

# **Special Education Alphabet Soup: IEPs, 504, RTI, FAPE – what's it all about?**

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# *Special Needs & the Educational System*



# Outline

- What are the options for supporting students in school?
- What laws outline the rights of students for academic supports and interventions?
- How are the needs of students with rare diseases unique?
- What resources exist to support educators and caregivers in learning more?





## *Let's start with teachers*

- Teaching is a very complex activity. Most teachers want to do a good job
- Many are getting fewer rewards than teachers used to receive
- Teachers may feel:
  - Vulnerable
  - Frequently feel blamed for problems within the education system
- Many teachers are under high amounts of pressure
- At the end of the day, they are trying their best





## *Ways to Receive Help at School*

- Unofficial arrangements with classroom teacher or other school personnel
- Response to Intervention (RTI)
- Section 504 Plan
- Individualized Education Program (IEP)

*Source: Cohen, MW. The Attention Zone: A Parents' Guide to Attention Deficit/Hyperactivity Disorder. 1998: 105-110; Alza Corporation. Concerta Slide Kit. 2000.*





## *Unofficial arrangements*

- Something the teachers provide because they see what works for the student
- Examples:
  - Noticing if a student needs to stretch
  - Arrangement for a snack
  - Special spot on the carpet
- This doesn't translate from year to year

