

# Advocating for Your Child at School

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## Polling Questions

# Objectives



Consider educational needs of your child



Understand the law and your/your student's rights



Understand the process for accessing support services



Identify resources to support you/your student in this process

# AFM & School

Complex medical problem

Symptoms have the potential to interfere with aspects of educational participation and learning

Importance of assessment to determine needs in the learning environment

# School Services for AFM



There is no one-size-fits-all approach.  
Services must be tailored to each child.

## How can schools assist students with acute flaccid myelitis?

### Academic

- Start academic interventions under one of two laws: IDEA (Other Health Impairment) or Section 504 to provide appropriate accommodations
- Make schedule adjustments so that student does not miss core subjects due to therapy and doctor visits
- If hands are affected, provide notes prior to class, give tests orally
- If hands are affected, allow extra time to complete assignments
- Accommodations for Physical Education class
- Assess for PT/OT and assistive technology as soon as possible

# School Services for AFM (continued)

## **Social/Emotional**

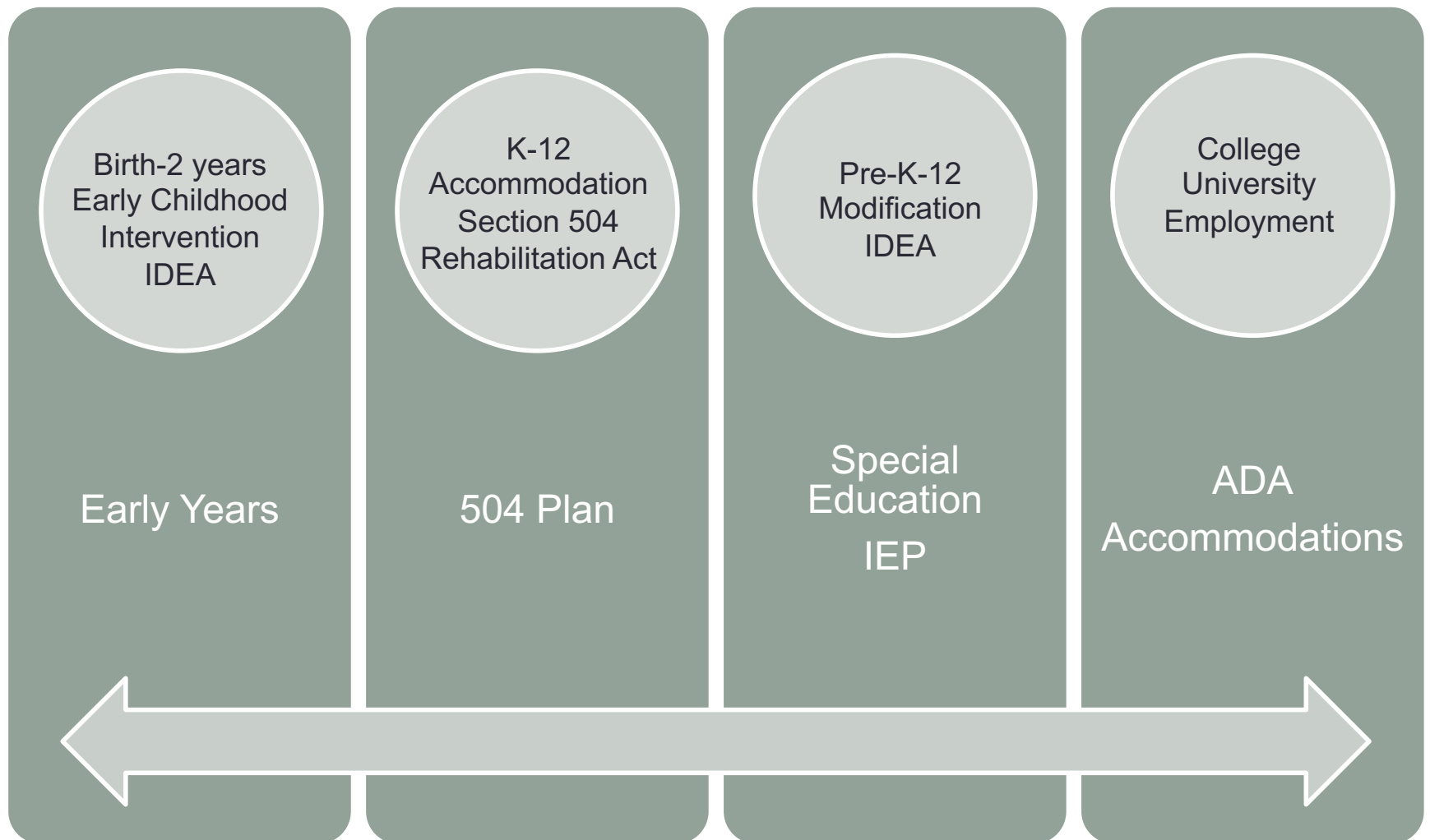
- Inform any staff who works with student to allow for monitoring
- Provide counseling to address any social and emotional stress
- Have frequent communication among student, parents, school nurse, and medical team

