Texas School Focus: Learning From Near to Far

Septo-Optic Dysplasia/ Optic Nerve Hypoplasia & Autism Spectrum Disorders

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Presented by

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Developed for

Texas School for the Blind & Visually Impaired Outreach Programs
Septo-Optic Dysplasia/Optic Nerve Hypoplasia
& Autism Spectrum Disorders:
An Opportunity to Explore their Features & Associations; Considerations & Implications for Educators

Terese Pawletko, Ph.D.

OBJECTIVES

- Septo-optic dysplasia – what is it? How is it diagnosed?
- Prevalence of septo-optic dysplasia/optic nerve hypoplasia and why are we hearing so much about it?
- What areas of the brain are involved?
- How does it manifest? What are the features? developmental trajectory, endocrine systems
- Risks/treatments – are there long-term health care issues? What are the implications of the physiological features for medical treatment and follow-up?
- Characteristics of SOD/ONH vs. autism? Why does it look like autism? Are some of the children autistic?
- What information do we have about prevalence of SOD/ONH and autism in combination?
- How do we work with these children effectively? Do positive behavior supports work? (house of human development)

WHAT IS SEPTO-OPTIC DYSPLASIA?

- Statistics
- NH = leading cause of childhood visual impairment in the US and Europe – 12% of children with VI (Blohme et al, 200, Hatton et al, 2007) or 1/10000 chn < 16 years of age (Patel et al 2006; Garcia-Filion et al 2008).
- Sixfold increase from 1977 estimate of 1.8/100,000 (Jan et al 1977)
- Agenesis of the corpus callosum (partial or complete) – estimated incidence 4/1000
- Autism spectrum disorders – 1/110

FORMERLY KNOWN AS ‘DEMORSIER SYNDROME’
GENERALLY AGREED THAT DIAGNOSIS OF SOD REQUIRED...

- Two out of the three:
  - Optic nerve hypoplasia
  - Absence of the septum pellucidum
  - Thinning of the corpus callosum
  - Pituitary hormone deficiency (added by Hoyt et al)

- Problem: a number of children with ONH and pituitary abnormalities can have septum pellucidum present but have same symptoms but get different diagnosis (Riedl et al 2008)

- Improvements in MRI imaging has demonstrated that ONH is associated with a wide range of CNS malformations including the absence of SP and corpus callosum but not limited to it and can involve schizencephaly, posterior ectopia and infundibular hypoplasia (Brodsky & Glazier, 1993)

- So... questioned whether concept of SOD is a distinct entity given the range of additional CNS structural abnormalities (Brodsky & Glazier, 1999; Garcia-Filion et al, 2008; Borchert, 2009 etc.)

IT IS A MUDDLE . . .

- Many studies
- Different foci (e.g., ophthalmological, neurological, radiological, endocrinological)
- Different approach to research (retrospective chart reviews, prospective, cross-sectional)
- When it comes to the issue of autism and brain abnormalities, different groups excluded based on whether or not could be formally tested, etc.

SEPTO-OPTIC DYSPLASIA

Variable combination of defects of midline brain structures including:

- Hypoplasia or absence of septum pellucidum (separating the anterior horns or the lateral ventricles of the brain)
- Agenesis (absence) or hypoplasia of the corpus callosum (white matter tracts connecting the hemispheres of the brain, integrating information)
- Optic nerve hypoplasia
- Hypothalamic-pituitary dysfunction (from isolated deficit of pituitary hormone to pan-hypopituitarism)
- Hippocampus and falx abnormalities (Riedl et al 2002, 2008)
- Heterogeneous/diverse presentations
- Ranging from normal development and good vision to significant neurological, systemic, and visual impairments (Garcia et al 2006)
WHAT ARE THE ASSOCIATED MANIFESTATIONS?

- Optic-Nerve Hyposplasia
- Non-progressive dysplasia of the retinal ganglion cell layer
- Reduced number of optic nerve fibers (axons)
- May occur as isolated abnormality in one or both (bilateral) eyes or in association with heterogeneous group of brain abnormalities (Chaplin et al, 2009)

OPTIC-NERVE HYPOSPLASIA - COMORBIDITIES

- Garcia, et al. (2006) retrospective chart review. Of 100 pts with ONH:
  - 75% bilateral ONH
  - Other conditions: 21% premature birth; 9% fetal alcohol syndrome, endocrine abnormalities 6%; developmental delay 32%, CP 13%, seizures 12% (mostly bilateral, abnormal gray/white matter development; two children with thinning or agenesis of corpus callosum).
  - Of those imaged: 60% abnormal scans: ventricles or white- or gray-matter abnormalities in 29, SOD in 10, hydrocephalus in 10, corpus callosum abn in 8. Clinical abnormalities in 57% with bilateral optic nerve ONH, 32% with unilateral.

WHAT AREAS OF THE BRAIN ARE IMPACTED?

Figure 1 Images of the brain from ONH booklet – Blind Babies
SEPTUM PELLUCIDUM

- Separates the anterior horns or the lateral ventricles of the brain
- May be completely or partially absent in individuals with ONH
- Range of findings:
  - No neurological symptoms in patients with SP remnants or unilateral ONH – were “associated with a milder SOD phenotype” (Riedl et al 2008)
  - Individuals with intact septum pellucidum in their study, 12/36 had abnormal pituitary on MRI (Riedl et al 2008) so labeled “SOD-like”
  - SP remnants: taller than those with absent SP, lower incidence of pituitary deficiency; none in their group had ACTH deficiency or diabetes insipidus; less likely to have neurological symptoms

WHAT IS THE SIGNIFICANCE OF ABSENCE OF THE SEPTUM PELLUCIDUM?

- Absence of SP in Garcia-Filion et al 2008 unrelated to development (was associated with CCH)
- Absence of SP (with no pituitary or cerebral abnormalities) was associated with “normal neurodevelopmental parameters” in language, IQ, behavioral functioning –
“neurodevelopmentally and endocrinologically inconsequential unless accompanied by posterior pituitary ectopia or cerebral hemispheric abnormalities” (p. 70, Brodsky & Glazier 1993)

ABSENCE/AGENESIS OF HYPOPLASIA OF THE CORPUS CALLOSUM

What is it? Tracts connecting hemispheres of the brain

Research shows:

- Smaller corpus callosum area identified in children with delayed personal social, adaptive, communication, cog and overall development (Garcia-Filion et al 2008)

- Others have found coordination problems, CP, communication/language problems, cognitive and psychosocial deficits; feeding, sleep, lower pain threshold yet more sensitive to touch; autism, LD, MR, OCD, DD, cleft palate, hypotonia, difficulties chewing and swallowing, satiate, sleep (see Doherty et al 2006)

OTHER AREAS OF THE BRAIN INVOLVED

- White matter abnormalities (e.g., maturation delay, hypoplasia, periventricular leukomalacia)

- Heterotropia, schizencephaly (abnormal gray matter-lined cleft that extend thru the cerebral hemisphere from the lateral ventricle to cortical surface – lining is comprised of small, irregular gyri), holoprosencephaly (Brodsky & Glazier, 1993) – cortical heterotropia – masses of normal neurons in abnormal locations due to arrest of normal neuronal migration along the radial glial fibers – don’t get to their target sites

- Hippocampus – anomalies of size &/or spatial orientation (in some unilateral, bilateral cases) - may be related to timing in fetal dev’t (10-20th weeks) when neocortex rapidly expanding, changes in orientation of structures. Other cortical malformations seen (ACC, holoprosencephaly, schizencephaly) Riedl et al 2008

- Falx abnormalities (Riedl et al 2008, tho not in SP remnant cases)

VISUAL FEATURES

- Optic nerve and chiasm hypoplasia (decreased # of fibers). Clinical signs: small optic disc, double ring sign and abnormal retinal vasculature

- Can affect one or both (80% of ONH, tho impact can be asymmetrical) eyes

- Visual acuity (may be near normal to NLP); high refractive errors (80% of bilateral in legally bl. rg.)

Note: degree of visual impairment correlated with presence of severe pituitary anomaly (Riedl et al 2008)

- May have field restrictions

- May have color blindness

- Nystagmus (may be ‘wandering’ if NLP)

- Strabismus
- May lack of depth perception if amblyopic
- May have mild photophobia (and squint, lower their head, avoid light by turning away, resist participating in outdoor activities)
- Microphthalmia, colobomas of the iris/choroids/retina

**HYPOTHALAMIC-PITUITARY DYSFUNCTION**

- May have pituitary aplasia, hypoplasia, absent stalk, ectopic posterior pituitary or radiologically normal gland; hypothalamic defect (Cameron et al 1999; Ek et al 2005)
- Unilateral risk for hypothalamic/pituitary dysfunction (69%), developmental delay (39%); are at lower risk than bilaterally affected (81% and 78%, respectively) (Borchert & Garcia-Filion, 2008)
- Broad range of impact from isolated deficit of pituitary hormone to pan-hypopituitarism (75-80% Borchert & Garcia-Filion, 2008)

**ENDOCRINE SYSTEM**

- Complex group of glands that make hormones that control activities in the body
- Different hormones control reproduction, metabolism (food processing, waste elimination), growth & development
- Control the way we respond to our environment; help provide the proper amount of energy and nutrition your body needs to function.
- Glands: thyroid, parathyroid, pancreas, ovaries, testes, adrenal, pituitary, hypothalamus

