




**Adult Developmental Disabilities  
Clinic at the University of Chicago**  
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**Midwest Region NMPRA  
Meeting: May 12, 2012**

## DEFINITION OF DEVELOPMENTAL DISABILITIES

- Disability is a mental or physical impairment or a combination of mental and physical impairments
  - Manifested before age 22
  - Likely to continue indefinitely
  - Results in substantial functional limitations in three or more of the following areas of major life activity;
    - (i) Self-care;
    - (ii) Receptive and expressive language;
    - (iii) Learning;
    - (iv) Mobility;
    - (v) Self-direction;
    - (vi) Capacity for independent living; and
    - (vii) Economic self-sufficiency.
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## DEFINITION OF DEVELOPMENTAL DISABILITIES

- Reflects the need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services that are planned and coordinated for that individual.



## TRANSITION TO ADULTHOOD

- More than 90% of individuals with severe disabilities reach adulthood.
- Each year in the U.S., ½ million children with special health care needs cross the threshold into adulthood.
- Spina Bifida: 70% - 80% of individuals will reach age 20
- Cystic Fibrosis: mean life expectancy in the U.S. is 26 years of age
- Cerebral Palsy: 95% with diplegia and 75% with quadraplegia survive until age 30(Rapp 2000)
- Mental Retardation (MR): 90% of children with mild MR & 65% with severe MR survive until age 30(Rapp 2000)



## CHALLENGES

- Deinstitutionalization of developmentally disabled adults since the 1970s
- Developmentally disabled adults now cared for by local, community physicians
- Few primary care physicians have formal training
- Many challenges for physicians:
  - Educational resources in this field for physicians are limited
  - obtaining records/informed consent difficult
  - developmentally disabled patients require more time for evaluation
  - changing reimbursement



# ADULT DEVELOPMENTAL DISABILITIES CLINIC POPULATION

- Intellectual disabilities with or without genetic etiology
- Cerebral palsy (with or without intellectual disability)
- Spina Bifida
- Autism
- Epilepsy
- Genetic Disorders:
  - Down Syndrome
  - Williams Syndrome
  - Fragile X
  - Bekwith-Wiedemann Syndrome



Adult Developmental Disabilities Clinic  
General Information Update

**Patient**

Name \_\_\_\_\_  
Date of Birth \_\_\_\_/\_\_\_\_/\_\_\_\_ Social Security \_\_\_\_\_

**Family**

Name \_\_\_\_\_  
Relationship to patient \_\_\_\_\_  
Phone Number \_\_\_\_\_  
Address \_\_\_\_\_

**Service Provider**

Agency \_\_\_\_\_  
Contact Person \_\_\_\_\_ Phone Number \_\_\_\_\_  
Address \_\_\_\_\_

**Guardian**, if applicable \_\_\_\_\_  
Address \_\_\_\_\_ Phone Number \_\_\_\_\_

**Person responsible for appointments**

Name \_\_\_\_\_  
Daytime phone \_\_\_\_\_ Relationship to patient \_\_\_\_\_  
Primary Care Physician \_\_\_\_\_

**Specialists** Name \_\_\_\_\_ Specialty \_\_\_\_\_



# HEALTH HISTORY FOR ADULTS WITH DEVELOPMENTAL DISABILITIES

- Active problem list
- PMH/PSH
- Seizure disorder
- Vaccination history
- Documentation of guardianship
- Home setting - family
  - group home
  - independent
- ADLs/functional capacity
- Day program/workshop





# HEALTH HISTORY FOR ADULTS WITH DEVELOPMENTAL DISABILITIES

- Durable medical equipment needs:
  - wheelchair, walker, cane
- Previous history of OT/PT services
- List of other providers from: orthopedics, neurology, psychiatry, dentistry, etc.
- Need for respite services



## MULTIDISCIPLINARY EVALUATION

- Primary Care(MD or NP) evaluation
- Social services
- Nutritionist
- Mental health services, resources for public aid insurance
- Physical therapy/Occupational therapy
- Dental Services:
  - Doral Dental Services: locate dental services for public aid patients based on patient's zip code: 1-888-286-2447
- Speech/swallow evaluation/speech therapy



## MULTIDISCIPLINARY EVALUATION

- Ophthalmology
- Audiology
- Orthopedic resources
- Neurology
- List of resources, websites of various disability organizations: e.g. ARC of IL, spina bifida, CP, Down
- Checklists for various disabilities



# ILLINOIS MEDICAID PROGRAM: INTEGRATED CARE PROGRAM (ICP)

- New program for adults over age 19 who have disabilities and receive SSI.
- Participation is mandatory
- Does not include individuals with Medicare
- Eligible patients who live in Suburban Cook, DuPage, Kane, Lake, Kankakee and Will Counties must choose one of two plans contracted through IL DHFS (excluding zip code areas that starts with 606):

**Aetna Better Health**

**IlliniCare**



# ILLINOIS MEDICAID PROGRAM: INTEGRATED CARE PROGRAM (ICP)

- Patients with Aetna Better Health or IlliniCare are given 90 days from the time they are enrolled to continue seeing current PCP

Aetna Better Health : 1-866-212-2851

<http://www.aetnabetterhealth.com/illinois/>

IlliniCare: 1-866-329-4701

<http://www.illinicare.com/>



# ILLINOIS MEDICAID PROGRAM: INTEGRATED CARE PROGRAM (ICP)

Illinois Client Enrollment Broker 1-877-912-8880:

<http://www.illinoisceb.com/>

- Provides more information about the ICP
- Can assist patients in choosing new PCP for their medical home



## IMPACT OF MANAGED CARE IN MEDICAL CARE FOR DEVELOPMENTALLY DISABLED ADULTS

- Many of the academic institutions in the Chicago area are not on the list of providers
- Long-standing primary care providers are being replaced by providers unfamiliar with patient's complex medical needs
- Less access to subspecialty providers; e.g. radius of orthopedic provider from patient's home may be 50 miles
- Less respite services funding
- Patients/families unable to advocate for themselves