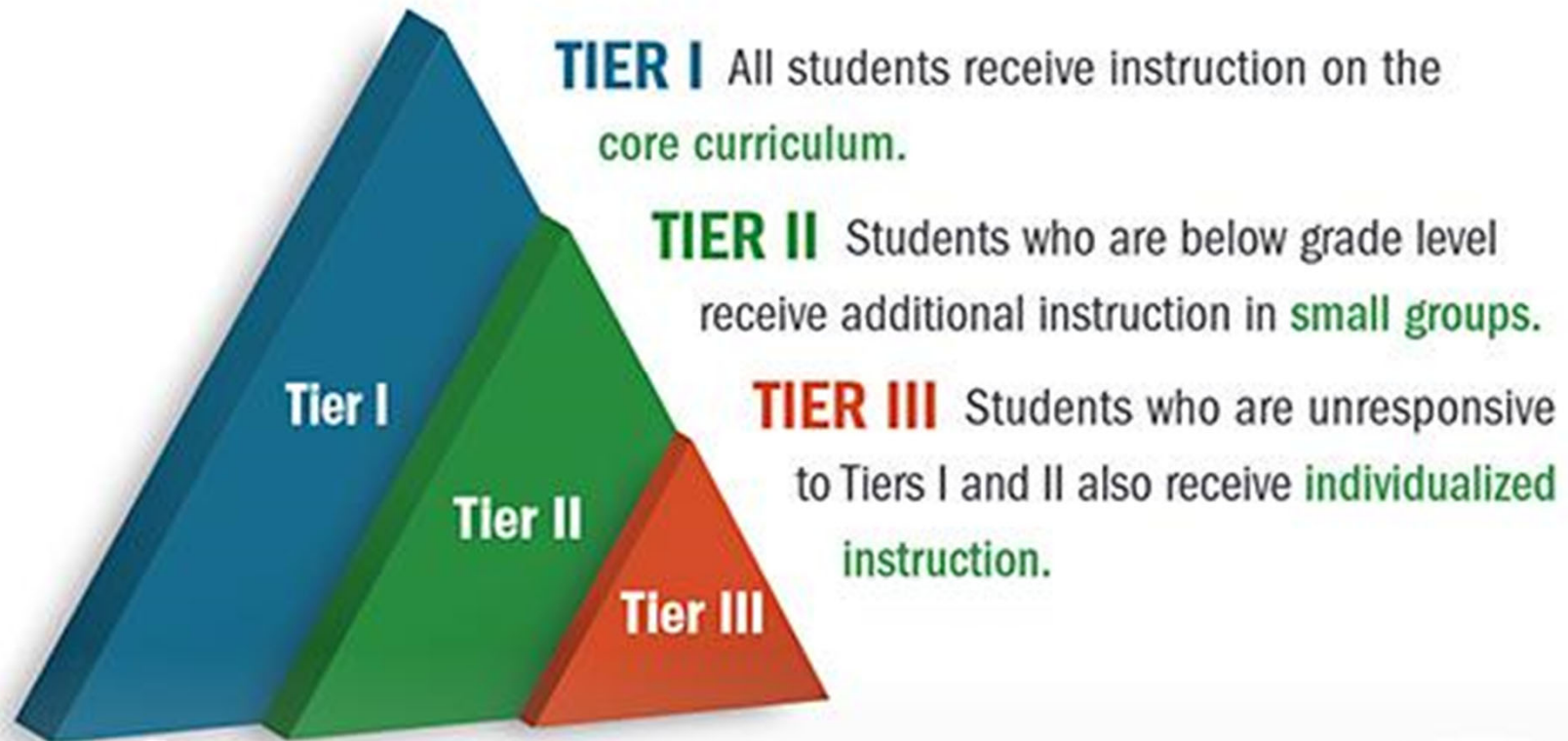






# Response to Intervention

*“Not all students who are at risk will need the most intensive interventions available...”*





## *Response to Intervention*

Per the National Center on Response to Intervention, essential features include:

- School-wide, multi-level system of research-based instructional and behavioral supports
- Screening and progress monitoring
- Data-based decision-making for:
  - Instruction
  - Determining movement within the multi-level system
  - Determining the need for Special Education







## *Section 504 Accommodation Plan*

- Aims to provide children with **equal access** to education
- Requires a written plan to provide reasonable accommodations, supports that enable the child to access the general academic curriculum
- In essence, a plan that “levels the playing field” so students can fully demonstrate their ability to meet educational goals at a level equal to that of non-disabled students





## *Individualized Education Program (IEP)*

- Individuals with Disabilities Education Act (IDEA, 1997) and the Individuals with Disabilities Education – Improvement Act (IDEiA; 2004)
- A federal statute specifically focused on supporting children who experience an adverse educational impact of a disability.





# *Individualized Education Program (IEP)*

- Functions as a **contract** between parents and the school
- Lists the special education services the child will receive, explains why these services are educationally necessary, and how progress will be measured
- Parents should communicate in writing to request meetings, discuss assessment, consider modifications to IEP





## *IDEA Six Core Principles*

1. Free & Appropriate Public Education (FAPE)
2. Appropriate Evaluations
3. Individualized Education Program, which contains info about:
  - Student's current level of ability
  - Short & long term goals
  - Special ed & related services for student (what, when, and provided by whom)
    - Speech Therapy, Occupation Therapy, Physical Therapy, Transportation, Personal Care Plan, Nursing, Assistive Technology, Resource Classroom, Paraprofessional Support
  - Student participation with other students, classroom setting, extracurriculars, etc.
  - Dates of service





# Example of an IEP

Services 01/17/2012 - 01/11/2013

Concurrent	Service(s)	Service Provider for Delivering Service	Monitor	Frequency	Location (setting)	Start Date	End Date
<b>Special Education</b>							
No	Math	SLC Tchr/Paraeducator	Structured Learning Tchr	40 Minutes / 1 Times Daily	Special Education	01/17/2012	01/11/2013
No	Reading	SLC Tchr/Paraeducator	Structured Learning Tchr	40 Minutes / 1 Times Daily	Special Education	01/17/2012	01/11/2013
No	Writing	SLC Tchr/Paraeducator	Structured Learning Tchr	40 Minutes / 1 Times Daily	Special Education	01/17/2012	01/11/2013
No	Social/Emotional/Behavioral	SLC Tchr/Paraeducator	Structured Learning Tchr	15 Minutes / 3 Times Daily	Special Education	01/17/2012	01/11/2013
No	Study Skills	SLC Tchr/Paraeducator	Structured Learning Tchr	5 Minutes / 3 Times Daily	Special Education	01/17/2012	01/11/2013

Total minutes per week student spends in school:

1000 minutes per week

Total minutes per week student is served in a special education setting:

900 minutes per week

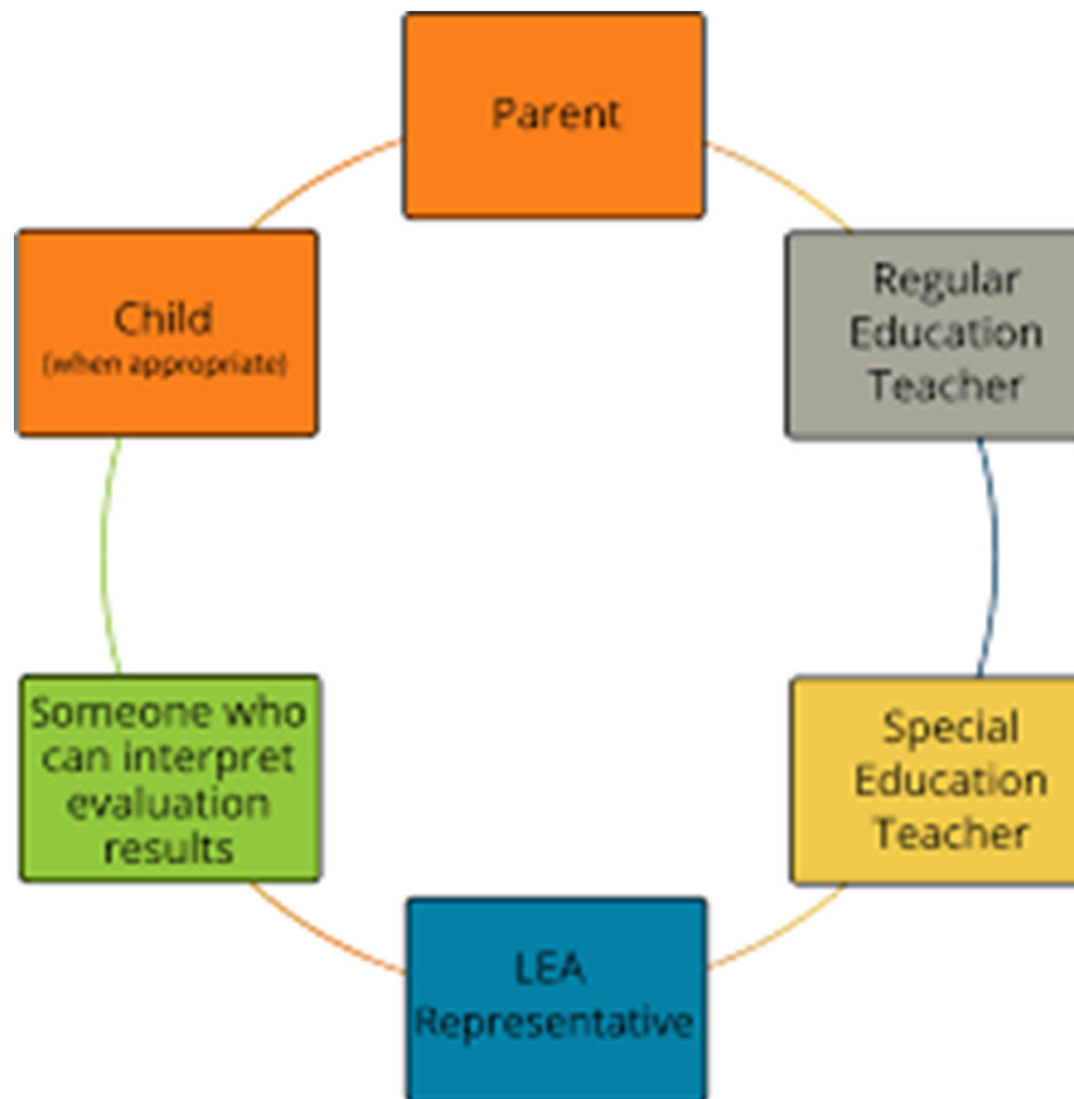
Percent of time in general education setting:

10% in General Education Setting





# *IEP Meetings*







## *IDEA Six Core Principles*

- 4. Least Restrictive Environment (LRE)
- 5. Due Process
- 6. Parent Participation





## *IEP Disability Qualifications*

- 1. Autism Spectrum Disorder**
- 2. Deaf and Hard of Hearing**
- 3. Deaf-Blind**
- 4. Emotional or Behavioral Disorder**
- 5. Developmental Delay**
- 6. Intellectual Disability (also known as Developmental Cognitive Disability)**
- 7. Specific Learning Disability**
- 8. Orthopedic or Physical Impairment**
- 9. Speech or Language Impairment**
- 10. Traumatic Brain Injury**
- 11. Visual Impairment (includes, but not limited to, blindness)**
- 12. Other Health Disabilities or Other Health Impairment**
- 13. Severely Multiply Disabled**





## *Special Education for Rare Individuals*

- Individuals with rare disease may have unique needs
  - Natural course of disease can lead to loss of skills or never acquiring skills commonly address in IEPs
  - IEPs should not prevent individuals from receiving beneficial services due to very low or worsening functioning

Eisengart, J. B., Esler, A. N., Ellinwood, N. M., Hudock, R. L., King, K. E., Klein, T. L., ... & O'Neill, C. (2021). Issues of COVID-19-related distance learning for children with neuronopathic mucopolysaccharidoses. *Molecular Genetics and Metabolism*, 134(1-2), 68-76.





# *Special Education for Rare Individuals*

- IEP goals should:
  - Focus on those that are most important and meaningful to the family and child
  - Balance the goal of learning academics with the children's stimulation, happiness, and quality of life
- Critical question:
  - ***How can the IEP focus on maintaining skills for, and ensuring access to, pleasurable and engaging activities for the child with a rare condition?***





## *Special Education for Rare Individuals*

- Consideration should be given to the physical manifestations of the disease that may be accommodated to enable a fuller participation in class activities





# *Special Education for Xeroderma Pigmentosum*

- Light safety needs (UV filters, UV meters, transportation, preferential seating)
- Adaptive Physical Education
- Mobility needs (wheelchair accessible buildings, monitoring for falls)
- Visual and hearing differences
- Intensive SLP, OT, PT
- Independent living skills instruction
- Extended School Year
- Personal Care Plan (access to sunscreen; UV protective gear; communication with the nurse; seizure protocol)
- Line of Sight/Supervision

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NEURODEVELOPMENTAL PROGRAM IN RARE DISEASE



The Neurodevelopmental Program in Rare Disease (NPRD) serves to advance the University of Minnesota's high standards for the care of people and families touched by rare disease conditions.

We are pediatric neuropsychologists, pediatric psychologists, autism specialty psychologists, and neuroscientists who aim to deepen the understanding of the functional, quality of life, and mental health impacts of rare diseases.

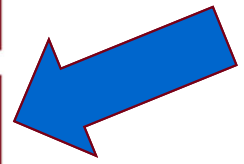
Our goal is to improve approaches for disease monitoring, predicting outcomes, and optimizing patient and family management.

Our focus on research serves to further characterize neurocognitive and neurobehavioral courses of disease, identify sensitive prognostic indicators of outcomes using both biomarker and functional data, and clarify and raise awareness about disease aspects that are under-studied but meaningful to the rare disease community.

< PROGRAMS, CENTERS & INSTITUTES

PATIENT RESOURCES

View Our Publication on the Impact of the Pandemic on Children with Neurodegenerative Disorders





## *Resources*

- Wrightslaw: Free, online information about educational advocacy  
[www.wrightslaw.com](http://www.wrightslaw.com)
- Office of Special Education and Rehabilitative Services  
<http://www2.ed.gov/about/offices/list/osers/index.html>
- Individuals with Disabilities Education Improvement Act of 2004  
<http://idea.ed.gov/>
- Center for Parent Information and Resources  
<https://www.parentcenterhub.org/>





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