**ENDOCRINE ABNORMALITIES**

- Endocrine deficits in 50% of all SOD patients and 80% of them had MPHD (Riedl et al 2008)
- Ahmad - prevalence rates of endocrinopathies associated with ONH in retrospective studies 27-81% may be underestimate - some problems may develop over time. 71% with “normal pituitary gland on imaging had endocrinopathy” – finding unrelated to SP
- Gradual loss of pituitary function in 60% of hormone deficient (perhaps related to young age of dx) with absent SP - high percentage of ACTH and AVP deficiencies (increasing risk of mortality during intercurrent illness, thermoregulatory dysfunction, hypocortisolism, electrolyte disorders) Riedl et al 2008

- Borchert & Garcia-Filion, 2008:
- GH deficiency: most common pituitary endocrinopathy (70%)
- Hypothyroidism (43%) – need thyroid hormone & glucocorticoids for water excretion – may get sodium/electrolyte imbalance if these hormones are delayed due to GHD, hypothyroidism, gonadotrophin deficiency
- Adrenal insufficiency (27%) – critical to identify as could result in cardiovascular collapse in stressful situation; leads to hypocortisolism & neonatal cholestasis, jaundice, and hypoglycemia; fatigue or irritability and increased duration of illnesses.
- Diabetes insipidus (5%)

**GROWTH HORMONE DEFICIENCY**
- Low adrenocorticotropic hormone
- Low thyroid stimulating hormone secretion
- Diabetes insipidus
- OR...
- High levels of prolactin
- High adrenocorticotropic hormone

**OTHER FEATURES**
- Seizures (most resulting from hypoglycemia or hyponatremia) (Cameron et al 1999)
- May have increased weight (44% of the 36 studied had weight >85th %ile) – appeared to be associated with increased initial serum prolactin (Ahmad et al) (may also be structural or functional defect of hypothalamus such that satiety and/or appetite regulation may be faulty) or may have hypophagia with or without wasting (Ahmed et al, Borchert & Garcia-Filion, 2008)
- Delayed bone age
- Sleep disturbance - suprachiasmatic nuclei in the anterior hypothalamus = biological clock; located above optic chiasm, receive optic nerve photic information to synchronize ‘clock’ to the 24-hour light-dark cycle. Disturbance of circadian rhythm impacts physiology and behavior
- Common to have children with ONH lose circadian rhythm and sleep or wakefulness distributed over the 24-hour day. May also have inadequate retinohypothalamic input to daily set the circadian clock so have unique sleep/wake cycles. May lead to behavior problems, family stress (Borchert & Garcia-Filion, 2008)
- Feeding difficulties (due to neurological, sensory and/or anatomical anomalies) (Cameron et al 1999, Borchert & Garcia-Filion, 2008). May be associated with:
  - Hormonal problems
  - Absent or diminished sense of smell and taste (decreased interest)
  - Sensory sensitivities (e.g., texture aversion) may lead to restricted food preferences
  - Feeding also associated with agenesis of the corpus callosum (oral, pharyngeal dysphagia, oral-sensory disorder) (oral defensiveness in 5/7 pts Ng et al 2004). Oral-motor weakness observed in all the pts – impacts strength and coordination needed for functional oral-phase swallowing.
TEMPERATURE REGULATION

- Medial preoptic region of the hypothalamus – involved in body temperature regulation; regulates fever response through communication with paraventricular nucleus – temperature regulation significant issue

OTHER FEATURES

Dysmorphic features:
- Midline facial features (e.g., frontal bossing, depressed nasal bridge)
- Skull – macro or microcephaly
- Musculoskeletal system (e.g., small hands, feet)
- Abnormal genitalia

HOW DOES IT DEVELOP?

- **Fetal Development**
- Optic nerve axon growth proceeds well into second trimester
- Possible mechanisms: disorder or neuronal migration, axon development, or dysregulation of developmental neuronal apoptosis (Ahmad et al 2006)
- Refinement of connections through programmed sequences continues across gestation (Garcia-Filion et al 2008).
- Hypothesis: vascular disruption during embryogenesis (Riedl et al 2008)

POTENTIAL CAUSES?

- Largely unclear
- Possible role of HESX1/Hesx1 gene important for development of prosencephalon

POTENTIAL RISK FACTORS AND ASSOCIATIONS?

- ONH in No. Amer. – perinatal & early postnatal risk factors (Garcia-Filion et al, 2008) large prospective study - 204 pts.:
- Birth characteristics: birthweight and gestation OK
- Increased frequency of C-sections, fetal complications (e.g., fetal distress*), neonatal complications (in 62%, e.g., jaundice* 93/127; hypoglycemia, 48/127; distress, 40/127; temp instability*, 15/127)
- Young maternal age (23 years vs. 27; 66% of sample <25)**, first pregnancies (76% of sample, higher than in general pop.)

*
MORE COMMON IN BILATERAL CASES

- **Riedl et al 2008 similar findings re: mat. age**
- Preterm labor, gestational vaginal bleeding (33% of 105 interviewed), anemia (31%) (similar in Mehta et al 2005)
- Low maternal weight gain in 29% of the 105 cases interviewed (22% were underweight at conception)
- Weight loss during pregnancy (in 48% of mothers; 33/50 lost > 1.4 kg (had low to normal pre-pregnancy BMI) 91% of weight loss in first two trimesters. Most of moms losing weight were younger (22 vs. 26 yrs of age). Need to examine role of wt. gain and prenatal nutrition as contributions to ONH risk
- No family history of ONH (Garcia-Filion et al, 2008), no siblings with the dx
- Gestational diabetes, hypertension and prenatal viral infection – not seen as key risk factors in this study
- Other factors reported in various studies (note: some limitations to investigations such as retrospective nature, selection bias, etc.): preterm birth; low birth weight, intrauterine growth restriction; twin-twin transfusion syndrome; young maternal age; prenatal exposure to smoking, alcohol & recreational drugs, first births, medication (e.g., antidepressants, anticonvulsants, anti-nausea, antifungal agents, infertility treatment), prenatal complications (e.g., gestational diabetes, toxemia, maternal anemia, viral infection). (Borchert & Garcia-Filion, 2008)

DIAGNOSTIC CATEGORY OF SOD/ONH?

- **Subgroups – in flux due to improvements in imaging**

One proposed 4 groups (Barkovich et al): at least two distinct MRI views:

- Grp 1: High incidence of malformations of cortical development (schizencephaly, gray matter heterotropia, partial absence of septum pellucidum); small optic nerves due to prenatal destruction of optic radiations
- Grp 2: Absence of septum pellucidum and hypoplasia of white matter with ventriculomegaly but normal cerebral cortex; some with hypoplasia of genu of corpus callosum
- Grp 3: posterior pituitary ectopia
- Grp 4: hypogensis of corpus callosum

NOMENCLATURE/DIAGNOSIS

- Given the complexity and heterogeneity of the population of individuals with ONH/SOD
- May be more meaningful to think of it as a of **septo-optic dysplasia complex** (Polizzi et al, 2006) or “syndrome” of optic nerve hypoplasia (Borchert et al, 2008) resulting from several different genetic abnormalities or in utero injuries (e.g., vascular disruption, migration difficulties)
LONG-TERM HEALTH CONSEQUENCES/CAUTIONS?

- Association of hypothyroidism and developmental delay independent of CCH or generalized pituitary dysfunction. 52% of Garcia-Filion et al 2008 subjects undiagnosed before enrollment – rarely detected in early infancy – thus can’t say what the benefit for early thyroid replacement would be for development.
- May ONH and GHD and show normal growth in infancy and early childhood (cited in Ahmad et al).
- Precocious puberty
- Delayed growth
- Diabetes insipidus
- Obesity
- Sudden death (Brodsky et al, 1997)
- Mehta et al (2005) found out of 57% of their pts with postnatal complications (e.g., hypoglycemia, prolonged jaundice, seizures, feeding difficulties, hyponatraemia, recurrent sepsis) only 23% were dx with hypopituitarism in neonatal period.

RECOMMENDATIONS/CAUTIONS

- Neonatal screening for primary hypothyroidism not sensitive enough for ONH related population (Garcia-Filion et al 2006, 2008)
- All individuals with ONH should be considered at risk for endocrinopathies with and without abnormalities in septum pellucidum and pituitary.
- Risk for delay still high even in absence of neuroradiographic or endocrine problems (true for unilateral ONH as well as bilateral) Garcia-Filion et al 2008 (45% of children with unilateral ONH in one study (Garcia et al 2006).

SUDDEN DEATH IN SEPTO-OPTIC DYSPLASIA
BRODSKY, CONTE, TAYLOR, HOYT, MRAK (1997)

- Inability to increase corticotropin secretion in response to stress (i.e., infection typically lead to pyrogens/fever inducing substance) - hypothalamic thermoregulatory dysfunction may predispose to life-threatening hyperthermia (high fever).
- May become hypothermic during episodes of hypoglycemia (seen in neonatal period and subsequent illness). Corticotropin deficiency results in body failing to respond to infection (e.g., sepsis) with a fever and delays recognition of life-threatening illness.
- Study group required multiple hospitalizations for dehydration, hypoglycemia, hypothermia, high fever (sequence of final illness – fever, dehydration to adrenal crisis and within days died) – diabetes insipidus may contribute to dehydration during illness and hasten shock.
Figure 4 Summary of neuroendocrinological disturbances leading to sudden death in septo-optic dysplasia.

