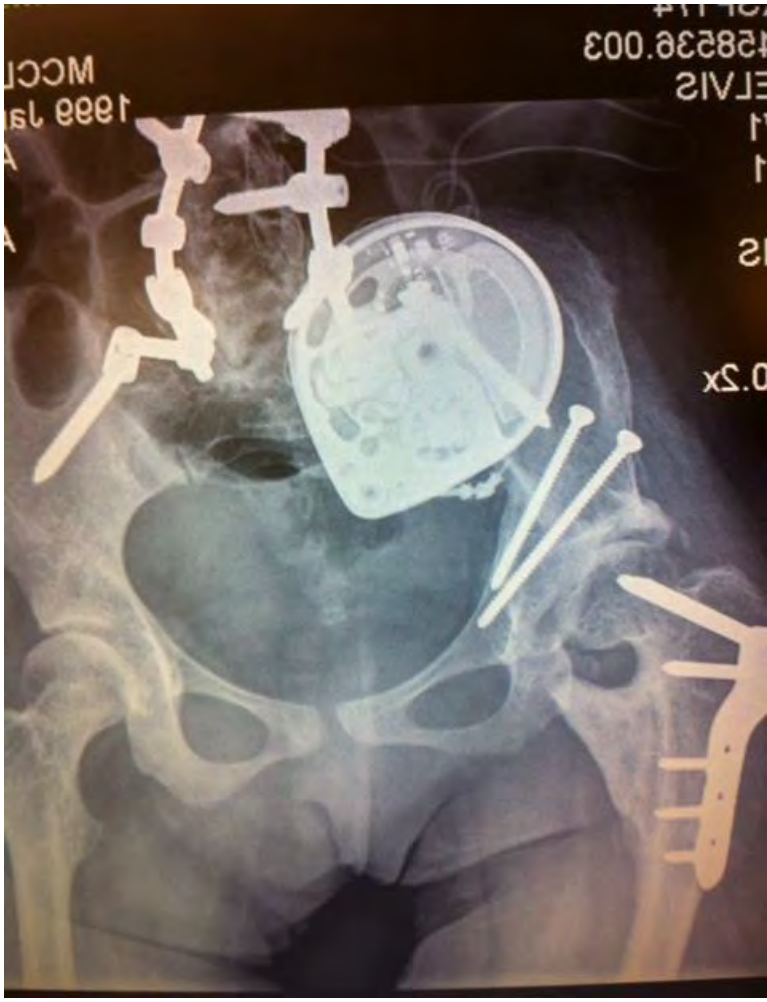
- He is followed by Dr. L. Spine.