## **Physical**

- Consider an extra set of books (one for school and one for home)
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- Student may be involved in school activities, but with possible accommodations
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# Legal Context and Student Rights

# Support Services





## Special Education: Individuals with Disabilities Education Act (IDEA)

- Entitles children to a **free appropriate public education (FAPE)** that allows for achievement
- To prepare students for further education, employment and independent living
- Places the burden on the school system to:
  - Identify children with special needs
  - Evaluate children to determine needs and presence of a disability
  - Plan educational services

# Special Education: Services Eligibility Categories

- Auditory Impairment (AI)
- Autism (AU)
- Deaf-Blindness (D-B)
- Emotional Disturbance (ED)
- Learning Disability (LD)
- Mental Retardation (MR)
- Multiple Disabilities (MD)
- Orthopedic Impairment (OI)
- Other Health Impairment (OHI)
- Speech Impairment (SI)
- Traumatic Brain Injury (TBI)
- Visual Impairment (VI)
- Non-Categorical

# Special Education: Individualized Education Program (IEP)

- Written plan, designed for one student
- Agreement between the school and parents on how the student will be educated
- States what special education and related services the school will provide, and when and where those services will be provided
- Must contain measurable annual goals in each area of need
  - Reviewed, and revised if needed, at least every year

## Step 1: Referral and Consent for Evaluation

- Child is suspected to have a disability
- Parent, teacher, or other professional involved in the child's education may refer child for an evaluation to department of special education
- School may gather information to decide if they should conduct an evaluation for special education eligibility
- School must give written notice if denying the evaluation, with reason and parent's right to appeal or meet with parent to sign informed consent

## Step 2: Full & Individual Evaluation (FIE)

- No cost to parent
- Does the student have (1) a disability under IDEA definition **and** (2) a need for special education resulting from the disability?

# Setting for Educational Services

## Range of Educational Settings

Least Restrictive

**General Education**

**External Support**

**In Class Support**

**Resource Room / Pull Out**

**Most Restrictive**

**Self-Contained Unit**



## Related Services

Student also entitled to other services to help the child benefit from special education:

- Speech/Language Therapy, Occupational Therapy, Physical Therapy
- Psychological Services
- Assistive Technology
- Interpreter Services
- Special Transportation

The related services must be educationally relevant.

# Procedural Safeguards for Special Education

- Consent, revocation of consent for services
- Independent education evaluation
- Re-evaluation (every three years or when change is noticed)
- Right to disagree, reconvene
- Annual Committee meeting
- \* Complaint process
- \* Mediation
- \* Due process hearing



## Section 504 of the Rehabilitation Act of 1973

- Civil rights law that prohibits discrimination on the basis of disability
- No program or activity receiving federal funds can discriminate against any qualified person with a disability
- Students who do not qualify for special education may qualify for services under Section 504

# Purpose of a Section 504 Plan

- Reasonably accommodate student so that needs are met as adequately as the needs of non-disabled students
- May receive accommodations for equal access to educational opportunities afforded all students
- Adjustments made to remove disability-related barriers to full participation in school: “leveling the playing field”

# Purpose of a Section 504 Plan

Academic modifications may be necessary even if major activity of “learning” is not affected.

- Examples: P.E. curriculum changes, school schedule
- Nonacademic AND extracurricular activities are included (e.g., field trips, athletics and assemblies)

