BACK TO SCHOOL CONSIDERATIONS FOR SPECIAL NEEDS/MEDICALLY FRAGILE STUDENTS

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Overview

- What Experts are Saying About Risk Considerations
- Educational Impact
- What Families Can Do
- What School Corporations Can Do
“Opening of schools does not significantly increase community transmission, particularly when guidance outlined by the World Health Organization, United Nations Children’s Fund, and Centers for Disease Control and Prevention is followed.”
“Immune deficiency is not a common feature of mitochondrial disease, and therefore most people with mitochondrial disease should not be at increased risk of contracting COVID-19 infection.”

“There is still much uncertainty about risks of COVID-19 infection in people with mitochondrial disease.”
### Potential Mental Health Indicators

#### Preschooler
- Thumb sucking
- Bedwetting
- Clinging to parents
- Sleep disturbance
- Loss of appetite
- Fear of dark
- Regression in behavior

#### Elementary
- Irritability
- Aggressiveness
- Clinginess
- Nightmares
- School avoidance
- Poor concentration
- Withdrawal from activities and friends

#### High School
- Sleeping and eating disturbance
- Agitation
- Increase in conflict
- Physical complaint
- Delinquent behavior
- Poor concentration

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Atypical behavior displayed longer than 2 weeks
TEACHING CHILDREN POSITIVE PREVENTION

Talking about their fears and giving them a sense of some control over their risk of infection can help reduce anxiety.
Be a Role Model

- Be aware of how you talk about health. Assure your child that your family is healthy and that you are doing everything in your power to keep the family safe. Listen or have your child draw or write their feelings and thoughts. Respond with truth and assurance.

- Let your child’s questions guide you.
  - Early Elementary: Brief information with appropriate reassurances that adults are there to keep them healthy and will take care of them if they do not feel well.
  - Upper Elementary-Middle School: Because they are more vocal and inquisitive, they may need assistance separating reality from rumor or fantasy – especially content found on social media.
  - Upper Middle-High School: Provide honest, accurate, and factual information. Include them in decisions about family plans, scheduling, and home chores.
Being Supportive

- Explain Social Distancing: Reducing the spread of infection
- Positive Time: Virtual sessions with friends, family activities
- Maintain daily routine
- Identify service projects
- Demonstrating deep breathing and nurturing mindfulness
- 20-second hand washing rule (Twinkle Twinkle Little Star)
- Build up immune system: balanced diet, adequate sleep, exercise
- Collaborate with treating physician regarding medical supports
Coordinated Interventions that Reduce Risk: American Academy of Pediatrics

- All students older than 2 years and all school staff should wear face masks at school unless medical and developmental conditions prohibit use

- Appropriate ventilation, quarantining, disinfecting, social distancing

- Monitor attendance of inclusive in-person and virtual settings
  - Proactive strategies to support attendance for all students
  - Differentiated strategies to identify and support those at higher risk for absenteeism

- Coordinate communication among school districts, state and/or local public health authorities, school medical providers, and local health providers

- Customize considerations and accommodations to account for students with medical needs, developmental challenges, or disability
Understanding 504 Plans & Advocating for your Child in School
First, a little about me...

Professional Background

- 11th grade history teacher for 24 years.
- All levels of student ability in an inclusive classroom
- Member of the Student Assistance Program
- M.Ed. in Educational Leadership from Lehigh University

Personal Background

- Mom to Luke (15, LCHAD/TFP)
- Active member of social media groups (MitoAction FAOD Families, LCHAD Warriors, Long & Very Long Chain FOD Food Group, FOD Family Support Group)
- Involved in Luke’s 504 collaboration since 2011
## 504 v. IEP: What’s the Difference

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<tr>
<th>Basic Description</th>
<th>504</th>
<th>IEP</th>
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<td>A blueprint or plan for how the school will support or remove barriers for a student with a disability.</td>
<td></td>
<td>A blueprint or plan for a child’s <em>special education</em> experience at school.</td>
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| What it Does | Provides services & changes to the learning environment to enable students to learn alongside their peers | Provides *individualized* special education & related services to meet a child’s unique needs. |
### 504 v. IEP: What’s the Difference

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<td><strong>Section 504 of the Rehabilitation Act of 1973</strong></td>
<td><strong>Individuals with Disabilities Education Act</strong></td>
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| 1. A child who has a physical or mental impairment that substantially limits one or more major life activities (for example learning, breathing, thinking, concentrating, walking, bodily functions).  
2. The disability must interfere with the child’s ability to learn in a general education classroom. | 1. A child has 1 or more disabilities listed in *IDEA* (usually these are specific learning challenges).  
2. The disability must affect the child’s performance in a regular ed. classroom & needs specialized instruction to make progress. |
Why Get a 504?