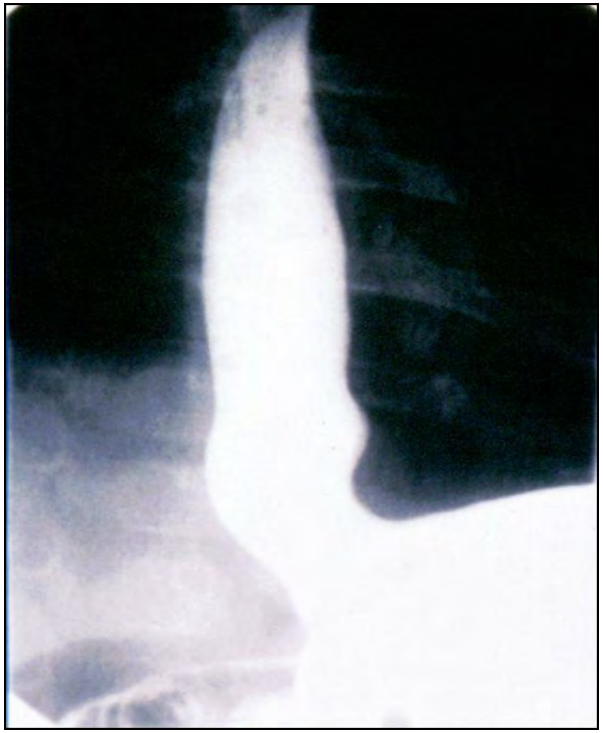
Hip Dislocation





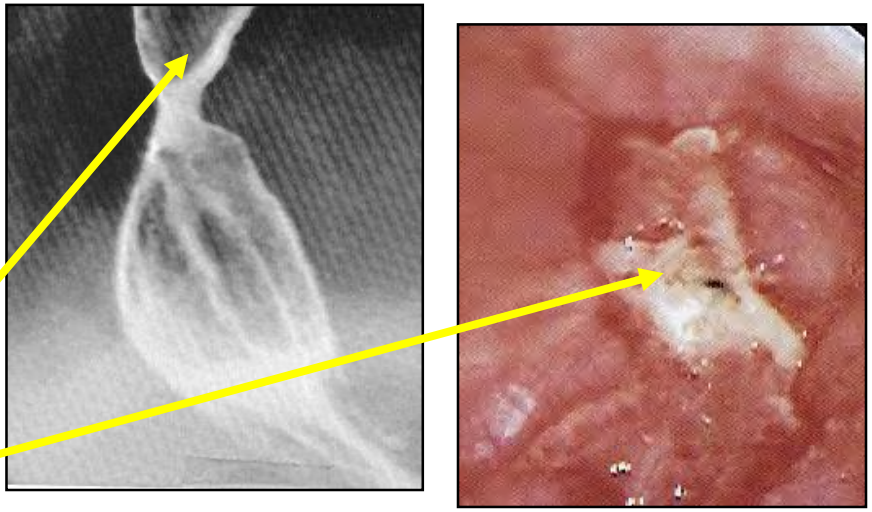
Gastroenterology

- He is currently followed by Dr. G.I. Tract for GERD & constipation. Medications include
  - Senokot, Colace, Lactulose, Cytotec,
  - Zantac, Propulsid, Maalox, Prevacid,
  - Milk of Magnesia, Agoral.
  - Karo syrup,
  - molasses, and
  - aloe vera juice.



