



# **Legal Advocacy in New York – Accessing Services and Supports for Children and Adults with FASD**

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# Introduction

**Disability Rights New York is the statewide Protection and Advocacy System and Client Assistance Program**

DRNY advocates for New Yorkers with disabilities to enable them to:

- Exercise their own life choices
- Fully participate in their communities
- Enforce their civil and legal rights

# Our History



**The federal P&A system started in New York State in the 1970's, as a result of an exposé on the deplorable conditions in the Willowbrook State**

# Creation of P&A System

Original purpose to protect people with developmental disabilities living in institutions from abuse and neglect

The P&A's mandate now covers:

- All people with disabilities
- A broad range of issues
- All settings that assist people with disabilities

# The P&A System

- P&A agencies exist in every state and territory (57 total).
- Mostly non-profits; 7 state agency P&As.
- Largest provider of legally-based advocacy for individuals with disabilities in the country.
- Cross-disability.

# **P&A Access Authority**

Federal law provides P&A's with broad access to monitor and investigate abuse and neglect, including to:

- Visit facility sites;
- Interview facility residents;
- Review individual records;
- Review records of investigations by other agencies.

# The Role of P&A Agencies

The P&A Acts assign to P&A agencies “a whistle blower, ombudsman, watchdog, advocacy and ‘private attorney general’ role.”

*- Indiana Protection and Adv. Serv. V. Indiana Family and Social Serv. Adm., 603 F. 3d 365, 383 (7<sup>th</sup> Cir. 2010) (Posner, Circuit Judge, concurring).*

# The Role of P&A and CAP

- Protect and advocate for the rights of people with disabilities;
- Have access to people with disabilities;
- Have access to the records of people with disabilities to facilitate investigations;
- Investigate incidents of abuse and neglect.



# The Role of the P&A and CAP

- Provide information and referral;
- Pursue legal, administrative, and other appropriate remedies and approaches
- Have authority to educate policy makers
- Establish goals and priorities
- Coordinate with other advocacy agencies

# DRNY's Offices

DRNY has three locations in New York State

**725 Broadway,  
Suite 450  
Albany, New York  
12207**

**25 Chapel Street,  
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Brooklyn, New York  
11201**

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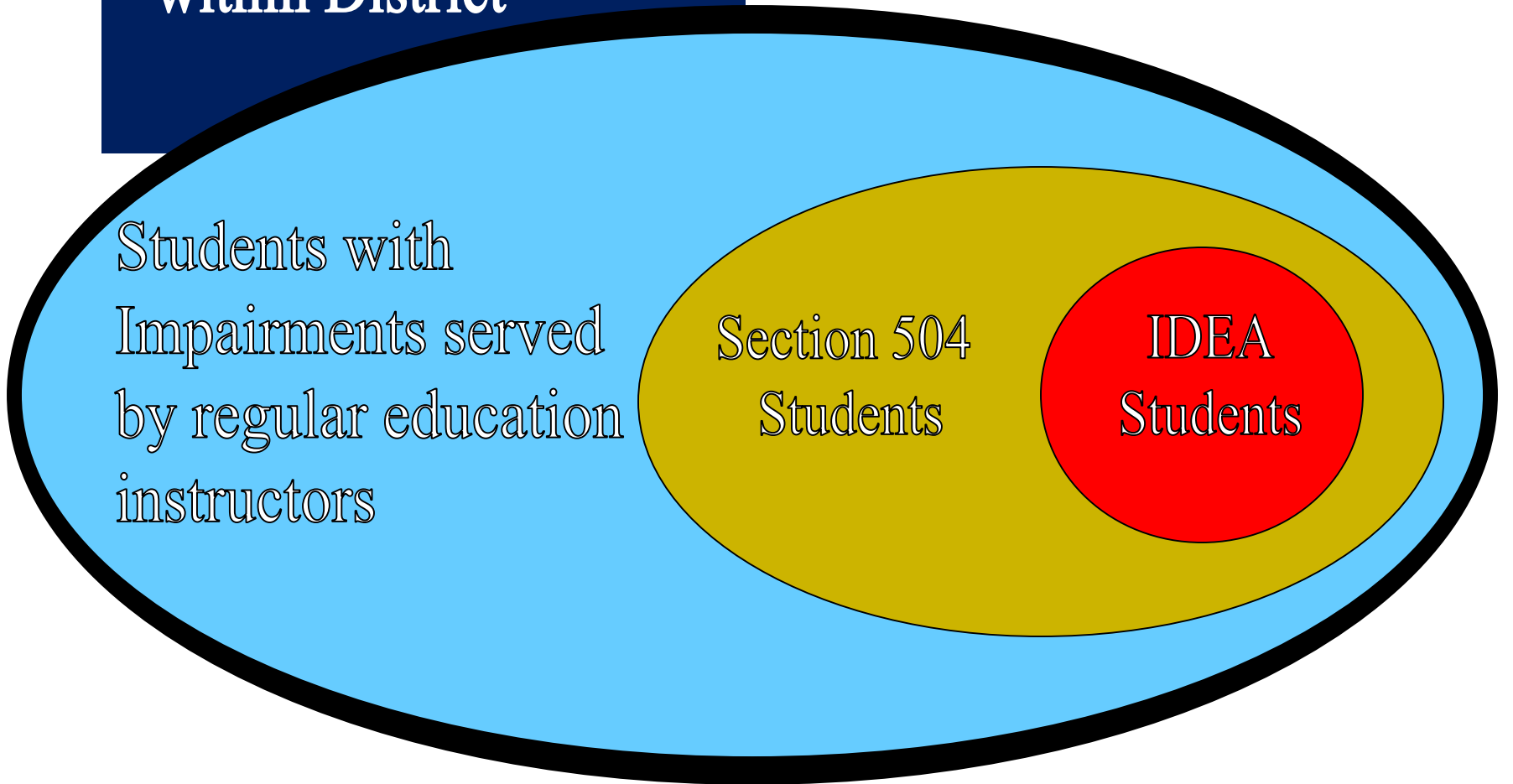
**Advocacy for  
Services and  
Supports School Age  
Children**