- It protects students from discrimination based on their disability & ensures equal access to the same education as their peers.
- It makes all school personnel in contact with students aware of their accommodations (ie. substitutes, cafeteria monitors, coaches, etc.)
  - Without a 504, school personnel (ie: counselors, school nurses, etc.) cannot share “education records” as outlined by FERPA..think HIPAA for schools.
  - “Haillee’s” story

  ▶ The Family Educational Rights and Privacy Act (FERPA) (20 U.S.C. § 1232g; 34 CFR Part 99) is a Federal law that protects the privacy of student education records.
Examples of 504 Accommodations for FAODs

- Regular snack breaks
- Unlimited access to bathroom or nurse
- Wiping down shared desks
- Extra set of textbooks for home
- Modifications/exemptions from PE
- Notify parent if child exhibits symptoms
- Rest breaks
- Extra time to complete assignments
- School nurse or parent must be on site for field trips, extracurricular activities, etc.
How Do I Acquire a 504 for My Child?

1. Document your child’s needs.
   a. In our case, Luke’s ER protocol letter on CHOP letterhead was enough

2. Find out who the school’s 504 coordinator is.
   a. Luke’s 504 is handled by his guidance counselor.
   b. Some schools may have a nurse or other specific coordinator who handles these.

3. Write a formal request for a 504 plan.

4. Follow up with a phone call or email to the school.

5. Go through the 504 plan evaluation.

6. Meet with the school to see if your child qualifies.

7. Work together to create a 504 plan

- Some schools make it easier for parents than others. Steps 4-7 were all handled at the same time for Luke when he was entering kindergarten.
Tips for Working with Schools

1. Be collaborative...this is a TEAM effort!
2. Be persistent in trusting what your child needs to be successful throughout his/her educational journey.
3. Involve your child in these discussions.
4. Offer to help the teacher/school with your accommodations (box of snacks, wipes, etc.)
5. Be patient...Understand that a teacher can have up to 35+ students in a classroom at a time. It takes time for us to get to know our students.
6. Understand that this is a living document which needs to be reviewed & amended each year. It’s easier to put something in at the beginning and take it out later if not needed.
What Happens When a School Isn’t Following the 504?

1. Reread the actual plan! Make sure that what you are asking for is actually covered in the language of the plan.
2. Keep good documentation -- Write down dates/times when the plan wasn’t followed.
3. Try to encourage self-advocacy skills for your child, if appropriate & non-emergency situations apply.
4. Email a gentle reminder to the teacher -- especially in a high school situation. (I have about 100 students per semester). Many times, this resolves the infraction quickest.
5. If 3 & 4 yield no action, now it is time to contact the 504 coordinator to schedule a meeting about non-compliance.
6. If there is still no resolution, go up the chain of command in the district (ie: Principal, Director of Pupil Services, are good places to start).
7. Consider a complaint with the Office of Civil Rights.
8. The “L” word -- lawsuit...No one wants to go down this road, but if you feel as though your child is being discriminated against because of his/her disability, you can file a lawsuit. These are expensive & time-consuming, so make sure you have a strong case and have documented all of the above steps.
School Hierarchy Cheat Sheet

- Teacher, aides, etc.
- Guidance Counselor / 504 Coordinator
- Principal
- Director of Pupil Services
- Superintendent
What About Private Schools?

YES and NO

Private schools who receive *direct federal funding* must adhere to Section 504.

If they do not receive federal funding, it is up to the individual school’s discretion.

Therefore, it is important for PARENTS to do some research!

[The Rehabilitation Act of 1973 (Section 504) as Applied to Private Schools](#)
Resources Used

https://kidshealth.org/en/parents/504-plans.html


https://thinkaplus.com/504-plan-why-is-it-important-and-who-does-it-serve/


https://www.understood.org/articles/en/7-steps-to-getting-a-504-plan-for-your-child

https://adayinourshoes.com/what-to-do-if-your-school-is-not-following-the-504-plan/

https://www.understood.org/articles/en/5-options-for-resolving-a-504-plan-dispute