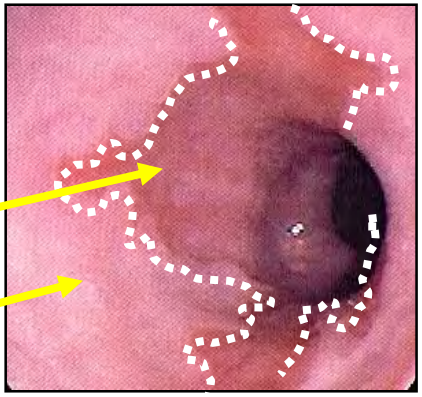
GERD Complications

Esophageal stricture secondary to GERD: radiography and endoscopy



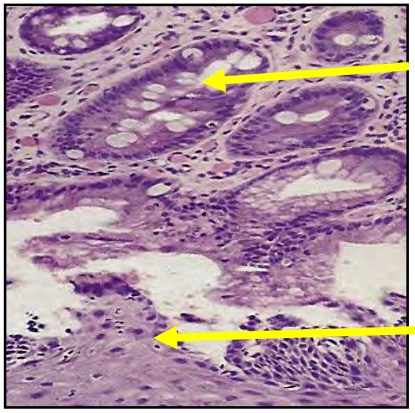
Stricture

Barrett's esophagus: endoscopy and histology



Barrett's

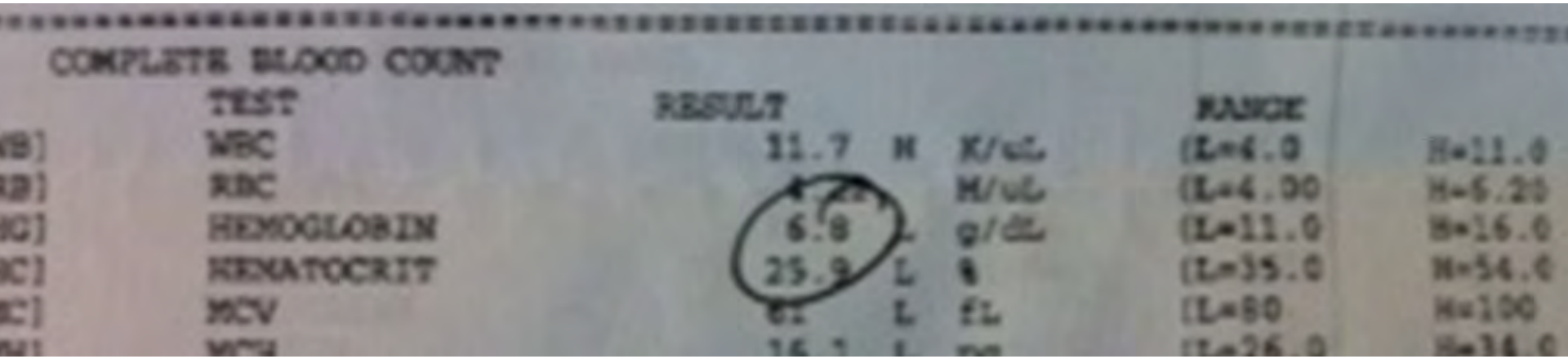
Normal



Barrett's

Normal

Complication of GERD

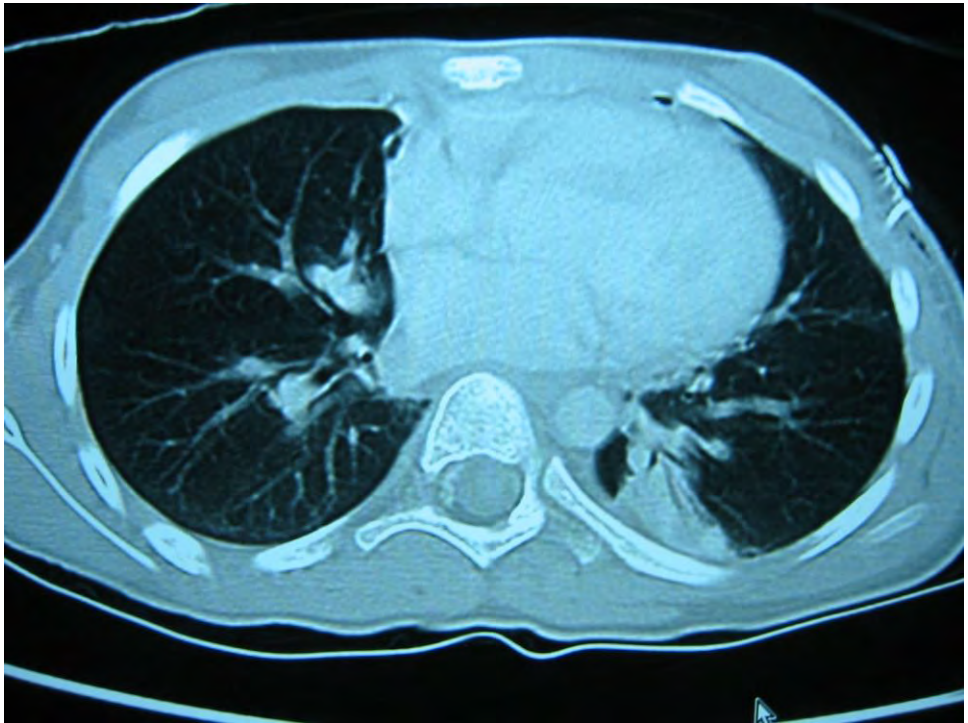


COMPLETE BLOOD COUNT

	TEST	RESULT			RANGE	
WB]	WBC	11.7	H	K/uL	(L=4.0	H=11.0
RB]	RBC			M/uL	(L=4.00	H=5.20
HG]	HEMOGLOBIN	6.8	L	g/dL	(L=11.0	H=16.0
HC]	HEMATOCRIT	25.9	L	%	(L=35.0	H=54.0
MC]	MCV	81	L	fL	(L=80	H=100
MH]	MCH	26.1	L	pg	(L=26.0	H=34.0

Pulmonary

- He has a history of recurrent aspiration pneumonia and reactive airway disease
- He is followed by Dr. R. Lung, Pulmonary medications include
  - Atrovent,
  - Intal and
  - Robinul

