



# School-Based Services for Children with RYR-1

RYR1 2018 International Conference



# Presentation Overview

- Legal requirements for helping children in school
  - General Education
  - Special Education
- Effective communication and advocacy
  - Doctors
  - School Staff

# Legal Requirements: Child Find

- The Individuals with Disabilities Education Act (IDEA)
  - Federal Law that requires school districts to “find” **identify, locate, and evaluate all children with disabilities**, regardless of the severity of their disabilities.
  - **all children with disabilities from birth through age 21.**
  - Including all children who attend **private schools and public schools, highly mobile children, homeless children, migrant children, and children who are wards of the state**

# Legal Requirements: Child Find

- Child Find includes all children who are suspected of having a disability, including **children who receive passing grades and are “advancing from grade to grade”**.

# Legal Requirements: Child Find Process

- General Education Screening – often 1 -2x's a year
  - Center rotations (vision, hearing, speech & language, social-emotional skills)
- Formal Assessment is offered & parents consent
- Assessment Outcomes
  - General Education Plan
  - 504 Plan
  - Special Ed Delays birth – 9 y/o (States can opt out, PA does not use the delay model)
  - Special Education Services
    - Preschool – individualized family service plans (IFSP)
    - Elementary & Secondary – Individual Education Programs (IEP)

# Talking with the Doctor

- Have open dialogue with doctor
  - Ask questions to make sure you understand diagnosis & treatment
- **Write down a list of questions/concerns before your appointment**
  - **Ask your school if they have Qs that you can take with you to the appointment**
- Take notes, or ask a friend or family member to take notes for and with you
  - Ask about symptoms and what they may look like in your child
    - Will the symptoms change as they age? Different for boys/girls?
  - **Ask questions about your child's specific abilities and limitations**

# Talking with the Doctor

- Ask how to access medical records, so you can keep track of treatment plans, medications, and documents to provide your school
- Ask for doctors contact information and **preferred method of communication** incase school needs additional information
- Ask if the physician's office has a school liaison

# Orienting the School

- Parents are the expert when it comes to identifying their child's strength and needs
  - Meet with teachers **prior to the beginning of the school year**:
    - explain how RYR-1 affects your child
    - provide recommended supports
    - allow them to ask Qs
  - **Schedule regular communications and/or contact during school year**
    - Determine preferred methods of communication
    - Frequency of communication
    - Clarify and reinforce your child's needs and track progress



# Orienting the School

- Important information to share with teachers are the:
  - Capabilities and limitations
    - **Challenges** those that are expected & those that would cause concern
      - In classroom
      - In elective classes (often called specials) - such as gym, art, music, etc.
  - Keep teachers informed of **changes at home with medicines, abilities, etc.**
  - Medicine administered at school
  - Documentation from doctor that explains the diagnosis (copy of health records)
  - Information about expected absences for to manage symptoms or attend appointments
  - **Who information can be shared with - confidentiality document**

# General Education Plan

- Parents and School Personnel can develop a General Education Plan that **starts immediately** based on the needs documented by the physician's.
  - Sometimes needed in the interim when setting up a 504 plan to special education IEP

# 504 Service Plan

- Section 504 of the U.S. Rehabilitation Act of 1973 is designed to **help parents of students with physical or mental impairments in schools work with educators** to design customized educational plans
- Students **educated in general education classrooms** along with services, accommodations, or educational aids monitored by teachers.
  - HOWEVER, they do not have the same protection and rights that an IEP can give and they may not be monitored by a team of support staff.
  - Rather, they are there to guide what the classroom teachers should do to support a student in the classroom

# Special Education

- School Age Special Education Eligibility Categories

- Autism
- Deafness
- Deaf-Blindness
- Hearing Impairment
- Intellectual Disabilities
- **Multiple Disabilities**
- **Orthopedic Impairment**
- **Other Health Impairment (OHI)**
- Serious Emotional Disturbance
- Specific Learning Disability
- Speech or Language Impairment
- Traumatic Brain Injury
- Visual Impairment, including blindness

# Individualized Education Program (IEP)

- Must meet the **individual needs** of the student
- Must be developed before services are provided
- An IEP is both a process and a written **legal document** which results in a meaningful IEP that provides a **free and appropriate public education (FAPE)**
  
- Your child's IEP should be used **AS A TOOL**

# Special Education Options: Schooling

- **Public Schooling**

- Places students in a **least restrictive (learning) environment (LRE)**
  - **This allows children to be able to social, have access to general curriculum, develop friendships, access peers for academic, social, and behavioral skills.**
- Full Inclusion
- Dedicated special education classroom
  - **IEP team will determine if this is necessary**
    - How much time spent here, technologies needed for learning, transportation to and from school, and other professionals that can be involved