# Section 504 Plan Process

Parent request for accommodation in writing

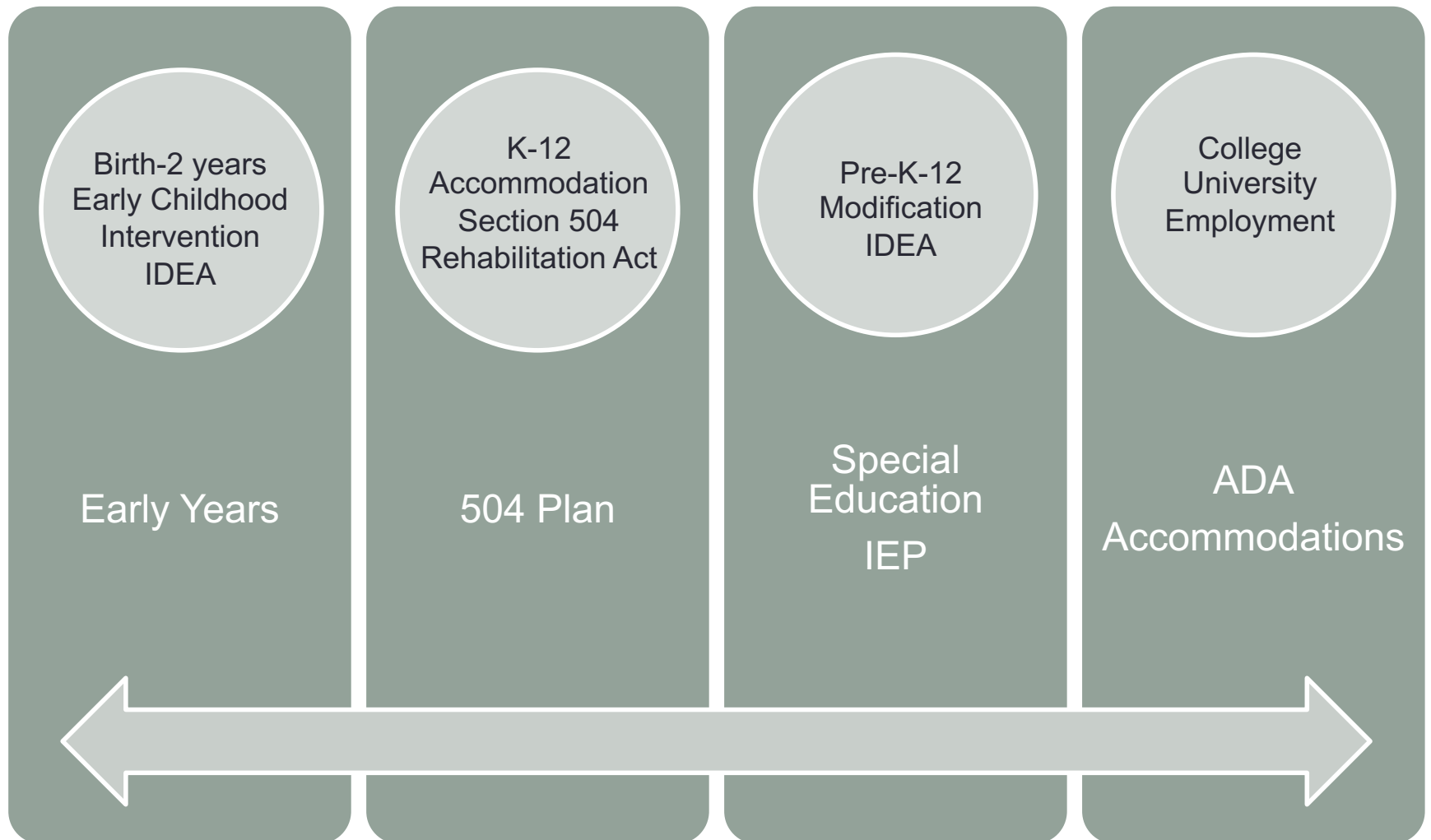


Meeting with school (Student Study Team (SST) or Section 504 meeting)



Section 504 plan developed

# Levels of Support



# Americans with Disabilities Act (ADA; 1990)

## ADA Amendments Act (2008)

Extends coverage of Section 504 to

- Employment
- Public and private education institutions
- Transportation providers
- Telecommunications



# “Otherwise Qualified”

- With or without reasonable accommodation, students with disabilities must meet the *same standards* required for other students
- The law is clear that, while institutions must provide academic adjustment, these may not compromise the essential requirements of a course or program

Section 504 of Rehabilitation Act



# Modification vs. Accommodation

- Institutions of higher education maintain academic integrity
- Coursework cannot be changed or modified in any way
- To “even the playing field,” students with disabilities may receive accommodations (e.g., extra time) in order to complete the same work as their non-disabled counterparts



# Examples of Academic Accommodations

- Priority Registration
- Note Taking Assistance
- Test Scribe
- Test Reader
- Reduced Distraction Environment
- Extended Time
- Preferential Seating
- Permission to Audio Tape Lectures
- Computer Access
- Reduced Course Load
- Books on Tape
- Retroactive Withdrawal