All students  
within District

Students with  
Impairments served  
by regular education  
instructors

Section 504  
Students

IDEA  
Students



# INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA)

- To ensure that all children with disabilities:
- have available to them a *free appropriate public education (FAPE)*
  - that emphasizes special education and related services designed to:
    - meet their *unique needs* and
    - prepare them for *employment, secondary education, and independent living,*
  - and to ensure that the *rights* of children with disabilities and parents of such children are *protected.*

# What are the Steps in the Special Education Process?

1. Initial Referral for Special Education Services;
2. Individual Evaluation Process;
3. Determining Eligibility for Special Education Services;
4. Individualized Education Program (IEP); and
5. Annual Review/Reevaluation.

# Child Find Obligation 8 NYCRR 200.2(a)(7)

- Affirmative duty to identify, locate, and evaluate students suspected of having a disability and in need of special education and related services, but no determination of prior eligibility has been made.
- The "child find" requirements apply even though the student is advancing from grade to grade (34 C.F.R. § 300.111[c][1]; see 8 NYCRR 200.2[a][7]).
- Board of education must have procedures in place that will enable it to find such children.

# IDEA Eligibility Determination

- ✓ After consideration of comprehensive evaluation
- ✓ Student aged 3 – 21 (unless earns a high school diploma)
- ✓ Meets definition of 1 or more of following

1. Autism
2. Deafness / HH
3. Deaf-Blindness
4. Hearing Impairment
5. Intellectual Disability
6. Multiple Disabilities
7. Orthopedic Impairment
8. Other Health Impairment
9. Serious Emotional Disturbance
10. Specific Learning Disabilities
11. Speech or Language Impairment
12. Traumatic Brain Injury
13. Visual Impairment / Blindness

- ✓ **AND** who by reason of their disability needs special education and/or related services in order to benefit from their education. (8 NYCRR 200.1[zz]) “Education” includes academic, social, physical, & functional standards. *Lack of instruction in reading or math, or limited English proficiency are not disabilities* 8 NYCRR 200.4(d)



# Initial Referral

- Who may make a referral?
  - The student's parent or person in parental relationship;
  - A designee of the school district
  - Commissioner/designee with responsibility for the student
- NOTE: School staff, physicians, judicial officers, staff of public agencies responsible for the student, or the student (if over 18) can **request** that the district refer the student for an initial evaluation.
- Referrals & requests should be in **writing** and addressed to Chairperson of Committee on Special Education or Committee on Preschool Education.

