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# **Legal and Advocacy Issues for**

- Children with Developmental Disabilities**

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Parent Partners in Health Education

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# The Federal Developmental Disabilities Act (10/2000) defines a developmental disability as a severe, chronic disability that:

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- Is manifested before the person attains age 22.
- Is likely to continue indefinitely.
- Results in substantial functional limitations in 3 or more of the following areas of major life activity:
  - Self-care
  - Receptive and expressive language
  - Learning
  - Mobility
  - Self-direction
  - Capacity for independent living
  - Economic self-sufficiency
- Is attributable to a mental or physical impairment or a combination of mental and physical impairments.
- Reflects the individual's need for a combination and sequence of special interdisciplinary or generic services, individualized support, and other forms of assistance that are lifelong or of extended duration and are individually planned and coordinated.

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# Diagnostic Criteria for Mental Retardation (DSM IV)

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- Significantly sub-average intellectual functioning: an IQ of 70 or below (for infants, a clinical judgment of significantly sub-average intellectual functioning).
- Concurrent deficits or impairments in present adaptive functioning in at least 2 of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety.
- Onset before age 18 years.

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# Legislation—tracing the history

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- 1964 *Civil Rights Act*
- 1968 *Architectural Barriers Act*
- 1973 *Rehabilitation Act*
- 1975 *Education for all Handicapped Children Act*, later renamed *IDEA (Individuals with Disabilities Education Act)*
- 1980 *Civil Rights of Institutionalized Persons Act*
- 1982 *Telecommunications for the Disabled Act*
- 1984 *Voting Accessibility for the Elderly and Handicapped*
- 1988 *Fair Housing Amendments Act*

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# Americans with Disabilities Act 1990

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- Title I through IV of the ADA addressed discrimination in employment, state and local government services and transportation, private accommodations and services, and telecommunications.

[www.usdoj.gov/crt/ada/adahom1.htm](http://www.usdoj.gov/crt/ada/adahom1.htm)

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# Education

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- **AAP Policy Statement June 2007: Provision of Educationally Related Services for Children and Adolescents With Chronic Diseases and Disabling Conditions** (Council on Children With Disabilities)

A multidisciplinary assessment within the school system is required in the initial evaluation of children to determine their eligibility for services within the educational system.

It is also necessary to maintain a comprehensive multidisciplinary approach in the provision of these services, which should be coordinated with the child's medical home professional.

The inequalities in the interpretation and provision of services between and within states and school districts need to be corrected.

The developmental, educational, functional, and medical needs of the child or adolescent should be determined first, and then the appropriate services to meet these needs should be provided in a timely manner.

Issues of who provides the appropriate services and how payment is to be made must be resolved in the context of maintaining the child in the appropriate educational environment.

<http://aappolicy.aappublications.org/cgi/content/full/pediatrics;119/6/1218>

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# Individuals with Disabilities Education Act (IDEA) ensures:

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- A free appropriate public education
  - An appropriate evaluation
  - An Individualized Education Program (IEP) or Individualized Family Service Plan (IFSP)
  - An education to take place in the least restrictive environment
  - Parent and student participation in making decisions
  - The presence of procedural safeguards
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- IDEA reauthorized/revised 2004

<http://idea.ed.gov/>

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# IDEA by age

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- *Part C: birth--2 years*

- Early Intervention

- Lead agency in NYC is the Dept. of Health
- Contracted agencies may provide service coordination and/or evaluation and/or therapy

- *Part B: ages 3--21*

- Early Childhood

Direction Center

- NYC Board of Education—CPSE, CSE

- VESID

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# Early Intervention

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- The New York City Department of Health and Mental Hygiene is the lead City agency; the New York State Department of Health coordinates the statewide network of services.
  - New York City:  
<http://www.nyc.gov/html/doh/html/earlyint/earlyint.shtml>
  - New York State:  
[http://www.health.state.ny.us/community/infants\\_children/early\\_intervention/](http://www.health.state.ny.us/community/infants_children/early_intervention/)
- Referrals now made by fax only:
  - Referral form:**  
<http://www.nyc.gov/html/doh/downloads/pdf/earlyint/ei-referral-form.pdf>
  - Confirmation form also!:**  
<http://www.nyc.gov/html/doh/downloads/pdf/earlyint/ei-referral-con.pdf>
- It is important to follow up after faxing form! Call 311

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# Early Childhood Direction Center

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- State-funded, county-specific; addresses needs of children 1-5 years old.
  
