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 minutes 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