# Section 504 of the Rehabilitation Act of 1973

*“No otherwise qualified individual with a disability...shall, solely by reason of his or her disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.”*

# Purpose of Section 504 = Equal Access

## **School programs must be accessible to students with disabilities**

Educational services are designed to meet the individual needs of children with disabilities as adequately as the needs of non-disabled persons are met (***accommodations***).

Each child with a disability is educated with non-disabled children to the maximum extent appropriate to the needs of the child with a disability.

# What Are Accommodations?

- Adjustments that allow a *student with a disability* **equal access** to the curriculum or content, or to complete assigned tasks.
  - E.g. John has difficulty sustaining attention for more than 5 minutes, so when taking tests, John will have additional time to take the test so he can take breaks to refocus
- Accommodations do not alter what is being taught.
- Must be *individualized to the student based on his or her needs*

# Example: Student with FASD

- **Environment** (e.g. seat location, noise level, organized workspace)
- **Routine** (e.g. visual schedule, presets, etc)
- **Focus & Attention** (e.g. scheduled breaks, signals, etc)
- **Instruction** (e.g. directions are clear, concise, simple, one step at a time, clusters, groups, sequencing)
- **Assignments/Work completion** (e.g. shorten, allow alternate response format, more time, visual aids, check for comprehension before beginning a task, etc)
- **Testing** (e.g. more time, different location, check for understanding of directions, allow oral responses or use of computer, etc)
- **Use of Assistive Technology/Visual Instruction tools** (e.g. graphic organizer, visual schedules)

# Eligibility Determination

1. Does the student have a ***physical or mental impairment*** supported by documentation or other reliable evidence?
2. Does the impairment affect one of more ***major life activities***?
3. Does the impairment ***substantially limit*** the student's ability to perform the major life activity?
4. Even if meet definition of disability, does the student need accommodations?

*504 Plan is required only if student is unable to equally access education (instruction, building, activities) as a result of the disability*

# The 504 Plan

- Identify student's disability, major life activity impacted, and *educational impact* of disability.
- Lists specific accommodations and when to be provided
- E.g. The Student will received 1.5 time for all tests requiring written responses exceeding one sentence.

**Advocacy for  
Services and  
Supports Office for  
People With  
Developmental  
Disabilities**



# Office for People With Developmental Disabilities

- To be eligible for OPWDD services a person must meet the definition of “developmental disability.”
- “Developmental disability” is defined by Mental Hygiene Law Section 1.03.

# Developmental Disability

- A person has a disability that:
  1. Is attributed to mental retardation, cerebral palsy, epilepsy, neurological impairment or autism; **or**
  2. Is attributed to any other condition of a person found to be closely related to *mental retardation* because such condition results in similar impairments of general intellectual functioning **or** adaptive behavior to that of mentally retarded persons **or** requires treatment and services similar to those required for such persons; **or**
  3. Is attributed to dyslexia resulting from a disability described in (1) or (2); **AND**

## Developmental Disability continued

- Originates before such person attains the age of twenty-two; **and**
- Has continued or can be expected to continue indefinitely; **and**
- Constitutes a *substantial handicap* to such person's ability to function normally in society.

# Determining Diagnosis

- A practitioner must designate a diagnostic classification that corresponds with the prevailing clinical nomenclatures (e.g. using ICD-9; DSM-IV; or APA).
- OPWDD will scrutinize diagnostic statements that are not supported by corresponding and appropriate clinical and psychometric assessment findings.
- For conditions other than Intellectual Disability (formerly called Mental Retardation) the diagnosis of the named condition is required.

# Determining Qualification Prior to the Age of 22

- A person must show evidence of history and presence of a developmental disability prior to the age of 22.
- When no information is available about the age of the onset of the disability:
  - Practitioners are advised to make efforts to acquire school records and medical reports, and should not assume that these do not exist;
  - Interviews with family members or other care providers may be helpful in establishing age of onset of disability;
  - Use of Medical Providers Opinion.