- ECDCs provide information about:
  - preschool programs
  - transportation
  - medical, educational, and social services
  - evaluation and assessment services
  - funding
  - parent education programs and resources
  - day care
  - the State's early intervention system

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# Early Childhood Direction Center

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## ■ Services Include:

- matching the needs of children with available services
- assisting parents in obtaining services
- following up to ensure that children receive services
- coordination of services between agencies
- education of parents of preschool children with disabilities

## ■ In Manhattan:

- Early Childhood Direction Center  
New York Presbyterian Hospital  
435 East 70<sup>th</sup> Street, Suite 2A  
New York, NY 10021  
Phone: (212) 746-6175  
Fax: (212) 746-8895  
E-mail: [mrubinst@nyp.org](mailto:mrubinst@nyp.org)

[http://www.health.state.ny.us/community/infants\\_children/early\\_intervention/transition/appendix\\_b.htm](http://www.health.state.ny.us/community/infants_children/early_intervention/transition/appendix_b.htm)

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# Committee on Preschool Special Education

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- Parent brochure on transitioning from pre school to kindergarten (also available in Spanish):

- <http://schools.nyc.gov/NR/rdonlyres/69D78629-9B1B-4247-A23B-C09B581AFAB1/15127/PreSchooltoSchoolAge102406ENGLISH.pdf>

Referral form for CPSE evaluation:

<http://schools.nyc.gov/NR/rdonlyres/F8C415BC-D16C-49C9-B842-EF504CDAE17B/0/SOPMFORMS.pdf>

Regional offices for CPSE:

[http://www.resourcesnyc.org/rcorrect.htm#Preschool\\_Admin](http://www.resourcesnyc.org/rcorrect.htm#Preschool_Admin)

District 75 Preschool program:

<http://schools.nycenet.edu/d75/ece/default.htm>

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# Committee on Special Education

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- School responsible to conduct “child find” activities
- Referrals can be made by any interested party
- Parents must consent to the evaluation
- All children (even in private school/home schooling) eligible
- Special Education Citywide District 75

<http://schools.nyc.gov/Parents/Essentials/Special+Education/Documents.htm>

<http://schools.nyc.gov/Parents/Essentials/Special+Education/contacts.htm>

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# VESID

Vocational and Educational Services for Individuals with Disabilities

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- Transitions young adults with disabilities from high school to vocational training
- Independent Living Centers

<http://www.vesid.nysed.gov/>

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# Financial Issues

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## ■ Health Insurance

- Medicaid (“Katie Beckett”) waiver—Medicaid coverage for severely affected children who have pvt.medical insurance.
- Medicaid managed care: as of 2007, some children with developmental disabilities can still avoid managed care.

## ■ SSI

- Provides monthly check if child medically eligible and family income low enough.
- <http://www.ssa.gov/pubs/10026.html>

## ■ Work

- Public assistance now limited to 60 mos unless recipient qualifies as being needed in the home full-time to care for an “incapacitated individual.”

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# Health Issues

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- Physical
- Mental
- Dental
- Sexual-Reproductive
  - <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;118/1/398>
- Transition to Adult Care

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# Home Care

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- [http://www.nyc.gov/html/hra/html/medical\\_insurance/serv\\_homecare.shtml](http://www.nyc.gov/html/hra/html/medical_insurance/serv_homecare.shtml)
- M11-q form: download here
  - [http://www.cap4kids.org/new\\_york\\_city/download/M11Q.pdf](http://www.cap4kids.org/new_york_city/download/M11Q.pdf)
- The M11-q form is submitted to the CASA office serving the child (by address)
  - [http://www.nyc.gov/html/hra/downloads/pdf/list\\_casa.pdf](http://www.nyc.gov/html/hra/downloads/pdf/list_casa.pdf)

# Housing

- “Section 8”:
  - The **Housing Choice Voucher Program** is a type of Federal assistance provided by the United States Department of Housing and Urban Development (HUD) dedicated to sponsoring subsidized housing for low-income families and individuals. It is more commonly known as **Section 8**, the reference to the portion of the U.S. Housing Act in which the program is authorized. As of May, 2007, NYC Housing Authority is accepting applications only from individuals who are homeless, or victims of violent crimes (incl. Domestic violence).
  - The National Council on Disabilities concluded in a 2001 report that “...civil rights enforcement by... HUD has left America, particularly those with disabilities, needing more.”
    - <http://www.ncd.gov/newsroom/publications/2001/pdf/fairhousing.pdf>
- Con Edison: life-sustaining equipment, permanent disability, medical hardship  
<http://www.coned.com/customercentral/specialservices.asp#six>

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# Transportation

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- MTA Guide to Accessible Transit:
  - <http://www.mta.info/mta/ada/ada.pdf>
  - Access-a-ride vans
  - Reduced fare metro cards
  - Medicaid transportation: form  
([http://www.health.state.ny.us/health\\_care/medicaid/program/update/2007/2007-04.htm#cod](http://www.health.state.ny.us/health_care/medicaid/program/update/2007/2007-04.htm#cod))

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# Family Support

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- <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;115/2/507>

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# Planning for the Future

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- At age 18, all U.S. residents are legally free of parental control
- Guardianship petition: establishes a legal guardian who can act in the parent's stead if parent unable to continue care
- Health Care Proxy
- Will