



Peel the Label

Sherrí Fickenscher, M.S., LSLSCert. AVEd, CED
Ashley Mahlstedt, M.E.D.



Clarke Schools
for Hearing and Speech

Objectives

1. The participant will list the pros & cons of labels(diagnosis).
2. The participant will discuss the benefits of a comprehensive team approach.
3. The participant will define Hunter Syndrome and explain treatment models.

Hunter Syndrome Facts

- Hunter Syndrome is part of a group of metabolic disorders called mucopolysaccharidoses; specifically MPSII
- Missing or malfunctioning enzyme
- Symptoms not present until as young as 18 months. HL usually first diagnosis.
- Symptoms include: hearing loss, stiff joints/carpal tunnel, skeletal and physical abnormalities, developmental delays, **progressive system deterioration**

Meet Ethan



- 20 months - diagnosed with bilateral, moderate sensorineural hearing loss
- Genetics counselor diagnosed Hunter Syndrome
- Early Intervention Services:
 - Teacher of the Deaf - 23 months
 - Occupational and Physical Therapy - 2yrs 3 months
 - Center-based Toddler Group - 2yrs 5 months - 3yrs 4 months; transitioned into preschool 5 days a week at 3yrs 5 months
- Various medical appointments at hospital including once weekly enzyme infusions

What can Hunter Look Like?



What did Hunter look like for us?

- Transition time was a trigger
- Head banging
- Being told “No”
- Screaming/crying/avoidance for long periods of time (at beginning of year for 2 hours)
- Refusal to participate in group activity
- Limited interactions with peers and other adults beside mom or dad
- Cognitive difficult to assess due to above aspects

Ethan transitions to preschool

- Strong partnership between EI staff and preschool staff
- Dad gave an inservice to all staff, observed for the first few weeks of school and offered input to staff
- Behavior Specialist and personal care assistant added to IEP
- We made sure a framework was in place
 - Closely monitoring Ethan's cognitive skills as well as his auditory, speech and language skills
 - Our motto became “Let’s give it a try!”
 - Time and time again Ethan rose to the occasion

What if

- We didn't partner with the parents?
- We focused on what Ethan couldn't do instead of what he could?
- We let 'Hunter' scare us
 - Fear was a factor for us all!
 - Can we meet his needs?
 - Can we keep him safe?
- We let Ethan's diagnosis drive his plan?

The Anatomy of Trust-Brene Brown



Boundaries-willing to say 'no'; respect my boundaries and that of others

Reliability-time and time again I do what I say I am going to do

Accountability-hold myself and others accountable. Admit when I am wrong.

Vault-I only share information that is mine to share

Integrity-I chose what is right over what is easy or convenient

Non-judgement-I respect that others feelings or experiences are different than mine

Generosity-Do you believe that people are trying their best?

Meet Ethan today



What can Hunter Look Like?



This is our starting point

(what was typical)

- Transition time was a trigger
- Head banging
- screaming/crying/avoidance for long periods of time (at beginning of year for 2 hours)
- Refusal to participate in group activity
- Limited interactions with peers and other adults beside mom or dad

This is where we are now

(what is typical)

- Transitions without difficulty
- Engaged and interactive with peers
- Participates in individual, small group, and large group activities
- PCA beginning fade out
- Huge change in participation in audiology appointments
- Cognitive skills are age appropriate
- Listening skills are near age appropriate

Ethan's parents have a message!



References



Brene Brown: The Anatomy of Trust

<https://www.youtube.com/watch?v=agOgnVpr2eg>

Mayo Clinic Hunter Syndrome facts: <https://www.mayoclinic.org/diseases-conditions/hunter-syndrome/symptoms-causes/syc-20350706>

Contact Information

Sherri Fickenscher sfickenscher@clarkeschools.org

Ashley Mahlstedt amahlstedt@clarkeschools.org

<https://huntersyndromefoundation.org>



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