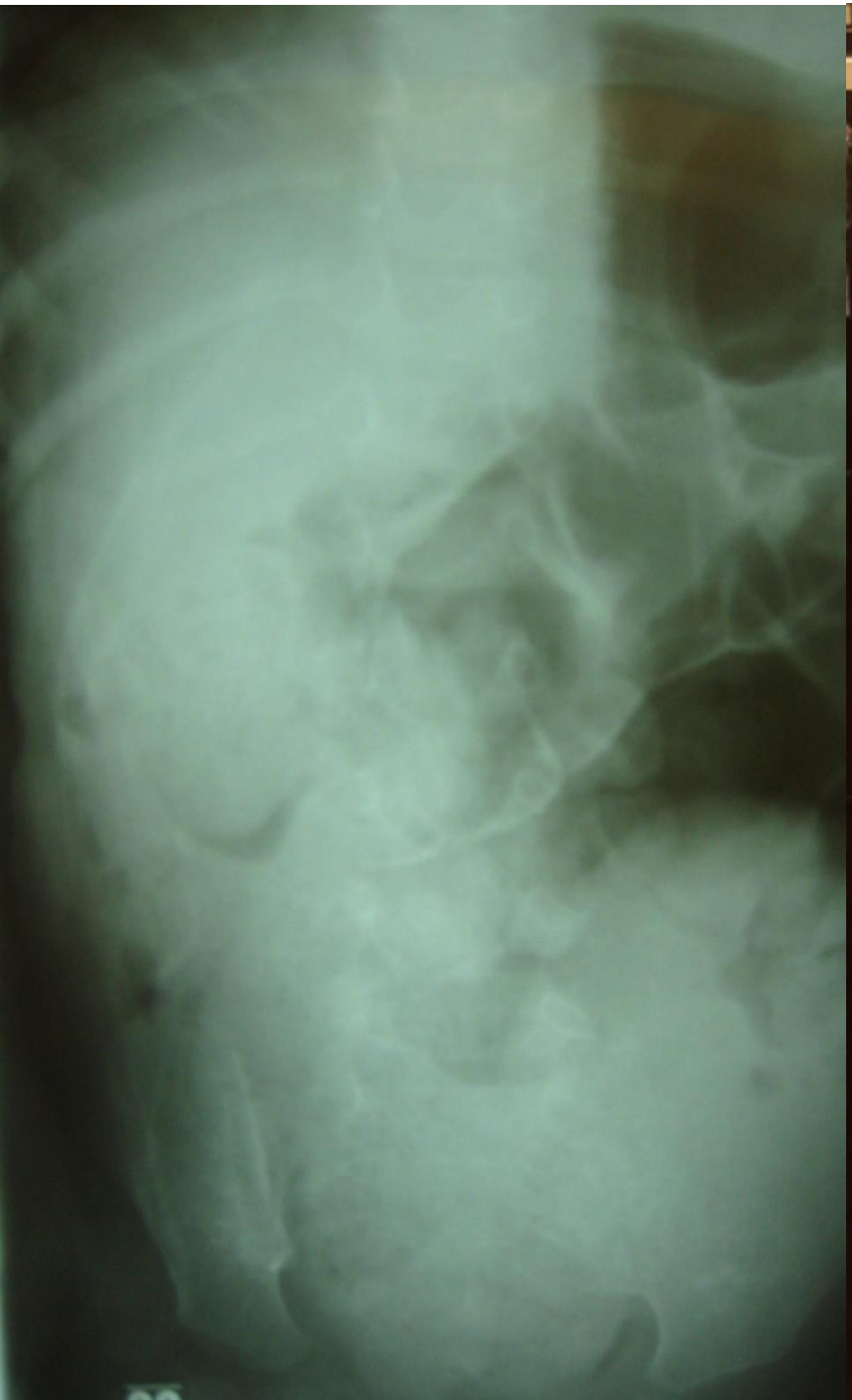


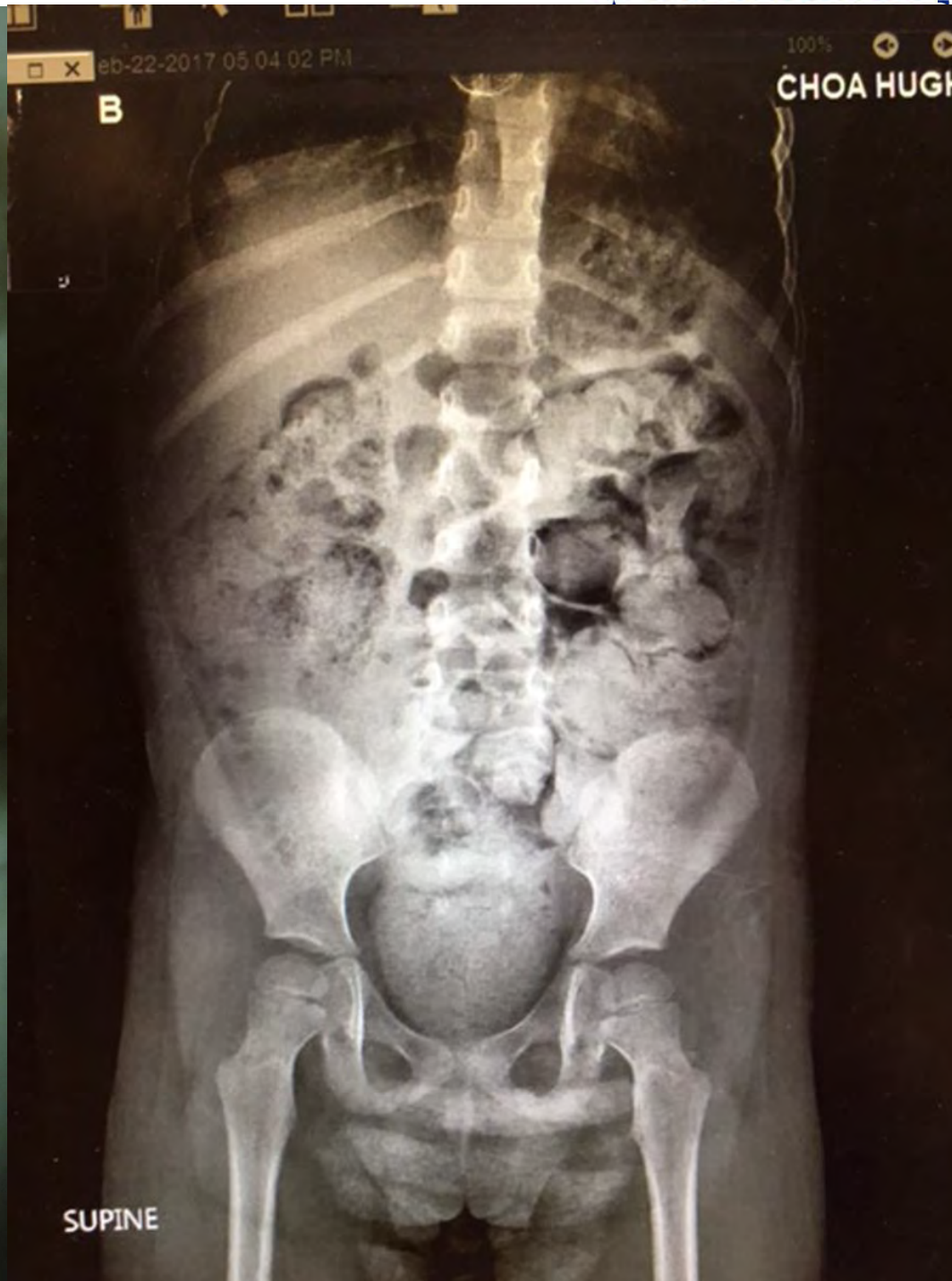
Profile of Health Care Needs

- *Survey of nursing and medical profile prior to deinstitutionalization of a population with profound IDD*

- Serious medical problems in decreasing frequency were
  - constipation (96%),
  - seizure disorder (70%),
  - poor dental hygiene (67%),
  - cerebral palsy (62%),
  - scoliosis (61%),
  - contractions (41%),
  - aspiration (44%),
  - skin lesions (40%), and
  - dysphagia (22%).