DEVELOPMENTAL IMPLICATIONS

- Developmental delay
  - 73 subjects dx <36 mo. At 5 years of age, delay present in 71% (39% of children with unilateral ONH, 78% of children with bilateral) – motor delays most common (75%); communication delays least common (44%) p. 657
  - Corpus callosum hypoplasia and size/area, and hypothyroidism - 93% had overall delay at 5 years of age - significantly associated with poor outcomes across dev'l domains of personal-social, adaptive, communication, cognitive as measured on the Battelle (Garcia-Filion et al 2008)
  - Developmental Implications
    - Corpus callosum area highly correlated with all domains except motor skills with the strongest association with cognition (3-fold increase in risk for delay with each unit of decrement in corpus collusum). Demonstrates importance of interhemispheric communication. Prevalence of CCH and DD and/or autism

DEVELOPMENTAL DELAY

- DD = most common associated finding (Garcia et al 2006 retrospective) 32/100 (primarily bilateral ONH)
  - Associated with abnormal ventricles, abnormal gray or white-matter development (statistically significant association).
  - Hypothyroidism significantly associated with delay in all dev'l domains (Garcia-Filion et al 2008)
  - Sometimes near normal intelligence (Ek et al 2005) 5/13 in study
  - Abnormal muscle tone (Riedl et al 2008)
DEVELOPMENTAL IMPLICATIONS

- Explosive behavior from early age
- Hard to satisfy
- Easily frustrated
- Severe mood swings
- Feeding/sleeping difficulties
- Preschool years – passive behavior, lack of initiative, hard to motivate unless engaged with own interests and routines, activity level “sluggish” in 6 of 13 children

INTERESTINGLY…

- 12/13 children disliked changes/preferred routines; required support for transition between activities
- “Behavioral peculiarities such as low frustration tolerance and narrow range of interest had puzzled and worried the family and the staff, but had mostly been attributed to the fact that the child was blind. However, during late preschool ages, it became evident that the symptoms were part of a more pervasive disorder.” p. 1424

EK ET AL 2005

- “Autistic style” – concrete thinking
- 9/13 deficits in theory of mind, executive functions (mediated by prefrontal or orbitofrontal cortex), central coherence
- Frequent verbal stereotypes
- Interest in verbal interactions with adults on their terms
- Interests: music, memorizing song texts, “collecting” words, phrases, and sounds – but these were not used for communication
- Superficially fluent language

DEVELOPMENTAL IMPLICATIONS

- Autism:
  - Polizzi et al: 1/8 subjects with SOD in study
  - Ek et al 2005 – 6 of 13 with bilateral ONH had autism, 3 more with autistic-like condition (across all cognitive levels)

A caution…few studies included nonverbal children – most included students with speech, so may not be fully representative of all individuals with SOD/ONH
WHAT IS AUTISM?

*Autism/ASD is a behaviorally defined syndrome…*

- Diagnosed by presence of various behaviors
- Syndrome – cluster of behaviors
- **Not etiology specific** though biologically based: represents developmental dysfunction in CNS within areas responsible for social & communication development (Gillberg, 1989; Volkmar & Cohen, 1988), other areas of brain re: regulation, integration, etc.

ASD ARE SPECTRUM DISORDERS IN THE FULLEST SENSE OF THE WORD

**BRAINS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS**

**Parts of the Brain Affected by Autism**

![Brain_Autism.png](curingoxygen.com)

**EVIDENCE SUPPORTING OVERLAP OF SOD/ONH AND AUTISM**

- Issue of Underconnectivity (Just et al, 2007): fMRI study of adults with HFA doing an executive function task -- “relevant parts of the corpus callosum, through which many of the bilaterally activated cortical areas communicate, were smaller in cross sectional area”
- In addition, the size of the genu of the corpus callosum was correlated with the frontal parietal functional connectivity – likely resulting lower degree of integration of information across cortical areas – functional connectivity lower for those with ASD in frontal-parietal network require for task. The genu and splenium regions were smaller and the frontal-parietal activated cortical areas correlated with the size of the genu.
Other researchers (e.g., Chung et al (2004) found reductions in white matter density in the genu, rostrum, and splenium (posterior part) of the CC in individuals with ASD (impacting interhemispheric connectivity in the frontal, temporal and occipital regions).

Differential pattern of impairment between simple and complex skills – children with autism had the greatest difficulty on tasks requiring integration of information (e.g., memory for large volumes of material, complex material; comprehension of text). Better on basic cognitive skills (associative learning, vocabulary, spelling). Williams et al 2006

EVIDENCE SUPPORTING OVERLAP OF SOD/ONH AND AUTISM

- Reduced size of the corpus callosum (affecting anterior part, diminished total cross-sectional area of corpus callosum and decrease in interhemispheric connectivity, as well as impacting frontal lobe dysfunction) (Hardan et al, 2000).
- Brieber et al 2007 found decrease in gray matter in bilateral inferior temporal gyrus and hippocampus-amygdala complex, left middle occipital gyrus and left premotor gyrus in individuals with autism.
- Abnormally elevated increase in head growth in most children with ASD – not present at birth but develops within two years of life (Courchesne et al 2003) – raised as a possibility in children with SOD/ONH
- Studies suggest that:
  - Some children with autism have multiple pituitary deficiencies (MPD) or hypopituitarism (Gingell et al 1996);
  - Some found significantly lower serum concentrations of cortisol, significantly higher concentrations of ACTH; higher prolactin concentration in autistic individuals with seizure disorders (tho still within nl limits) (Marinovic-Curin et al 2003)
  - Marinovic-Curin et al 2008 – slower cortisol response during ACTH stimulation test in autistic children (note, had same salivary cortisol circadian rhythm and daily cortisol excretion but find differences in cortisol response to ACTH stim or other types of stress) (at the 90 min. level in particular)
  - Findings again suggesting dysfunction of the hypothalamo-pituitary-adrenal axis in individuals with autism – levels were within normal range but significantly different than for control subjects.
  - Hypothalamus plays key role in integration of autonomic and endocrine functions and serves regulatory roles – important in regulation of feeding behavior, body water and endocrine system thru production of releasing factors for various hormones.

NOTE: Not all children with MPD have ASD and not all children with ASD have MPD. (Gingell et al 1996)
“TO DIAGNOSE OR NOT TO DIAGNOSE, THAT IS THE QUESTION…”

WHY GET THE DIAGNOSIS?

“How can we throw another label at the parents, especially when it is the BIG A?”

ADULT ON A LIST SERVE FOR BLIND/AUTISTIC ADULTS EXPLAINS…

“The Asperger’s causes me many more problems across a wide spectrum which blindness does not do and it has ever since I was a small child. The symptoms of both autism and depression have been devastating throughout. When I was growing up, my tantrums from sensory over stimulation were attributed to being a spoiled child and I was treated as such leaving me with a sense of inferiority and hopelessness…”

WHAT ARE SOME OF THINGS TO KEEP IN MIND WHEN WORKING WITH A CHILD WITH ONH?

- Inter-hemispheric connections, connections in general may be weak or non-existent
- Ability to regulate multiple facets of one’s internal environment (temperature, emotion, response to various inputs from the external environment, etc.) may be limited and/or variable day to day, moment to moment
- Skills may be variable across domains

WHAT ARE THE AUTISM SPECTRUM DISORDERS?

They all share impairments in 3 key areas…DSM-IV TR

- Impairments in communication
  - Delay in, or total lack of, the dev’t of spoken lang. (not accompanied by attempt to compensate thru alternative modes of communication such as gesture or mime)
  - In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others; may have problems understanding & using language flexibly (both verbal and nonverbal forms of communication); exhibit stereotyped and repetitive use of language or idiosyncratic language
  - Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
- Impairments in the ability to form and maintain social relationships, as manifested by at least 2 of the following:
  - Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
  - Failure to develop peer relationships appropriate to developmental level
  - Lack of spontaneous seeking to share enjoyment, interests, achievements w/other people (e.g., lack of showing, bringing, pointing out objects of interest)
  - Lack of social or emotional reciprocity at level commensurate with their cog./dev’l level
Restricted repetitive and stereotyped patterns of behavior, interests & activities, as manifested by at least one of the following:

- Encompassing preoccupation w/one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
- Apparently inflexible adherence to specific, nonfunctional routines or rituals
- Persistent preoccupation with parts of objects
- Stereotyped and repetitive motor mannerisms (e.g., hand, finger posturing, complex whole-body movements)
- All present prior to the age of 36 months…

WHY MIGHT SOME CHILDREN WITH SPECIFIC EYE CONDITIONS BE MORE VULNERABLE? WHAT MIGHT BE THE COMMON THREAD?

- They share evidence of early developmental errors of ocular structures, cranial nerves, systemic organs and more than chance presence of autism spectrum disorders” (Miller et al, p. 112), may be associated with early insult during embryonic development
- At least 1/3 of groups of children with visual impairments (due to Mobius, CHARGE, SOD) in their study had autism or “autistic-like” (meeting 4+ criteria in DSM-IV, “immediately below the score indicative of autism”) conditions
- Critical window…23-27 weeks gestation…

LET’S WATCH SOME CLIPS OF CHILDREN WITH SOD, ON THE AUTISM SPECTRUM

ASSESSMENT OF STUDENT WITH SOD/ONH

Let's roll the DVD…
Austin
TWO MODELS/WAYS OF THINKING…

- Iceberg
- House of Human Development

KEEP THE ICEBURG IN MIND!

