Successfully Educating Students with ONH

how educators can make a difference from the start
“A diagnosis of optic nerve hypoplasia warrants neuroradiographic and endocrinologic testing for risk factors of delay and developmental assessments for early intervention planning.”
Demographics

- At NMSBVI preschool campus 18% of our population has a diagnosis of ONH
- Presently 32 confirmed cases under 3 years old – baby program
- 50% of the students in my classroom are diagnosed with ONH
- 1977 – 1.8 per 100,000
- 2006 – 10.9 per 100,000
Incidence at NMSBVI

NMSBVI – ECP
2010 – 2011
ONH 16%

- Cortical Visual Impairment (CVI)
- CVI due to Non-Accidental Head Trauma
- Optic Nerve Hypoplasia
- Coloboma
- Retinopathy of Prematurity
- Ocular Impairment
- Retinal Dystrophy
- Other

2011-2012
ONH 26%

- Neurological Visual Impairment
- Visual Impairment Due to Non-Accidental Head Trauma
- Optic Nerve Hypoplasia
- Coloboma
- Retinopathy of Prematurity
- Ocular Impairment
- Other
National Demographics

• Among children under 5 years of age
• Prenatal Cataract is the leading cause of legal blindness, accounting for 16% of all cases.
• Optic nerve atrophy (12% of all cases) and Retinopathy of Prematurity (9% of all cases)

(National Society to Prevent Blindness, 1980).

A study of children in schools for the blind in the United States revealed that 19% of 2553 children were cortically blind, and 12% had visual loss from optic atrophy or optic nerve hypoplasia

What educators need to know about ONH

• Defining Characteristics
  - Underdeveloped optic nerve

Clinical Associations:
- Hypopituitarism dysfunction
- Developmental Delay
- Social Delay
- Motor Delay

Developmental specialists look for visual cues when identifying ONH in children
- Small stature
- Sensory issues
  “pallor”
  “small optic nerve”
  “Underdeveloped optic nerve”
When a child has a visual diagnosis of ONH, there are a host of other medical issues to test for.

- Brain evaluations and tests (CT, MRI)
- Hypopituitarism (pituitary malfunction)
- Growth Hormone (blood tests are required to measure growth hormone)
- 6:10 children with ONH do not make enough GH.
- Hypothyroid (TSH) “Thyroid levels should be checked when the diagnosis of ONH is made and at least every year after diagnosis.”
• Sex hormones (Endrocinologist will perform a blood test. Tests should be performed when child is diagnosed or at less than 8 or 9 months of age)
• Cortisol production deficiency
• Low Blood Sugar “Lack of growth hormone, lack of cortisol or lack of both can cause a body’s blood sugar level to be low.
• Low ADH (Diabetes Insipidus) dehydration and high sodium content

*also available in Spanish
Strategies for Success: educating students with ONH
Educational Impact

• From – *Optic Nerve Hypoplasia* (presentation)
  Julie Greenlee and Angela Howe
  Stephen F Austin State University

  *The student will require some medical monitoring as well as educational assessment*

  *Depending on visual impairment increase or decrease font to meet needs of acuity and/or visual field*

  *Will likely need an O&M evaluation*

http://www.faculty.sfasu.edu
Effective Teaching Strategies (general)

- Flexibility is key
- Adapt according to child’s mood
- Discern causes of discomfort and stress
- Utilize quiet times of day for optimal learning
- Limit exposure to busy environments
- Be persistent
- Defined limits for behavioral challenges
- Consistency and communication for all team members
- Give the student coping strategies
- Keep calm
- Organize activities so the child is “in charge”
Specific Strategies

Simple

complex
Increase sensory information according to child’s cues

- Simple
- Single demand
- Familiar environment
- Reduced noise
- No peers
- 1 staff member
• Outside
• Windy, cold, sunny
• Noisy
• Pulling
• Walking
• Touching railings
• Ascending
• Instruction
Increasingly complex social situations and demands
Flexibility within instruction is vital because

• Sensory integration issues
• Discomfort brought on by incontinence, clothing, hunger, thirst, etc. . .
• Inability to deal with stress
• Irritability
• Fatigue/sleep issues
• Poor health
Keys to educational success for students with ONH

• Medical issues must be addressed before programming can be effective

• Advocates for the student must be able to explain “behaviors” based on their knowledge of the condition

• Think. . . .
Not....
What is the role of the TVI/Early Interventionist?

• Provide medical information associated with ONH to both families and professionals
• Develop strategies with the team and ensure communication and consistency
• Debunk ONH stereotypes
Tools and Adaptations

- Object Permanence
Pre-literacy
Pre-braille
Assistive Technology

ZOOLA

FUN SOUNDS

MONSTER MELODY
"Feel Better"

Menu

Water
Whimic
Squeeze
Wedge

Listening
Gum
Brush
Take a walk
Jump
J, 3 YEARS OLD

- Bilateral ONH
- Pituitary issues
- Sensory integration issues
- Difficulty dealing with stress
- Urinates frequently
- Poor appetite
- PICTURE OF JULIE NOW!
J, Now 5 Years

- Butterfly Protocol
- Choices
- Expectations
- Social success

- Active role during meals
- “Happy Plate”
Behavior Strategies

Allow student to participate in planning Process

Provide one on one time with an Adult before integration into group

Self-evaluation

Outcomes

Social Awareness
S, 3 years old

- Bilateral ONH
- Sensory integration
- Orally defensive
- Growth hormone
- Gross motor delays
- Language delays
E, 4 years

- “Extreme” Bilateral (NLP)
- Pituitary deficiencies (cortisol and thyroid)
- Gross and fine motor delays
Resources

- Dr Mark Borchert presentation in Albuquerque, 9/09
- Septo-Optic Dysplasia/Optic Nerve Hypoplasia & Autism Spectrum disorders, Terese Pawletko
- From – *Optic Nerve Hypoplasia* (presentation)
  Julie Greenlee and Angela Howe
  Stephen F Austin State University
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