Kozma et al, Georgetown University Medical Center




eb-22-2017 05:04:02 PM
100%
CHOA HUGH
B
SUPINE

Complications of Constipation

- Hemorrhoids
- Rectal Prolapse
- Diverticulitis
- Megacolon
- Volvulus
- Perforation
- But more commonly……
- Discomfort and Distress

In summary:

- Severe neurological disorders
- Multiple medical problems
- Multiple medical providers
- Multiple medications
- Multiple surgeries
- Multiple hospitalizations
- Multiple emergency room visits
- Multiple assistive devices
- Needs 24 hour care

Specific Syndromes

- Physical Characteristics
- Congenital Anomalies
- Neurological Characteristics
  - Neuromotor
  - Neurocognitive
  - Neurobehavioral
- Specific Medical Conditions
  - Organ System
  - Endocrine

Health Care Needs for Individuals with Down Syndrome

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Congenital Heart Disease	60%
Later – Mitral Valve Prolapse	20%
GI Tract, e.g.Duodenal Atresia, Hirschprung's	2%
Recurrent Otitis affecting Hearing	70%
Eye Problems, e.g. Strabismus, Cataracts	50%
Endocrine – Thyroid Disease	15%
Endocrine – Diabetes	2%
Alzheimer's Disease	70%

Down Syndrome and Alzheimer's Disease

- 10%-25% of patients with Down syndrome have Alzheimer's disease at age 40-49 years,
- 20%-50% have Alzheimer's disease at age 50-59 years
- 60%-75% have Alzheimer's disease when older than 60 years of age.
- The first symptoms usually develop at age 50 years, and diagnosis is usually made by age 52 years.
- Death occurs at an average age of 60 years.

Prader Willi Syndrome

- Partial Deletion chromosome #15
- Newborns are often small and floppy
- Feeding difficulties in infancy with failure to thrive
- Then insatiable appetite with dramatic weight gain and development of morbid obesity
- Metabolic complications of obesity
- Challenging behaviors

Angelman Syndrome

- Partial Deletion chromosome #15
- Developmental Delays
- Intellectual Disabilities
- Unusual Motor Patterns vs. CP
- Seem to be Happy
- Seizure Disorders
- Constipation

Health of adults with IDD

- Health Risk Behaviors
  - Overall, 55% overweight or obese
  - Smoking rates approached national average (20%)

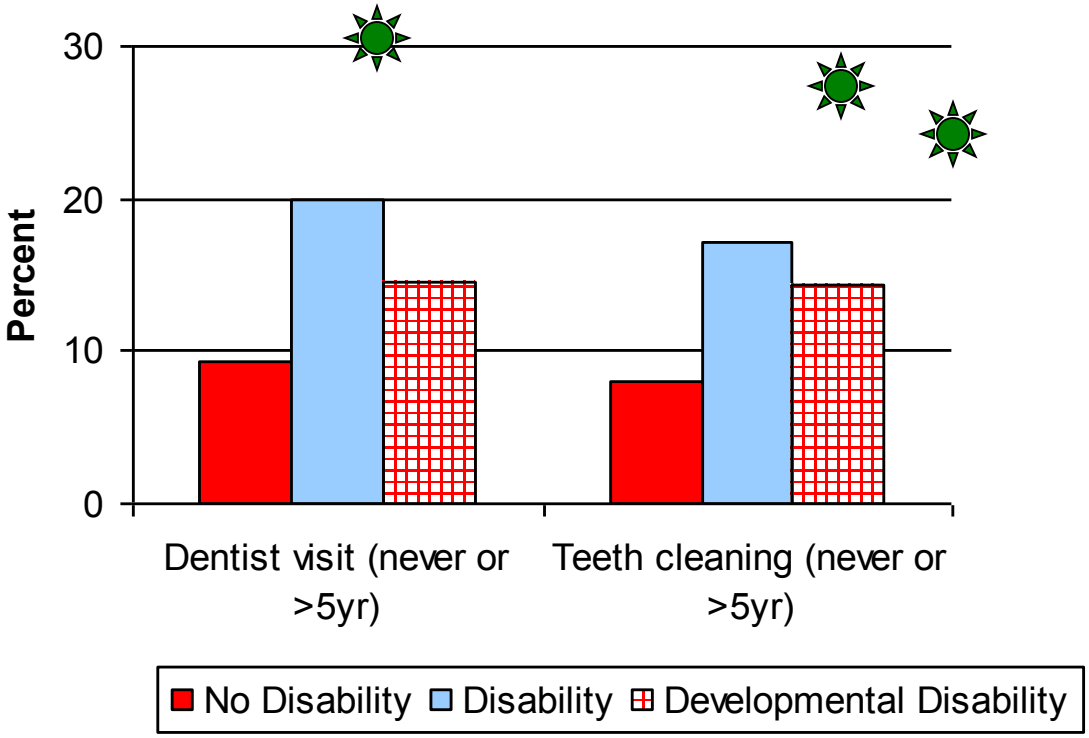
Lanterman California Study

Physical activity among adults with IDD

- Only about 10% of adults engage in physical activity a minimum of 3 days a week.
- Most leisure-time activities are sedentary, such as watching television or listening to the radio.
- A combination of sedentary lifestyles, high fat diets, and low fruit and vegetable diets is a major contributor to increased health risk