- Monologue vs. conversation
- (Difficulties with persp. taking, shifting attention, flexible use of language)
- Holds ears when hears people talking (Difficulties regulating sensory input)
- Avoids eye contact (may have difficulty with facial complexity or with looking and listening)
- No pretend play (literal interpretation, diff. w/persp tkg)
- Tantrums with change (relies on routine for stability, predictability)

What are you seeing? Why might you be seeing it? The why is beneath the surfaces . . . and is important to understand . . .
THE HOUSE OF HUMAN DEVELOPMENT
Model proposed by Terese Pawletko

Developing an educational program requires a multidisciplinary team, environmental instructional modifications,

AND integrated approaches and starts from the bottom up…

SENSORY-MOTOR

SENSORY/SENSORIMOTOR PROCESSING

- Involves taking in and managing information from our internal and external environments (ideally without conscious thought/effort)
- In individuals with ASD, varies from hypo- to hypersensitive responses to sensory stimuli

ASD: UNUSUAL RESPONSES TO SENSORY STIMULI

- Tactile – clothing and food textures; intensity, lightness, malleability of materials; weight of materials (including blankets)
- Auditory – certain frequencies; perfect pitch; figure/ground
- Visual – may be overwhelmed by certain stimuli/amount of stimuli, fixated on certain types of visual stimuli
- Temperature (may have difficulties regulating own temperature; indicate stress through changes in body temp; have strong reactions to certain temps; want foods a certain temp, etc.)
- Vestibular – need to move, to exercise, reactions to movement
- Olfactory – e.g., colognes, foods, cleansers
- Other: internal sensations/changes such as associated with a virus or allergies coming on
MORGAN IN THE CAFETERIA

CUMULATIVE EFFECTS VS. “PURE”

Figure 6 Image of a faucet dripping water into an almost full bucket.

CRITICAL COMPONENTS

- Conduct THOROUGH assessment of all child’s sensory areas via structured interview, environmental “inventory” (e.g., Sensory Profile, Behavioral Challenges checklist by Dalyrimple & Ruble)
- Try to keep the environment as low key as possible (e.g., visually clear including worksheet/work space level, sound absorbing materials, no extraneous noise or conversation; balance lighting needs for children’s visual impairment with those of arousal).
- Be aware that even normal levels of auditory and visual input may be perceived as “too much” or “too little”
- Tactual if possible, identify those types of clothing experienced as distressing and avoid them (e.g., could be certain styles, certain fabrics, seasonal changes) otherwise may be unable to focus on anything but the distress caused by the clothes; illness related sensations (e.g., changes in sensations could result in distress)

REMEMBER

can’t think right if underwear is too tight…

Hanes (T. Bolick)

- Foods - e.g., “food of the month”
- Can impact tactual “defensiveness” re: materials, consider working hand under hand; May need to “prepare the child’s hand to receive information” thru massage/deep pressure routine that ends at the hands
- For tactual sensitivities, it may not be possible to desensitize by immersion in the activity or graduated exposure due to the child’s “wiring” – may need to “prepare the child” to receive certain inputs, use routines
- Proprioceptive input – make sure that the furniture fits the child, provides good support
- Remember, child needs heightened features in materials (e.g., more weight, more substance) for things to register; perhaps more repetitions

**BEN AND GENTLE EATING**

VHS/DVD 3 #8 -- may have to move on – can take time to watch at the end

Use child’s sensory seeking behaviors functionally, structuring activities and/or building them into daily routine (e.g., define when, where vs. have child engage in them whenever, wherever pleases)

- Provide advance notice of fire drills
- Monitor temperature changes as some children are heat/cold sensitive; also as indications of their stress levels
- Monitor smells (e.g., cleaning fluids, cafeteria smells, perfumes, cosmetics) - and remember, get a “fresh nose” in to evaluate your room as we habituate
- Respect the fact that these sensory sensitivities, if not respected, drain the child’s “battery”/ compete for attention, may cause child to retreat in order to cope with the situation, etc. Our sensitivity to their sensitivities should also guide our approaches, etc.

**SENSORY ISSUES**

For more able students:
Teach self-advocacy AND and strategies like sound blocking ear muffs, other sensory management strategies

**VISUAL FUNCTIONING/SUPPORTS**

Complete functional vision assessment
Good contrast, lighting; bold colors
Monitor visual complexity of near (e.g., worksheets, work surfaces) and distant ‘views’ (e.g., bulletin boards, reading/play corners)

**REGULATION**

- Self-regulation and ASD
  - Problems in self-regulation are often the parent’s first cause for concern - tantrums, difficulties with transition and the unexpected, insistence upon sameness
  - Rigid adherence to routines and rituals often represents the child’s “best” way of managing himself and the world
  - Think of what we do to self-regulate every day
  - Ways You Might Be Regulating Today

**DIFFICULTIES WITH REGULATION**

- Attention – heighten features you want child to attend to; help child shift attention
- Arousal
- Affect – can’t be stressed and engaged – may benefit from sandwiching new activity between ‘tried and true’ /mastered, preferred
- Activity level

How to address child’s needs for regulatory support?
COMMUNICATION

- Impairments in Communication

Receptive
- Difficulties understanding what is said to them (or what they read)
- Slow to process language; processing of signal may be variable, may appear “deaf,” background noise may compete (and may be more “meaningful”/predictable)
- Literal in interpretation of language; difficulties with idioms, humor, words with multiple meanings

Expressive:
- May have delay in or lack of expressive language -may have speech early on and lose it; may have jargon or idiosyncratic language; pre-linguistic
- Echolalia common & persists beyond 24 - 32 months - includes immediate or delayed literal repetition of others’ speech (may appear non-communicative, but may in fact be used to communicate; may be self-stimulatory; anxiety management) (see reference from Indiana Resource Center for Autism & Elisabeth Fields)
- May speak more words than understands – many have good rote memory, but not necessarily able to understand what you say or what she says
- Need to examine indirect/behavior as “communication”
  - Spinning, flapping, clapping, foot tapping - “I’m anxious” (e.g., unclear re: waiting; change in routine; drowning out extraneous noise I can’t control)
- Those with speech (e.g., HFA, Asperger Syndrome), may have trouble with prosody (e.g., pitch/inflection may be monotone to sing-song; rate may be too fast or too slow; rhythm may be unusual; volume may be too loud or soft; stress may be improper)
- Awkwardness in communication, despite strong vocabulary and grammar (e.g., literal, pedantic); may perseverate on topic
- May have difficulties with pragmatics – e.g., initiating conversation, using social or conversational rules, maintaining topic, interrupting, rigidly

CAUTIONS AND CONSIDERATIONS

Do not assume that a child understands just because he talks - have heard things like…
- He understands everything I say
- He understands, he is just being bad
- She knows her schedule, doesn’t need the tactile schedule cards

SEVERAL WAYS TO THINK “EVALUATE” CHILD’S COMMUNICATION/LANGUAGE

- Formal testing – has limits
- Language samples (functions demonstrated, absent)
- Checklists geared for ASD (e.g., Quill, Bolick, Dalyrimple)
- Various VI-related checklists (e.g., Developmental, concept, curricular such as the Oregon Project)
- Observations across settings (also examining the opportunities for language development, communication and the level of support provided; appropriate to context versus unrelated to current activity?)
- Listen with third ear, look with third eye
QUESTIONS RE: COMMUNICATION WISCONSIN GUIDELINES (AN EXAMPLE OF ONE STATE’S ATTEMPT TO SYSTEMATIZE THINGS)

- Pre-language and language level communication questions
  - Does the student exhibit intentional communicative behavior?
  - Functions of communication? (e.g., protest, comment, request)
  - Thru which means does the student communicate?
  - Is the student able to initiate, respond, and/or maintain a communicative exchange?
  - Which contexts are most facilitative of communicative behaviors?

- Speech and Language
  - Does the student read, use and respond to body language?
  - Does he/she use language functionally?
  - Does the student demonstrate a range of functions?
  - Does he/she demonstrate communicative intent?
  - Does the student have literal interpretations of language (receptive and expressive)?
  - What pragmatic (expressive and receptive) skills does he/she demonstrate?
    - Verbal: turn taking, intonation, inflection
    - Nonverbal: eye contact, proximity, facial expression, posture, turn taking
  - How much verbal input is the student able to respond to? Amount? Complexity?
  - Does the student establish a shared referent (context specific, previous association)?

LANGUAGE BUILDING

- Remember, children slow to process, have auditory “competition”
- How to support? How to slow the world down . . .
- Don’t repeat or rephrase
- Augment with tangible
- Layer – show first, then language over . . .
  - Less is more – control the amount if language you are using; pace/allow for processing time
- “Clear out extraneous”/competing
- Provide deliberate teaching, concrete examples vs. “taling thru”
- Using routines
  - Helps children anticipate next activities
  - Know where they are in the day
  - Learn skills

LANGUAGE DEVELOPMENT AND COMPREHENSION

- Motivating? (this includes things like Braille reading)
- Functional? (e.g., concepts; braille reading)
• Enough exposure within functional routines to be meaningful?
• Fun?
See Hagood article, Stokes (online), Quill, etc.