# Determining Qualification of “Condition Continue Indefinitely”

- A person must show evidence that the condition has continued or can be expected to continue indefinitely.
- OPWDD looks to standardized testing and clinical impressions of the treating doctors.

# Determining “Substantial Handicap”

- OPWDD defines functional limitations which constitute a substantial handicap as:
  - Significant limitations in adaptive functioning that are determined from the findings of assessment by using a nationally normed and validated, comprehensive, individual measure of adaptive behavior, administered by a qualified practitioner.

# Substantial Handicap -Continued

- Functional Limitations will be considered to constitute a substantial handicap when:
  - They prohibit a person from being able to engage in self-care or exercise self-direction independently or when development of self-care and self-direction skills are significantly below an age-appropriate level.
  - Such limitations may also seriously disrupt age-appropriate social and interpersonal relationships.



## “Substantial Handicap” Continued

- A low IQ does not automatically validate substantial handicap;
- With a formal assessment finding of an IQ less than 60, OPWDD may permit clinical assessment of adaptive behavior instead of using a comprehensive individual measure of adaptive behavior. (e.g. interviews with caregivers, review of records, direct observations).

# Assessing “Intellectual Skills”

- Requires a nationally normed, validated, and comprehensive individual measure of intelligence that is administered in a standardized format;
- However, when a qualified practitioner finds standardized formats inappropriate, other formats can be used, but the **format and rationale must be thoroughly documented.**

# Assessing “Adaptive Behavior”

- Must use nationally normed, validated, comprehensive, individual measure of adaptive behavior;
- For measures that use an overall composite or summary index score, substantial handicap is defined as **2.0 or more** standard deviations below the mean or within the range of adaptive behaviors associated with an intellectual level of mild or profound mental retardation.

## Adaptive Behavior -Continued

- For adaptive behavior scales that use factor or multiple scale summary scores, adaptive behavior means the majority of the factors/summary scores lie **2.0 or more** standard deviations below the mean.
- This means that a person can qualify if the majority of subtest scores fall at least 2.0 standard deviations below the mean, even when the composite score does not.

# Adaptive Behavior -Continued

- Adaptive behavior measures that do not use an overall or factor scale are **unacceptable** as a means of determining presence of functional limitations constituting substantial handicap.
- Acceptable Adaptive Scales:
  - AAMR Adaptive Behavior Scale;
  - Adaptive Behavior Assessment System (ABAS)
  - Comprehensive Test of Adaptive Behavior;
  - Scale of Independent Behavior; and
  - Vineland Adaptive

# Children Age 0-7

- DDRO may grant Provisional Eligibility, based on clinical judgment, when a young child presents with developmental delay and evidence of functional limitation, but without specification of a named qualifying diagnosis.
- Children with provisional eligibility are periodically reviewed, based on new clinical information, to reassess continued eligibility.
- DDRO determines regular eligibility (or ineligibility) at any time, but no later than child's 8<sup>th</sup> birthday.

# Children 0-7 continued

- Psychometric and developmental measures that derive a developmental quotient or mental age may be acceptable to prove functional or intellectual delay. Including:
  - Battelle Developmental Inventory (BDI);
  - Bayley Scales of Infant Ability –Revised;
  - Differential Ability Scale (DAS);
  - Infant Toddler Developmental Assessment (IDA);
  - Kaufman Assessment Battery for Children (K-ABC);
  - Stanford Binet Intelligence Scale –Fourth Edition (SB-IV);
  - Wechsler Intelligence Scale for Children (WISC);
  - Wechsler Preschool and Primary Scale of Intelligence (WPPSI);
  - Woodcock Johnson Psychoeducational Battery

## Children 0-7 continued

- Substantial handicap can be documented by the results of an individual evaluation that includes:
  - A 12 month delay in one or more functional area; **or**
  - A 33% delay in one functional area, or a 25% delay in each of two functional areas; **or**
  - A score of 2.0 standard deviations below the mean in one functional area, or a score of **1.5** standard deviations below the mean in two functional areas.



# Complete Documentation for Eligibility Determination

- Current psychological evaluation including IQ and Adaptive Behavior Scale (current for 18 and younger is defined at 3 years);
- Psycho-social history or background information;
- For persons (other than mental retardation) relevant medical or specialty reports including health status and diagnostic findings;
- Recent medical reports, when available; and
- Documentation verifying age of onset of significant functional limitations.