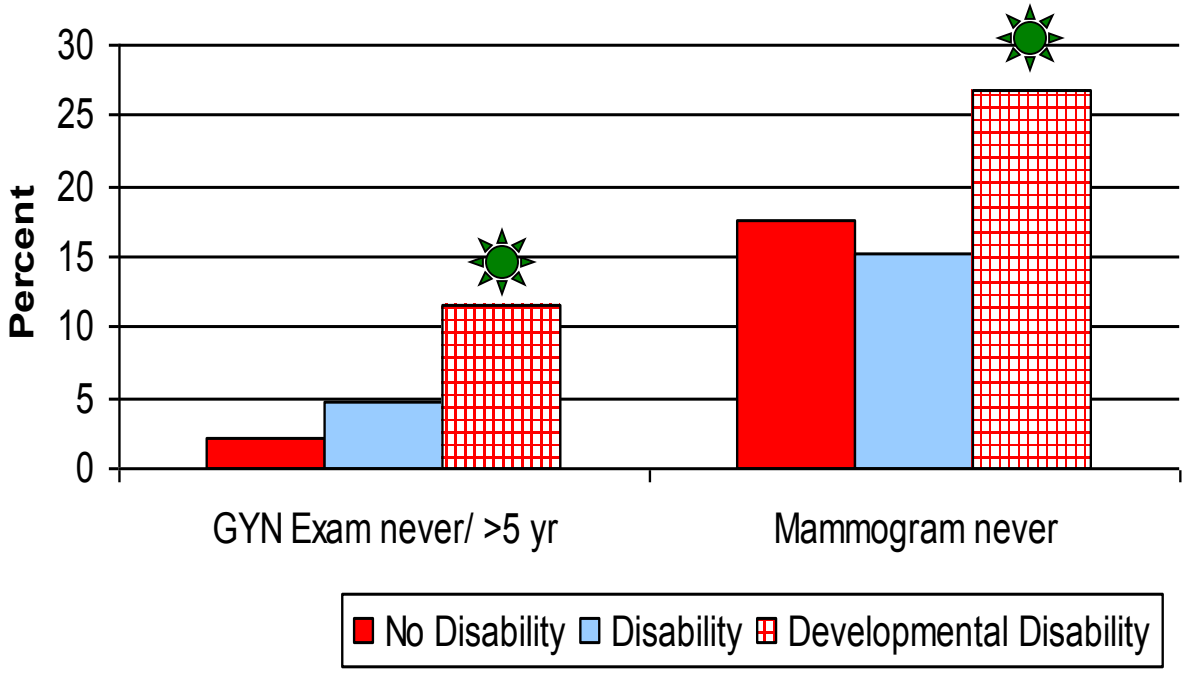
Tamar Heller 2005

Limited Access to Oral Health care



Havercamp et al 2004 State Surveillance Data

Limited Access to Women's Health Care



Havercamp et al 2004 State Surveillance Data

Mental Health

- Prevalence of comorbid mental disorders that is estimated to be 3 – 4 times greater than the general population ~ 35%

- Contributing Factors:
  - Underlying predispositions e.g. Autism
  - Difficulty in communicating needs & emotions
  - Limited control over environmental stresses
  - Limited social and emotional support

Psychiatric admissions for people with IDD

- Retrospective review of 198 consecutive admissions to and inpatient psychiatry unit for individuals with intellectual and developmental disabilities

Charlot et al, UMASS Medical Center, 2007

Findings:

- Multiple Medical Conditions
  - Constipation 55%
  - Gastroesophageal Reflux 37%
  - Seizures 25%
- Average of 3 psychoactive medications/person
- Side effects of psychoactive medication
  - EPS 19%
  - Dystonia 15%
  - Dysphagia 13%