- **Homebound**

- Provides children continuous educational support

# Professionals who may be assisting your child

- **Parent\*** you are an expert on your child
- **Teachers\***
- **School Administration\***
- **Special Education Teacher\***
- **School Psychologist\***
- **Speech Language Pathologist**
- **Occupational Therapist**
- **Social Worker**
- **School Nurse**
- **Paraprofessional**
- **Doctor (as requested)**

# The IEP Team

- **Mandatory participants:** parent or legal guardian, special education teacher, general education teacher, representative from the local education agency (often a school administrator), and someone who can interpret results of the evaluation report
- Teams must meet once a year at minimum
- **Any team member (including parents) can request an IEP meeting at any time!**



# Special Education for Students with RYR1

Provide specific information about your child's muscle weaknesses

Protocol to rest the eyes

- Modified schedule
  - Academic classes are followed by specials/electives
- **Planned rest periods** after reading or screen time
  - For every 20 of reading, 5 min break

# Special Education for Students with RYR1

Protocols to rest the body (chest or torso)

- Classroom
  - Plan proximity: classroom, locker, bathroom, cafeteria
  - Plan access to ramps, railings
  - Use elevator instead of stairs
  - Tables & Chairs with modified heights
    - Higher furniture to increase independence
    - Higher toilets to increase independence

**\* Plan rest periods**

# Special Education for Students with RYR1

Protocols to rest the body (chest or torso) continued

- Classroom
  - Plan for getting up & down from the floor
    - gym, crafts, picking up trash, managing obstacles
  - Plan for on/off & in/out
    - bus, auditorium seating
      - child may want to go last when footing can be secure
      - use of walkers
  - 2 sets of books (classroom & home) reduce backpack travel time

# Special Education for Students with RYR1

- Modified curriculum can allow for a reduction in workload
  - Modified classes
    - Ex: accommodations and modifications for classes such as physical education
- May include intermittent homebound which can help **facilitate instruction in times when the student is not able to attend school**
  - Flexible attendance

# Special Education for Students with RYR1

Protocol to reduce cramping

- Water, massage, heat, cold, stretching

Are there additional needs?

- Planning for common colds & illness
- **Specialized medical equipment** for breathing
  - training for teachers and school professionals

# Special Education for Students with RYR1

## Protocol to manage stress

- Psychoeducational materials
  - Student monitoring of symptoms
  - Student advocacy & assertiveness for needs in the classroom
- Health and Wellness
  - How to address Qs from peers
  - Thoughts and feelings about RYR-1
  - Managing chronic exhaustion
  - Self care

# Components of an IEP

- **Levels of academic performance and functional performance**
  - Test scores to measure current status and track progress
    - health; emotional & social development; vocational skills
- **Measurable annual goals including short-term objectives (benchmarks)**
  - Academic and Functional (e.g., social, emotional, physical)
- **Recommended special education programs & related services**
  - Areas where child might need extra assistance
    - SLP, OT, PT, counseling services, special transportation

# Components of an IEP continued

- **Modifications or supports for school personnel to use**
  - Accommodations necessary to measure academic and functional performance state or district wide testing
- **Explanation to the extent to which the child will not participate with nondisabled peers**



# Components of an IEP continued

- Projected date for the beginning of related services, and the **frequency, location, and duration** of services
- **Transition services/goals and plan** should be in place can **begin at age 14 and are required at age 16**
  - Plan and services that will assist the adolescent with a disability to successfully move from school to post-school activities
  - Plan provided for handling SAT's, ACT's and other examinations to prepare for college
  - Understanding the transition that occurs from high school to college and what **services are provided in college.**

# International Programming

- Meet with teachers and administration to discuss available special education (special needs) services in the area
- Schedule and maintain regular communications and/or contact with teachers and service providers during school year
- If moving overseas, travel with an updated copy of your child's IEP
- **Overseas Schools Offering Support to Children with Special Needs 2017-2018**  
(comprehensive list of school that follow USA or UK Special Education protocol)
  - <https://www.state.gov/documents/organization/176076.pdf>

# Educational Advocates Can Help

Free resources may include

- Consultation hotlines and mediators funded by your state, province, or region
- School districts may have special education advocates on staff
- Online advocacy and parent organizations

Paid services may include

- Local law offices
- Advocacy groups

**Important Note: In the U.S., you have the right to seek an independent evaluation by outside experts paid for by the school if you disagree with the school's re-evaluation.**

# Who to contact for help

- Ask your school psychologist
  - **Every school has one!**
- **Ask more than one person to make sure you are covered!**
  - Principal, nurse, teacher
  - Advocate, social workers
  - Medical professionals