SET UP OPPORTUNITIES TO COMMUNICATE – WORK IN SMALL INCREMENTS
• Begin with what the child is motivated by – may find that music is a pattern that ‘makes sense’ to the child
• Set up situation so have repeated opportunities to engage, in close proximity
• One word-items, activities, actions (with objects present)
• Facilitate communication occurring without item present
• Requests with carrier phrase: e.g., “I want . . . “

SEVERAL WAYS TO THINK “EVALUATE” CHILD’S COMMUNICATION/LANGUAGE
• Observations across settings (also examining the opportunities for language development, communication and the level of support provided);
• Facilitate comprehension through:
  • Make language meaningful (e.g., associated with what child is experiencing/touching directly) and at level can comprehend; with preverbal child going to use objects and simplify language
  • Pre-teaching vocabulary, concepts
  • Use of task cards to converse, engage in routines, etc.
  • Remember she/he is literal in interpretation, context dependent – that abstraction is hard, requires flexible thinking
• Set up situations for communication (using forms that are meaningful – cup, picture, verbal request, etc.) (See Quill, Hodgdon, McEachern, Hanen, Giggle Time) for instance . . .
• Requesting (e.g., snack, toy, more swinging)
• Refusal, appropriate means of protest
• Situations to encourage commenting (e.g., objects from box, play activities)

I HEAR “CHILD SAYS THINGS UNRELATED TO QUESTION OR TASK”. YOU NEED TO FIGURE OUT WHY . . .
• Is it because you’re relying on the excellent auditory memory (child reciting verbatim), but there is no comprehension of what she/he is saying or what you are talking about/asking about?
• Is it an expressive or receptive communication issue? Social pragmatic issue? Stress management? Memory issue? Multi-sensory processing issue?
• Attend to what child is “saying” (verbally, nonverbally as a way to gauge) --- may need to simplify the environment, help child see forest for the trees.
• Verify comprehension of words child is using (e.g., Morgan), read the child’s cues
• Avoid metaphors, words with double meanings; teach meaning directly, true even for math (e.g., division meltdown)
GIVE THE CHILD THEIR WORDS

Figure 7 Objects from MacDonalds meal.

STORY BOXES – RECEPTIVE AND EXPRESSIVE FUNCTIONS

Figure 8 A box contains items from a birthday party; on the lid is a list of vocabulary. A small green felt board that is folded sets along side.

Figure 9 Felt board contains symbols and print vocabulary words for Ice cream and plate for the box of birthday items.

LANGUAGE/COMMUNICATION

- Can provide nonverbal instructions through layout of materials (next slides)
- Passage of time
- By setup of activities
- Through use of timing devices
- Develop closing cues (e.g., use of musical ditty, counters)
STRUCTURED READING ACTIVITY

Figure 10 Cardboard display of picture symbols set along side a child’s book with matching pictures on each page.

Figure 11 Lego-type blocks set in a small basket inside a tub of sand. A picture sequence strip of building a house with the blocks is placed at the top edge of the sand tub.

IMPORTANT TO KNOW WHAT LEVEL OF COMMUNICATOR THE CHILD IS...

- SCERTS
- Hanen: More than Words - 4 stages in Child's Communication

Why? Guides where you begin, how to expand…

OTHER MEANS OF SUPPORTING UNDERSTANDING

COMPONENTS OF STRUCTURED TEACHING

- Physical Structure – organization of room, location of activities
- • What activity will occur in “X” location?
- • What amount of social interaction will occur in that location?
- • What sensory sensitivities need to be addressed by the physical structure?
- Schedules
- • What will we do?
• In what order?
• Individual Work Systems
• What am I going to do?
• How much will I do/for how long?
• When will I be finished?
• What comes next?

Adapted from TEACCH, June, 2000

EXAMPLE OF PHYSICAL STRUCTURE IN AUTISM CLASS:
Different areas, different purposes (e.g., work in the work area, play in the play area, teacher directed instruction in one area, independent work in another area). Same is true for home life…

Figure 12 Photo courtesy of Room5 website showing the interior space in a classroom.

TIME MANAGEMENT SKILLS: DEFINE THE PASSAGE OF TIME...
How long do you want me to brush my teeth?

Does every child you work with get a schedule?
Is the final goal a whole day picture schedule?

CHILD WHO IS A “PRE-SCHEDULE” CHILD
Work at developing routines, predictability through activities and systematic, meaningful repetition of those activities

INDIVIDUALIZE, INDIVIDUALIZE, INDIVIDUALIZE…
TYPES OF SCHEDULES: MAKE IT MEANINGFUL, INDIVIDUALIZED

- All day, part day, single event (pre-schedule child)?
- Calendars: weeklong, month long (and what used for and why)?
- Form?
- actual object (to actually use in the activity? to represent the activity? Issue of miniatures)
- object symbol
- photo or line drawing (with or without writing);
- written (print, Braille)
- And, is it a “take away” or a “check off” system?

- **Location**: Stable (e.g., on child’s desk)? at transition zone? totally portable (e.g., notebook, tote-able box), etc.? General tip: Needs to be sturdy, durable, replaceable

FULL DAY OBJECT/PICTURE CALENDAR

Figure 13 Full day object calendar using plastic baskets on a shelf.

Figure 14 Actual objects used in activity
PART DAY OBJECT/OBJECT-SYMBOL SCHEDULE

Figure 15 Calendar showing series of objects representing activities on a card board strip.

WHOLE DAY, PRINTED, PORTABLE SCHEDULE

Figure 17 Calendar with printed daily schedule and paper markers to highlight additional information.
INDIVIDUALIZING WORK SYSTEMS – ANSWER QUESTIONS

 What am I going to do?
 How much will I do/for how long?
 When will I be finished?
 What comes next?

Predictable, methodical, consistent approach to tasks - takes advantage of autistic individual’s love of sameness - follows left to right, top to bottom format
Modify work system based so child can be successful in independent completion of task - if can’t be independent, back down and add more structure (TEACCH)

 What makes sense in light of child’s visual functioning level? Cognitive level? Tactual organizational level?
 Can they use a written system? Picture? Object? (e.g., written sequence of events; for some may break down what goes on within each subject; may even preview afternoon before or morning of…)
 A matching system?
 Left to right - make sure you define or label left in some fashion (e.g., color, tactual indicator)
 Note: these systems, like all else, must be taught…

SAMPLE WORK SYSTEMS

Figure 18 A white basket sets inside a blue basket near a small table and book shelf.

OBJECT SYMBOL PHOTOS A WITHIN SESSION SEQUENCE

Figure 19 A calendar strip includes 4 object/print symbols.
COGNITION

- Information Processing
  - Tendency:
    - One piece at a time (sequential)
    - Concrete
    - Gestalt (sometimes from one small piece of information)
  - Weaknesses:
    - Integration info, generalizing across situations
    - Dealing with abstract thought, social cog info
    - Analytical
    - Comprehension
    - Executive functioning, attn (e.g., relevant/irrelevant, shifting), cognitive flexibility (i.e., rigid thinking)
    - Social-cognition (concrete > theory of mind)

MEMORY AND ASD

- For individuals with Asperger Syndrome, strengths in verbal memory, especially for factual information, relative to visual/motor memory
- For individuals with autism, visual memory is more likely to be stronger than verbal memory
- Strong memory for preferred sequences, linear thinkers
- Many with challenges encoding and retrieving patterns/categories/concepts - knowing when to retrieve, how and what to retrieve…
- Many have difficulties with memory for faces and “personal characteristics”

SEQUENTIAL PROCESSING AND ASD

- Sequential processing of auditory verbal information is often a strength for children with Asp.; visual sequencing may be strength for children with autism
- Strengths in logical sequential verbal processing can be used to counteract visuo-spatial challenges for children with Asperger’s; visual supports for can counteract the verbal deficits for children w/autism

COGNITION AND ACADEMICS

- Most children with ASD are great at rote tasks
- Many are skilled in early academics (except for those with visuo-spatial/math glitches)
- Fine motor/visuo-motor challenges may lead to resistance to “color-cut-paste” tasks
More difficulties as academics become more abstract—inferring and predicting in reading comprehension, estimating and trading in math

Written expression may be difficult

**INTERVENTIONS RE: COGNITIVE FUNCTIONS**

- How to address cognitive deficits, learning styles (e.g., Smith-Myles, Bolick, others)
- Use strengths and interests to address deficit areas (match perceptual skill strengths – e.g., visual-spatial? Reading?)
- Use concrete language (e.g., be specific), use visual and/or tangible supports; routines
- Highlight key information, eliminate extraneous
- Structure social routines, teach social skills, social rules, social stories
- Re: executive functioning –
  - minimize # transitions
  - organize work (e.g., sequence of activity, physical layout within activity); build structures/templates to match task
  - build in routines/sequences (anticipate potential break-downs in ANY activity, proactively program for them – e.g., Eric and the discover center)
  - do things in manageable chunks
- Need for sameness
- Use structure, schedule, routines
- Prepare for change in advance (e.g., zigger zagger)
- Re: restricted interests/anxiety – identify set times to engage in behaviors
- Use interests to teach skills, content

**NEED TO BE THEIR ‘EXECUTIVE MANAGERS’**

May need to provide concrete structure and rules for student to succeed in new environment – be it a field trip, sports event, etc.
SCHEDULE FOR THE WEEKEND

10:30 AM  Go to bus room with belongings
           Give Mr. D your packing list
2:30 PM   Arrive at campus
           Get dorm assignment
           Unpack - Have Mr. D check where you put things
           Hang out with Mr. D’s group during free time – no leaving
5:30      Dinner
7 PM       Watch events
9 PM       Supervised free time – pick from “watch a movie, play games…” - no going to other kids rooms, no walking campus
10 PM      Get ready for bed (wash face, hands, brush teeth put everything back where it belongs)

MATTHEW’S MORNING SEQUENCE AND PACKING LIST

Figure 20 Printed schedule in a three-ring binder

KEEPING TRACK OF MY MONEY AND MY IDENTIFICATION CARDS…IT’S NOT OUT OF SIGHT OUT OF MIND ANY MORE!