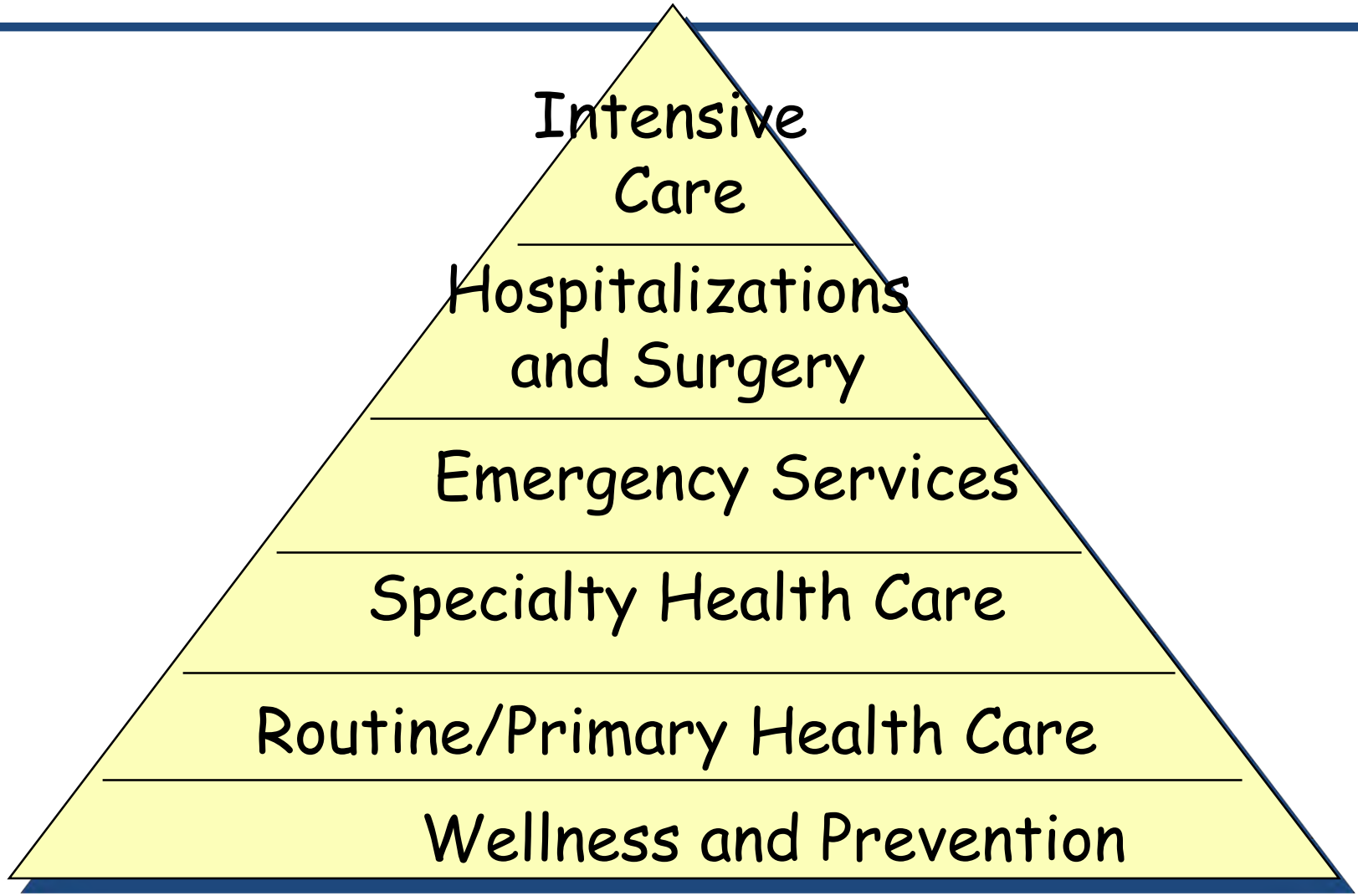
Charlot et al, UMASS Medical Center, 2007

Health Care Needs

- Primary Care
- Prevention of Secondary Disorders
- Specialty Health Care
- Coordination of Care
- Emotional and Social Supports
- Assistance with Legal Aspects, e.g. guardianship, surgeries & end-of-life

Medical-Legal Partnerships

Health Care Infrastructure



Ecology of Challenges to the Provision of Health Care

- The Person with IDD
- The Family and Support People
- The Health Care Needs
- The Providers of Health care
- The Health Care Delivery “Systems”

The Person with Developmental Disabilities

- Limited understanding of health care
- Limited knowledge of prevention
- Limited ability to accurately report symptoms
- Limited ability to remember past medical history
- Possibly limited cooperation

Family and Support People

- limited knowledge of medical conditions
- limited knowledge of who would provide the best care
- challenges of coordination of information
- challenges in representing the past and necessary health care information
- challenges in advocating for improved health care

Providers of Health Care

- limited training
- limited knowledge of the health care needs
- limited information on the presenting problem
- limited information on past medical history
- limited knowledge of the other aspects of the person's life

Health Care Systems

- Chronic Disorders
  - require long term relationships
  - require preventive approach
  - require multiple providers
  - are more costly
- Managed Care
  - stresses brief encounters
  - does not fund preventive approach
  - tries to keep number of providers down
  - reduced incentive to provide care

Some Solutions

- improve training and education for .....
- improve communication between .....
- improve coordination of .....
- improve the availability of information about .....
- improve access to consultation and expertise on .....