## For Parents

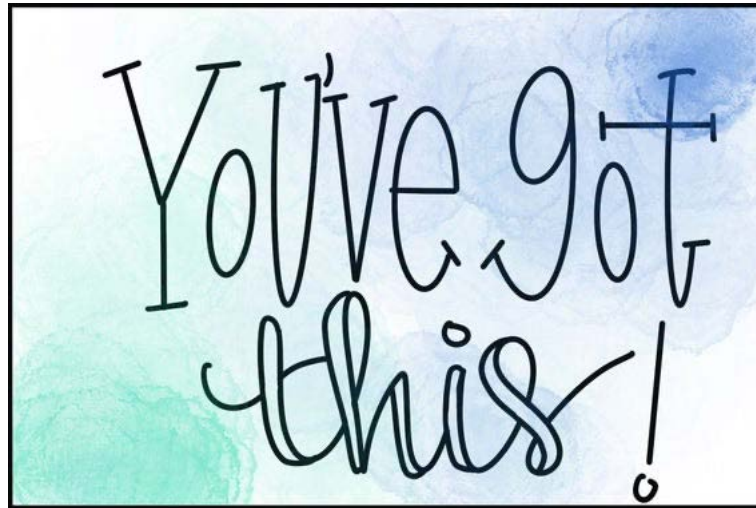
- Educate yourself on the process
- Understand student rights
- Help your child learn to self-advocate particularly with increasing age
- Always put requests/information for school in writing!

## For Medical Teams

- Partner with team members who are knowledgeable about school services
- Partner with schools
- Recommend eligibility category(ies) such as Other Health Impairment
- Provide assessment findings/testing scores
- Provide detailed information about the child on school forms/letters that must be signed by a physician (504, letter of diagnosis, OHI)
- In your notes, avoid use of acronyms only

# For Students

- You are your own self-advocate
- Significant change from high school to college
- Reduced parental involvement



# Whose Responsibility Is It?

ISSUE	K-12	COLLEGE
Identification	School	Student
Assessment	School	Student
Programming	School/Parent	Student/College
Advocacy	School/Parent	Student
Decision Making	Placement Team	Student
Transition Plan	Placement Team	Student

# Resources

Familiarize yourself with your state education agency and state-level educational and disability advocacy groups.

Issues with Special Education: Contact your state education agency.

Speak with your medical teams – psychologists, neuropsychologists, social workers, school liaisons, physicians, nurses

Issues with 504 Services: US Dept of Education, Office of Civil Rights [www2.ed.gov/about/offices/list/ocr/504faq.html](http://www2.ed.gov/about/offices/list/ocr/504faq.html)

*IDEA The Manual for Parents and Students about Special Education Services in Texas*

[www.thearcoftexas.org/idea-manual/](http://www.thearcoftexas.org/idea-manual/)

Information on education law and advocacy for students with disabilities: [www.wrightslaw.com](http://www.wrightslaw.com)

# School Guide on AFM



## A School Guide for Students with Acute Flaccid Myelitis (AFM)

### What is acute flaccid myelitis?

**Acute flaccid myelitis (AFM)** is a very rare but serious condition. AFM affects the nervous system, specifically the area of the spinal cord called gray matter, which can cause weakness or even paralysis of muscle groups. The symptoms come on suddenly and each case is individualized. Most cases of AFM have been in children, but it can develop in adults. AFM can cause respiratory failure if the muscles involved with breathing become weakened. The extent of recovery varies. Although some people make a full recovery, most have continued muscle weakness even after a year. Long term outcomes are not known. Treatment is individualized to each patient. AFM is not contagious.

### How can acute flaccid myelitis affect school performance?

The symptoms may vary depending on the area of the spinal cord affected, but can include:

- Sudden (acute) weakness in the arm(s) and/or leg(s)
- Loss of muscle tone
- Decreased or absent reflexes
- Facial weakness
- Drooping of eyelids
- Difficulty in moving eyes
- Slurred speech
- Difficulty swallowing
- Trouble breathing
- Bladder or bowel dysfunction

### How can schools assist students with acute flaccid myelitis?

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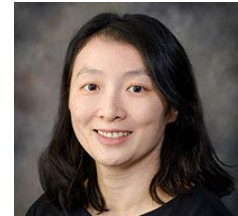
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#### Resources:

<http://kidshealth.org/en/parents/brain-nervous-system.html>  
<https://rarediseases.info.nih.gov/diseases/13142/acute-flaccid-myelitis>  
<http://www.cdc.gov/acute-flaccid-myelitis/index.html>  
[www.myelitis.org](http://www.myelitis.org)

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**UT Southwestern**  
Medical Center





# Join us in the **Sessions area**

## Second Panel Discussion and Q/A



### **CDC updates**

Alexandra Hess, PhD.  
Sarah Kidd, MD

### **Habilitation**

Janet Dean, MS, RN, CRNP

### **Advocacy in AFM**

GG DeFiebre, MPH  
Rebecca Whitney

**Coping and adjustment**  
Maggie Tunney, PsyD.

**School system advocacy**  
Lana Harder, PhD