Figure 21 A young man stands with his arms behind his back displaying a wallet that is attached to a fanny pack.
SOCIAL-EMOTIONAL

- Significant impairments in social understanding
- Impairments in imitation
- Difficulties establishing relationships; not show, bring, point out things they find interesting
- Limited social interactions of those with ASD not reflect lack of desire, but impairment in reciprocal social interaction
- Difficulties taking the perspective of others
- Difficulties understanding social cues - verbal and nonverbal (knowing what to say, when, and how)
- Difficulties with “theory of mind”
- Difficulties reading and understanding social situations, recognizing and applying social rules, social standards and protocol, & norms flexibly (e.g., difficulty attending to relevant social cues; shifting attention; impairment in use & interpretation of nonverbal gestures)
- Play often lacking in imaginative qualities (requires perspective taking, symbolic representation) - tend to play with toys or objects in stereotypic ways
- Quality/quantity of interaction ranges from aloof to active

COMPLEX SOCIAL ENVIRONMENT, SIMULTANEOUS, NANO-SECOND PROCESSING & DECISION MAKING

The Barnes and Noble Rule Book (Garcia-Winner, 2005)

SAMPLE ASSESSMENT TOOLS

- Kathleen Quill -- Core Skills
- ADOS information
- Hanen Foundation Materials
- Play behavior and interest inventories, etc. etc.

SUGGESTED INFO TO GATHER RE: SOCIAL DOMAIN (WISCONSIN) – RE: OBJECTS

- What does the student do with objects?
- Does he/she seek out objects? What kinds?
- What range of functions does the student demonstrate with objects?
- How long does he/she interact w/particular object(s)?
- What affect do you see? Curiosity? Pleasure?
- What problem solving strategies do you see? Does he/she ask for assistance, for example?
- Does he/she engage in imaginative play with objects?
SUGGESTED INFO TO GATHER RE: SOCIAL DOMAIN (WISCONSIN) – RE: PEOPLE (SAMPLING)

- Does he/she imitate people and/or objects?
- Does the student demonstrate pleasure in interactions?
- Does the student appear to be aware of others around them? Does he/she see people as being connected with objects or activities?
- Does the student see others as a source of assistance?
- Does he/she demonstrate the ability to shift attention?
- Does he/she shift attention between people/activities in a timely way?
- Does the student demonstrate preferences for certain people?
- How does the student use proxemic behavior (e.g., awareness of personal space, reactions to touch, acceptance of touch)? Does the student intrude on the personal space of others? How does the student respond to the approach of others into his/her personal space?
- What do physical interactions with others look like?
- What is the nature of his/her play? Is it isolated, in proximity to others, parallel to others, associative, cooperative?

WHAT CAN YOU DO?

- Incorporate what you know about the child's communication level…

RESOURCES FOR “FOLLOW-THE-CHILD’S LEAD” STRATEGIES:

- Giggle time (Sonders)
- Co-active movement (VanDijk)
- Floor time (Greenspan and Wieder)
- Incidental teaching (Koegel)
- More than Words (Hanen Foundation)
GIGGLE TIME – GAMES THAT ARE PRE-CONVERSATIONAL

Figure 22 Cover of the book, “Giggle Time”

- Sequencing communicative turns (do something, wait for response)
- Mutually satisfying interactions
- Beginning/middle/end
- Predictable sequence, cues, reinforcers

FOLLOW THE CHILD’S LEAD

- FOR YOUNGER/LOWER FUNCTIONING STUDENTS, ASK
  - What motivates this child?
  - What is the child attending to right now?
  - Where might you join him/her?

PERSPECTIVE TAKING

Help them develop a sense of an “OTHER” by…

- Using Follow-the-Child’s Lead strategies/Co-active movement
- Next step - turn taking - e.g., Social Lap Games where there is routine; OR play involving an object that allows adult to insert a “turn” (e.g. toy piano; pat mat; NOT V-Tech toys!)
  See Hagood article!!! Good ideas, expansions

OLDER, HIGHER FUNCTIONING

- Checklists (see Jed Baker books; Bolick’s Competence checklist in handouts)
- Michelle Garcia Winner’s interview
- Attwood’s Friendship Observation Schedule (www.tonyattwood.com/au)
- Michelle Garcia Winner -- Structured Interview
- ADOS
- Theory of Mind tasks, etc.
WHERE TO START WITH SOCIAL SKILLS...

- What is expected based on age, grade, developmental level (observe across settings)
- What are prior experiences?

EXAMPLE OF ASSESSMENT AND GOAL AND INTERVENTION

- Diane’s assessment of what Morgan’s peers/sister was doing
- Teaching language associated with activity
- Set-up (how to set games up)
- Turn-taking

Practice with adult, transition to peers

MORGAN

Waiting story  vhs/dvd 1, track 8

Work on specific social skills based on assessment

- What level of communicator/perspective taker do you have?
- What does child understand re: social rules, roles? Have to teach “hidden/unspoken curriculum” directly - simple exposure to peers isn’t enough, not learn from modeling.
- Begin with something short, structured, teacher directed, and success oriented (e.g., using child’s interests so long as it isn’t too intense). Keep in mind that a child cannot be pushed to acquire social skills.
- Need to have chance to learn social interactions and participate in variety of natural environments
- Need to address social cognitive deficits deliberately, with “understanding” embedded - go beyond rote/scripted skills (M. Garcia-Winner)

SUPPORT SOCIAL SKILLS DEVELOPMENT

- Teach coping strategies:
- Teach key phrases (e.g., “no big deal…” “not whether win or lose but how play the game”)
- Provide positive/corrective feedback
- Teach self-talk
- Provide social stories (see Morgan & Diane)
- Provide a “safe place”
- Teach relaxation
REPETITIVE RESTRICTED RANGE OF INTERESTS, REPETITIVE BEHAVIORS

UNUSUAL BEHAVIORS & INTERESTS

- Insistence on sameness, show resistance or strong reaction to interruption, distress over changes
- Restricted range of interests (e.g., preoccupation with one interest or object - line up toys; parts of objects); may be attached to inanimate object (e.g., piece of string, shoelace)

*Will come back to this one re: play…*

- Rigid adherence to nonfunctional routines or rituals, insistence on following routines (e.g., same route to store)
- Stereotypic/repetitive motor mannerisms (e.g., clapping, finger flicking, rocking, swaying, toe walking, spinning objects; unusual body postures)
- Is there a driven quality to it?

WHY DOES THIS HAPPEN? WHY DOES THE CHILD SEEM TO PERSEVERATE/GET STUCK? SOME REASONS INCLUDE…

- Child having difficulty processing more than one stimuli at a time, making sense/attributing meaning to the event or activity or material – something about it makes sense
- Child having difficulty shifting attention
- Child may view the ritual as soothing; may experience it as a pattern that “makes sense” when the rest of the world does not
- Doesn’t know what else to do (I NEVER ASSUME UNLESS I’VE TAUGHT THE SKILL)

Examples of insistence on sameness?

Figure 23 Young man sits cross-legged on the grass
NEVER ASSUME THAT THE CHILD KNOWS WHAT TO DO WITH HIS OR HER HANDS, HOW TO PLAY ALONE...LET ALONE WITH OTHERS...

LOOKS LIKE IT COULD BE FUNCTIONAL PAY

Figure 24-25 Toddler plays with dollhouse

With a child’s passions, intense interests...are there ways you’d use them? OR conditions under which you’d avoid using them?

YES, GOOD TO USE …

- If there is a comfort with them, a way to link them with other students such as Legos clubs, Anime clubs, etc. (so long as paired with social instruction such as turn taking, negotiation, etc.)
- To harness motivation for academic lessons – Use “special interests” as basis for lesson dev’t, teaching the 3R’s
e.g., human digestive system; selling popcorn, etc.

AVOID/THINK TWICE ABOUT USING THEM...

When the child has too strong an association, too many rituals around them e.g., Ricky and Thomas the Tank, Jihad and sound production, Ben and the knob puzzle

BEN AND THE KNOB PUZZLE…

DON’T WE WANT TO EXTINGUISH THE REPETITIVE BEHAVIORS?

- Keep in mind that the routines and self-stim behaviors are things that the child understands best & may serve as a “life-preserver” for the child. It is the child’s retreat to his comfort zone.
- The child’s reliance on such behaviors will tend to increase in times of stress and anxiety (e.g., transition, lack of clear expectation, challenges). Ask yourself “why is the child engaging in this now?”
- The child is looking for pattern in the environment and if it isn’t clear, isn’t there, isn’t understood, they’ll go back to their “own pattern.”
They may serve a regulatory function and we need to provide a range of activities and environmental supports to help the student regulate and learn to self-regulate and advocate…

Identify a time and place when the child can engage in his self-stimulatory behavior (see also Hagood’s article on expanding within social/communication context)

Look for ways to tighten up the structure, schedule, routine to decrease anxiety and increase non-verbal information, plan for changes in routine, etc.

Preview, pre-teach new situations (e.g., tasks, environments, activities)

Remember unstructured time is deadly for children on the spectrum

LET’S TALK ABOUT PLAY FOR A FEW MINUTES…

FOR THE CHILD WITH AUTISM…WORK IS PLAY, AND PLAY IS WORK!!!

Autism already features restricted interests, and that is for children with sight… Now add the restrictions imposed by a visual impairment…

Never assume that the child knows what to do with his or her hands, how to play alone…let alone with others…

GOALS AND IMPLICATIONS:

Current play behaviors/interests (Quill, Wolfberg, etc.)