Core Values

- Promote Optimal Health
- Maximize Quality of Care
- Respect and Dignity for All
  - individual
  - family
  - care providers
- Maximize Quality of Life

Primary care of adults with IDD Canadian consensus guidelines

- Implementation of the guidelines would improve the health of adults with IDD and would minimize disparities in health and health care between adults with IDD and those in the general population.

Can Fam Physician 2011;57:541-53

The Medical Home

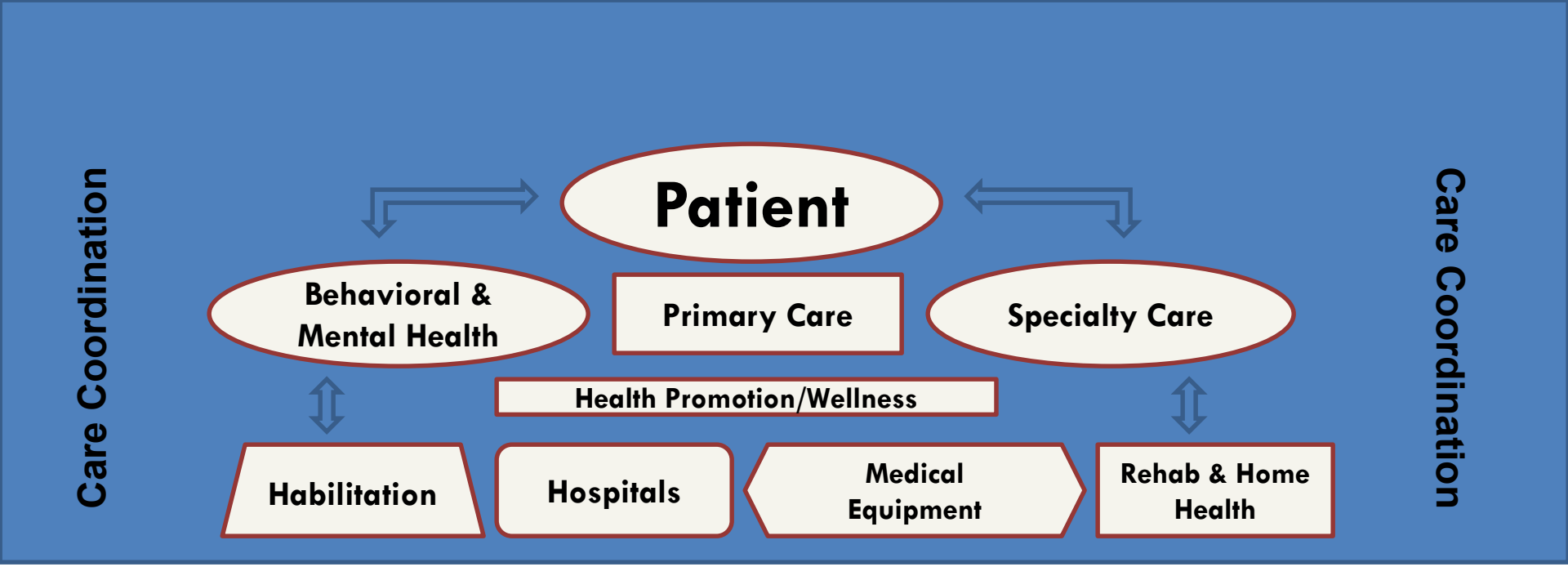
American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™

*A medical home is **not** a building, house, or hospital, but rather **an approach** to providing comprehensive primary care.*

A system of delivery of primary care that is

- *accessible,*
- *continuous,*
- *comprehensive,*
- *family centered,*
- *coordinated,*
- *compassionate, and*
- *culturally effective.*



- Provide exceptional healthcare to people with IDD
- Offer integrated multidisciplinary healthcare that is patient-centric and increases quality of life
- Deliver a warm, welcoming environment
- Customize healthcare and healthcare delivery that is sensitive to past experience

START Program

- Is a *Mental Health Medical Home* providing:
- Coordination of care for individuals with IDD who have mental and social health challenges
- Family support
- Continuity of care
- Facilitated interaction with healthcare professionals

Interdisciplinary CP Clinic at CHOA Hughes Spalding

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Promoting Health: physical and physiological perspective

- Diet and eating patterns
- Exercise patterns
- Sleep patterns
- Bowel patterns

Promoting Health: medical perspective

- Screening for at-risk conditions
- Management of existing chronic medical conditions
- Coordinating Care

Promoting Health: emotional, social and spiritual perspective

- Daily activities
- Preferred activities
- Personal relationships
- Social activities
- Personal time

WHO Definition of Health

- The promotion of
  - Physical
  - Emotional &
  - Social Well Being

Conclusion

- Individuals with IDD are likely to have complex physical, medical, emotional and social problems
- They need a lot of care from a lot of people in a systematic, interdisciplinary and coordinated manner
- It can be costly to do this well
- W
- But we must continue to strive to do the best we can for each individual and family….
- …..in the most thoughtful, respectful & efficient manner

Ultimately the practices and values of a society are judged by how they treat their most vulnerable citizens

Thank You……