# Responsibility of Referring Party

- Must provide complete clinical information needed for eligibility determination (See above).
- DDROs may assist in completion of some of these components on a case-by-case basis, but availability varies by location (*meaning do not count on DDRO to complete any evaluations*).

# The Process

## Step One

- The Front Door intake personnel receive the completed intake paper work;
- The DDRO will render determination decisions for those applicants where developmental disability is readily evident.
- For those lacking complete documentation, the designated Front Door personnel will request additional documentation from the referring sources.

## Step Two

- Each DDRO has a second step developmental disability determination team.
- If the DDRO intake personnel is not able to determine eligibility then the application is automatically referred to Step Two.
- At minimum, the team must be composed of a Licensed psychologist and Certified Social Worker.
- The team often includes a licensed physician, physicians assistant or nurse practitioner.
- The team may ask for additional documentation or conduct assessments of the person referred.

## Step Three

- This review involves a panel of clinicians formed by senior clinical and management staff at OPWDD's Central Office.
- No clinician involved in this appeal will have had any involvement in the other denials of possible eligibility.

# The 3-Step Process

- Except in unusual circumstances where additional information is needed, OPWDD makes eligibility determinations within 90 days of the date that the application and supporting documentation is received by Front Door.

# Step 1 Review

- Step 1 Response Letter must inform the individual that *based upon the information provided*:
  - has a developmental disability and is eligible to apply for OPWDD services; or
  - Is provisionally eligible (due to young age); or
  - Eligibility can not be determined and information has been forwarded to Step 2 Review; or
  - Additional documentation is needed to determine eligibility (letter describes the type of information needed).

## Step 2 Review

- The team must review documentation from Step 1 Review;
- May ask for additional documentation (must inform the individual by letter and give a date certain to submit additional information);
  - If no response from individual by date certain, DDRO makes determination based upon information available.
- May conduct face-to-face meeting;



## Step 2 Determination

- Results in letter informing individual that:
  - Eligible;
  - Additional documentation is needed; or
  - Not eligible.

## Step 2 Denial Letter

- Must offer the individual the opportunity to:
  - Meet with DDRO/Front Door Staff
  - Request a Step 3 Review
  - Request a Medicaid Fair Hearing, if applicable.

*The individual may choose one, two or all three options.*

# Face-to-Face Meeting

- Purpose of the Meeting is to:
  - Address questions concerning basis of denial;
  - Present additional documentation, if any;
  - Explain what additional documentation may be helpful;
  - Discuss misunderstandings
- Post-Meeting Confirmation Letter:
  - Summarized discussion and record review;
  - Reminds individual of Step 3 option and Fair Hearing.

## Step 3 Review

- This is a records review by Eligibility Review Committee.
- Committee reviews all documentation submitted to DDRO, consults and forwards **recommendation** to DDRO Eligibility Coordinator (is advisory to the DDRO).
- Sends a letter to the individual of any change in the DDRO determination.

# Fair Hearing-Notice of Decision

- Notice of Decision (NOD) is issued with Step 2 Denial Letter when the application indicates the individual's interest in a Medicaid funded services.
- Informs the individual of right to request a Fair Hearing, conference or both.
- NOD is on a form approved by NYS OTDA.
- Fair Hearing involves single issue of whether individual has a developmental disability.

# Notice of Decision

- Two types of NOD:
  - Denial of Services –for individuals not receiving OPWDD Medicaid funded services;
  - Termination of Services –for individuals already receiving OPWDD Medicaid funded services (may request continuation of benefits during appeal).

## Step 3 Review and Medicaid Fair Hearing

- If an individual requests a Fair Hearing OPWDD will automatically send the information to a Step 3 review.
- The Step 3 review should be conducted prior to a Fair Hearing date.

# OPWDD Memorandum and Guidance Documents

- OPWDD issued guidance documents to describe the eligibility process.
- Practice Tips:
  - Letters from Practitioners;
  - Records in the File;
  - Sample Reconsideration Memorandum;
  - Guidance documents;
  - Fair Hearing Preparation.



# Contact Information

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