Managing Hyperinsulinism in School

Dina Tallis
About Me

• Mom of Ashlee, 13, HI-HA
• 11 years of elementary teaching
• 4 years of elementary principal

Unique Perspective?
What School Should Be

- Fun
- Exciting
- Friendships
- safe
Educator Roles

• Teacher
  – Scared of unknown
  – Your child’s main influence away from YOU

• Principal
  – Train staff
  – Encourage parents
  – Earn parental trust
How Will They Meet My Needs?

- Depends on where you live
  - Fact, schools do not have to provide or have nurses
  - Fact, schools have to utilize current staff for medical accommodations and train accordingly
  - Fiction, that means schools don’t care
  - Fiction, If I yell loud enough, they’ll get me one
So What Are My Choices?

• Medical Plan
  – Plan with specifics about child’s medical condition and care

• Section 504 Plan
  – Legally binding plan with specifics about child’s medical care

• IEP
  – Legally binding plan with specifics about child’s medical care and academic accommodations
So What Are My Choices?

• Medical Plan
  – Plan with very detailed information about child and child’s care. Created with a team including child, parent, principal/administrator, teachers, specialists, etc.
  – Not legally binding
So What Are My Choices?

• 504 Plan
  – Plan with very detailed information about child and child’s medical care. Created with a team including child, parent, principal/administrator, teachers, specialists, etc.
  – Legally binding; regulated by the Office of Civil Rights
So What Are My Choices?

- IEP
  - Plan with very detailed information about child and child’s care; including academics. Created with a team including child, parent, principal/administrator, teachers, specialists, etc.
  - Typically students with HI will qualify for an IEP; however, accommodations may not be academic. Assessments and data will determine if child needs academic support.
So What Are My Choices?

• IEP
  – Children with medical needs are not automatically learning disabled, which is what IEP’s most often identify
  – Note, HI diagnosis and early symptoms may put some HI children at a higher risk for some learning disabilities….and IEP would address both medical and learning in this case
What Is Right For Us?

• You have the right to chose!
What Is Right For Us?

• Scenarios
  – My child needs to check her sugar levels before lunch each day and when she is symptomatic. She is relatively stable and I feel like the school is doing a great job meeting her needs.

• Medical Plan
  – Know school staff, know they are trained, know they care about my child, and know they will take care of my child.
What Is Right For Us?

• Scenarios
  – My child must check her sugars at specific times each day and she has regularly scheduled snacks that she needs. In addition, she becomes symptomatic quickly and we follow very specific guidelines to keep her stable. I think the school is doing a good job meeting her needs and promises us they will take good care of her.
  • 504
    – New school, no relationships with staff, student needs are extremely specific, tried medical plan which didn’t get followed through with, legally binding
What Is Right For Us?

• Scenarios
  – My son suffered dozens of seizures or episodes due to his HI. The result has been some late development in all areas. He shows signs of sensory issues and is not always a great eater. In addition, the seizures appear to have created some learning difficulties we are noticing.

• IEP
  – Medical needs extreme, learning disabled, needs high level of extra support in learning, or, medical needs so severe they need a one-on-one aide
What YOU Can Do:

• BE PREPARED
  – Documents with details about HI
  – Emergency sheet created
  – Supplies full and ready
  – Binder with emergency information
  – Blank sheets for recording sugars
  – Good contact information
Conclusion

• You have rights
• You are your child’s greatest advocate
Resources

- http://www.ldonline.org/article/6086/
- http://congenitalhi.org/
- http://sur1.congenitalhi.org/hyperinsulism.htm
- http://abcnews.go.com/Health/DiabetesScreening/story?id=3812946#.T1jQAsD2af4