Survey sensory interests/aversions

Assume will have some resistance to anything new

Pacing/facilitating/joining in

Ability to organize self, materials, play

Attention, regulation)

The issue of “new” (“transition” from familiar), choice, teaching, problem solving (e.g., possible glitches)

BEN AND POSITIONING

VHS/DVD-3 #7

TYPES OF PLAY

Solitary, parallel, cooperative

Active, motor involved (playground, bike riding)

Constructive

Arts and crafts

Games (gross motor, table; recreational, gym class)
TYPES OF PLAY (QUILL)
Easiest:
- Closed ended
- Utilizes limited toys and materials
- Involves one partner
- Each child has own set of toys and materials
- No sharing, turn-taking or waiting required
- No listening, no language required

TYPES OF PLAY (QUILL)
Most complex
- Open ended
- Unpredictable
- Utilizes multiple toys and materials
- Involves large group
- Requires sharing, turn-taking and waiting
- Language based

QUALITIES OF MATERIALS
- Interesting?
- Make sense in light of neurodevelopmental challenges and levels (e.g., weight, texture, stable, motor capabilities)
- Issue of “new” (“transition” from familiar)
SAMPLE ACTIVITIES

Figure 25 Position-board with a variety of objects on it.

- Fine motor, “constructive,” tactile
- Bright colors, interesting textures

MAGNEATOS

- Constructive
- Motor-friendly, stable
- Could do patterns

Figure 26 Young boy playing with Magneatos

- Where will leisure occur?
- How do I transition/get into the leisure area?
TRANSITION TO PLAY AREA

Figure 27 Calendar used to transition to next activity.

- What are my choices?
- Are they based on my interests?
- On a leisure assessment?

TRI-WALL CHOICE BOARD

Figure 28 Tri-wall choice board with object symbols.

OBJECT SYMBOL LEISURE CHOICE

Figure 29 Two object symbols reflecting a choice for recreation and leisure.
WHICH SONG DO I WANT TO LISTEN TO?

Figure 30 Three-choices of tapes with tactual symbols.

- What are my motor skills like?
- How motor friendly do things need to be?
- What is my visual function?
- Do I need materials organized for me?
- Do I need the activity structured/sequenced for me?

STRUCTURED ART/COGNITIVE ACTIVITY

Note…before you organize…see what child does spontaneously!

Figure 31 Mr. Potato Head organized using small containers on tray.

STRUCTURED ART/COGNITIVE ACTIVITY

[container organized, self-contained]

Figure 32 Cafeteria tray organizes activity of following a pattern to assemble plastic Easter egg.
MICHELLE’S PLAY YARD

Figure 33  Four images of a play yard that include: swing set, slide, a rope stacked to make a path to follow to playground and trampoline.

WHEN WILL IT END?

- Need to problem-solve - how will you let the child know how long play will last?
- What will you do about “unfinished projects, games, videos?”

Figure 34 Image of timers.

EXAMPLES...

- Timer
- Opening/closing ritual
- Transition object
- Schedule in advance, tape in advance
- Social story about the situation
- When is “later?”

OK, so we’ll use tactual information, and auditory, access the remaining senses . . . Considerations when developing and presenting activities
SUBSTITUTE TACTUAL OR AUDITORY INFORMATION?

- Limited at best:
- Not always able to translate information from visual to auditory, or to tactual
- Not always able to provide a gestalt (elephant/blind men scenario; issue of miniatures)
- Signing is fleeting as language

INTRODUCE CONCEPTS, ORGANIZATION SYSTEMATICALLY

- Function of the set-up: convey things non-verbally/provide tangible supports re: “task instructions, concepts, length of time working, etc.
- Visual clarity - Highlight relevant concept
- Exaggerate feature/contrast (e.g., huge vs. small; heavy vs. featherweight)
- Totally blind student: Examine how meaningful the activity is in light of vision e.g., sorting/matching socks to teach “thesame” - Functionally better for totally blind child to match them going into the laundry bin with sock lock; OK for low vision child

TASK SET-UP – CLEARLY ORGANIZED, BUT ALSO ORIENTING INDEPENDENT OF THE ACTIVITY

“Visual” organization - organize materials and individual work space
- Orientation to space - continuous contact with working surface as scan with the student; define work space (e.g., work tray)
- High contrast - easier to locate materials, but also want to exaggerate features want child to focus on; quiet surfaces
- Organization: separate into containers, stabilize materials, highlight left to right (tactual cue/anchor “top/left hand corner”)
- Special considerations: adequate spacing of materials to enable scanning (may be able to gradually decrease spacing)

ORIENTATION OF CHILD TO TASK, PRESENTATION OF/EXPERIENCE WITH THE MATERIALS

- How? Hand under hand, working from behind.
- Child resistant? Demo via arm to arm contact.
- “Tactually defensive?” Could be learning history was traumatic (e.g., hand over hand)
“CHALLENGING BEHAVIOR” CHALLENGING US

- Why Behavior?
- Low and Slow
- Rage Cycle/Tantrumming

REMEMBER THE ICEBERG...BEHAVIOR IS COMMUNICATION!

Have to examine what the child is trying to communicate, what functions the behavior is serving (e.g., escape, avoidance, attention-seeking, communicating physical state (discomfort/pain), confusion/misunderstanding, etc.)

CHALLENGING BEHAVIORS

- Multiply determined
- Perform FBA, examine vulnerabilities in light of autism spectrum disorder (e.g., sensory, communication, difficulties with transition, skill level/task demands mismatch)

HAVE A GOOD SENSE OF YOUR STUDENT’S PROFILE:

- How does s/he understand his/her world?
- What are his/her developmental skills and cognitive profile?
- What sensory sensitivities does s/he have?
- How does s/he deal with change?
- What health ‘risks’ does s/he have (e.g., allergies, GI symptoms, sleep disruptions, constipation, menses)?

FILTER BACK THROUGH THE FEATURES OF ASD

- Language/communication – concrete, literal; whatever way learned the word is what expect it to mean (so are there things that s/he may be struggling with?)
- Difficulties with change, preference for predictability/routines
- Executive functioning (e.g., difficulties sustaining attention, shifting attention; organizing and monitoring approach, etc.)

PREVENTION IS THE BEST STRATEGY...

- Provide the needed visual supports
- Schedule
- Social story
- Preview (e.g., via internet)
- Look at goodness of fit between skills and task
- Monitor sensory demands of the environment; the wellness/illness of the child (e.g., allergy, fatigue), other changes (e.g., time change)
- Anticipate potential breakdowns e.g., not being able to finish something, unified arts different from last week…

**UNDERSTANDING THE “NONCOMPLIANT CHILD...”**

- Curt - child with anophthalmia, SOD, ASD, velocardiofacial syndrome
- Setting: inclusion, PE class, 1:1
- Week 1: jump rope (plastic beaded), jumping over, did great
- Week 2: same activity - goes to look for rope - first one has broken bead, para-pro and he go to another basket - all have at least one broken bead - MELT DOWN!!!!
- So what do we do about it?
- Make him jump rope anyway? Make him stay in for recess?
- Make him write, “I will follow my teacher’s directions” 100 times?

**WHY DID CURT MELT DOWN?**

- Hypotheses:
  - Behavior problem - didn’t get his way, wanted what he wanted, wouldn’t listen to teacher saying “it’s OK, just one or two beads are broken, we can still use it”
  - OR…
  - Go back to the features of ASD:
    - Literal - unitary, egocentric “definition” of the word “jump rope”
    - Reliant on sameness - last week all of the jump ropes were intact
    - Difficulties shifting, taking teacher’s perspective & reassurance; only knows what his experience was last week – rigid interpretation

**FEATURES OF ASD - SAMENESS, DIFFICULTY WITH FLEXIBILITY, LITERAL/CONCRETE, ETC.**

- “Specials” are in the same location, with same teacher & kids, at the same time each day & week BUT WHAT YOU DO MAY CHANGE each week
- Tend to be less structured, can be somewhat noisier environments (may “pull” for certain behaviors – e.g., Curt may not sing in music because he is listening to others sing)
- May require some more flexibility in language or technique

**SO WHAT DO WE DO ABOUT IT?**

- Anticipate situations that may break down - look at the situation from the student’s perspective, with their vulnerabilities in mind
- Develop a plan:
  - Once in the situation - what do you need to do RIGHT NOW to keep the child safe?
- Does child need weekly preview?
Does child need direct instruction about:
  o Vocabulary, materials
  o Rules, roles
  o Being a good sport

DEVELOP A SOCIAL SCRIPT BASED ON WHAT YOU LEARN ABOUT CAUSES OF MELTDOWN:

“Things sometimes go crunch when kids step on them by mistake…we can still use the rope …etc.”
OR...
Based on the “what” they’re doing with the rope...

Figure 35 Little girl walks a balance beam
Figure 36 A jump rope.

Sometimes kids get to jump over things in gym. One day I got to jump over a rope. There are many different things that kids can jump over in gym. I am a very good jumper. Some days we might jump a rope, but other days we might jump over a balance beam, a hula hoop, or a thick rope. It can be a lot of fun to try to jump over many different things. I will try to jump over something new. My mom and teachers will be very proud of me for trying to jump over something new.

RESPECT THE FACT THAT …

- The child may not REALLY know what that word means unless
- That they are CONCRETE in how they interpret what we say to them - they don’t “read between the lines” (e.g., “hop to it”)
- Variability in skills (e.g., rote memory) can be vast
- They are NOT incidental learners
- They process at very different rates
CASE STUDIES
Sydnee
Katie

A FEW PEARLS

- I never assume that a child “knows something” unless I’ve taught it - pre-teach, reinforce
- Sequential learners
- Children with ASD package by context
- Be aware of your language - rate, volume, complexity and that of those around you
- Be aware of competing stimuli
- Less is more. Short and sweet, be concrete.
- Remember to pause, allow more processing time; don’t be quick to repeat question
- Just because he talks, does not mean he understands
- Remember to watch for any gesture, vocalization, etc. as attempts to communicate
- Provide tangible supports – physical layout, schedules, work systems, clearly tactually defined activities; task cards; also supports expressive communication (mental set associated with them)
- Use visual supports (print, Braille, picture) – write it down! Write it down, write it down! There is “POWER in print!”

STOP FOR A MOMENT AND TAKE A SLOW DEEP BREATH…

- Remind yourselves that you are part of a team…
- That you are not expected to remember all of this
- There will not be a test
- The field is VERY YOUNG
- And that if you have learned one new thing you’re doing very well…
MEET THE CHILD ON HIS/HER PLAYING FIELD

Figure 37 Children and adults play together in play area.

Figure 38 Older girl kneels to play hand-game with young boy.

Thank you for your time and attention!
SELECTED RESOURCES

RESOURCES FROM "BLINDNESS/NEUROLOGICALLY VULNERABLE" INCLUDING SEPTO-OPTIC DYSPLASIA, OPTIC NERVE HYPOPLASIA


RESOURCES FROM AUTISM/BLINDNESS


Hagood, L. (2008). Better Together: Building relationships with people who have visual impairment and Autism Spectrum Disorder. Austin, Tx.: Texas School for the Blind and Visually Impaired. [see also other web articles by Linda Hagood!]


OTHER REFERENCES:


INTERVENTION RELATED BOOKS:
Assessment and Intervention-related: (note: there are as many books on interventions as there are models of/approaches to intervention – these are a sampling)


Baker, J. (2003). Social Skills Training for Children and Adolescents with Asperger Syndrome and Social-Communications Problems. Arlington, TX: Future Horizons. (See also his Social Skills Picture books for young children through high school.)


AUTISM RELATED WEBSITES (THERE ARE 1000’S):

Very brief sample…

- Autism Speaks: www.autismspeaks.org
- Autism Research Institute: www.autism.com. Note: this site will soon "house" the Sensory Impairments and Autism Network
- First Signs: www.firstsigns.org
- Floortime: www.floortime.org
- “Oops, wrong planet...”: http://www.isn.net/~jypsy/autilink.htm
- TEACCH: http://www.teacch.com [overview, interventions, etc.] e.g., An Introduction to the Medical Aspects of Autism; Evaluation Guidelines When Considering Nontraditional Therapies in Autism; The Culture of Autism;

EDUCATIONAL APPROACHES; COMMUNICATION APPROACHES, ETC. ETC. ETC.

- TEAACH information on their training: http://www.med.unc.edu/cgi-bin/teacch/training.cgi (note, they have a 5-day training for vocational, residential staff)
- Lovaas Institute for Early Intervention: www.lovaas.com
- http://www.maapservices.org MAAP Services for Autism and Asperger Syndrome – nonprofit organization dedicated to providing information and advice to families of More advanced individuals with Autism, Asperger syndrome, and Pervasive developmental disorder (PDD).
- http://info.med.yale.edu/childstdy/autism/pddinfo.html Yale School of Medicine
SCERTS:  http://www.scerts.com

Relationship Development Intervention (RDI) http://www.rdiconnect.com

The Ziggurat Group  http://www.texasautism.com (materials, presentations, free forms to download)


SOD/ONH SPECIFIC SITES: (A SAMPLING)

http://www.magicfoundation.org/www

http://www.focusfamilies.org

SOME OF MY HANDOUTS AND WEB-BASED ARTICLES...


Social Skills- IEP Goals for Students with Visual Impairments and Asperger’s Syndrome: http://www.tsbvi.edu/Education/vmi/aspergers.htm


AUTISM AND VISUAL IMPAIRMENT:

http://www.focusfamilies.org/focus/newsletter/Focal_point_Fall.pdf [in newsletter]


Scottish Sensory Centre – includes papers from a conference on Visual Impairment & Autism held in 1996

http://www.ssc.mhie.ac.uk/docs/boyce.html

http://www.ssc.mhie.ac.uk/docs/jordan.html

http://www.ssc.mhie.ac.uk/docs/hcass.html

http://www.ssc.mhie.ac.uk/docs/ohare.html

Norwegian Project

http://www.novir.net/NOVIR/autisme/visual_impairment_autismrelated_project.htm
Other

- [http://www.tiresias.org/research/publications/pring.htm](http://www.tiresias.org/research/publications/pring.htm)
- Blind/savant: [http://www.wisconsinmedicalsociety.org/savant/default.cfm](http://www.wisconsinmedicalsociety.org/savant/default.cfm)
- [http://www.focusfamilies.org/focus/](http://www.focusfamilies.org/focus/)
- [http://www.focusfamilies.org/focus/docs/blindnessandautism.pdf](http://www.focusfamilies.org/focus/docs/blindnessandautism.pdf)
- [http://www.focusfamilies.org/focus/ONHbooklet/ONHbooklet.pdf](http://www.focusfamilies.org/focus/ONHbooklet/ONHbooklet.pdf)
- [http://www.astridvanwoerkom.com/](http://www.astridvanwoerkom.com/) website of recently diagnosed adult
- [http://www.e-advisor.us](http://www.e-advisor.us) vision simulations
- [www.ropard.org](http://www.ropard.org) Information on prematurity
- [www.blindbabies.org/factsheet_ona.htm](http://www.blindbabies.org/factsheet_ona.htm) - information on optic nerve hypoplasia
- [www.tsbvi.edu](http://www.tsbvi.edu) fabulous vision related website
- [http://www.cdc.gov/ncbddd/autism/index.html](http://www.cdc.gov/ncbddd/autism/index.html) – includes articles, videos, information, prevalence data, podcasts, etc.

LISTSERVS AND BULLETIN BOARDS AND EYE CONDITION SPECIFIC GROUPS (where issue of autism and blindness has been discussed)

- Early Intervention in Visually Impaired: [EARLY_INTERVENTIONVI@listserv.arizona.edu](mailto:EARLY_INTERVENTIONVI@listserv.arizona.edu)
- Albinism Listserv: [albinism_development@yahoogroups.com](mailto:albinism_development@yahoogroups.com)
- Lebers Congenital Amaurosis website and listserv [note, surf the web for new website info.]
- Septo-optic Dysplasia: [http://www.focusfamilies.org/focus/](http://www.focusfamilies.org/focus/)

1. The Magic Foundation: [www.magicfoundation.org](http://www.magicfoundation.org) Foundation to provide support for families of children afflicted with various chronic and/or critical disorders, syndromes, diseases that affect child’s growth (including SOD/ONH).

2. WAGR: [http://www.wagr.org](http://www.wagr.org)
RESOURCES FROM THE DEAF-BLIND LITERATURE


- **Websites**
  - D/B-Link: http://www.tr.wou.edu/dblink/index2.htm
  - Extensive information and product line with much applicable for pre-linguistic students.

MAKING MATERIALS (E.G., FOR COMMUNICATION SYSTEMS, ADAPTIVE EQUIPMENT)

- **Cardboard Construction Books:**
  - Campbell, Molly & Truesdell, Alex (2000). *Creative Constructions - Technologies that make adaptive design accessible, affordable, inclusive and fun*. To order: Creative Constructions, 659 Green Street, Cambridge, MA 02139. Email: Mollycampbell@comcast.net
  - Triwall tools and books on cardboard carpentry also available from:
    - 68A Broadway, PO Box 436
    - Arlington, MA 02174
  - Note: When trying to locate sources of Tri-wall ask cardboard manufacturers about “industrial strength/grade corrugated cardboard.” Look in the Yellow Pages under “cardboard” or “packaging” for a manufacturer in your area. Companies often will donate their “scrap” [which are more than adequate for your purposes].

- **Communication strips/Velcro-able fabrics for boards/books:**
  - Tempo loop type fabric available from: Lockfast, 10904 Deerfield Road, Cincinnati, Ohio 45242 Ask for educators/seconds discount.

- **Pre-made Velcro-able books available from:** http://www.augresources.com/augresvol8.pdf

- **http://www.creativecommunicating.com/velcro.html** -- suggestions for variety of things to do to encourage communication, literacy, etc.
GETTING ADAPTIVE MATERIALS MADE
Contact: Alex Truesdell  Adaptive Design Association, Inc.
www.adaptivedesign.org

EQUIPMENT:
You set the red disc counterclockwise to the desired time interval. The disc diminishes as time elapses until no red is visible on the timer face.

SOME RESOURCES YOU MIGHT WANT TO CONSIDER INCLUDE:

- Calendars for Students with Multiple Impairments Including Deafblindness by Robbie Blaha (book), http://www.tsbvi.edu/publications/calendar.htm
- Let me check my calendar. Robbie Blaha  Winter 1997 See/Hear (available on www.tsbvi.edu)
- Conversations without Language: Building Quality Interactions with Children Who are Deaf-Blind by Linda Hagood. See/Hear www.tsbvi.edu
- Beginning to Use an Object Calendar by Stacy Shafer (article), http://www.tsbvi.edu/Education/early-childhood/object-calendar.htm
- Routines by Millie Smith  www.tsbvi.edu
- What A Concept! by Jim Durkel (newsletter article), http://www.tsbvi.edu/Outreach/seehear/spring00/concept.htm
- Language Assessment & Intervention With Children Who Have Visual Impairments by Maria Munoz (booklet), http://www.tsbvi.edu/publications/la.htm
- Information by Terese Pawletko (articles, etc.)--just do a search on TSBVI website: www.tsbvi.edu
- Information by Marnee Loftin (articles, etc.)--just do a search on TSBVI website: www.tsbvi.edu
- Non-Verbal Communication: Cues, Signals, and Symbols by Jim Durkel (article), http://www.tsbvi.edu/Education/vmi/nonverbal.htm
PLEASE HELP: OPTIC NERVE HYPOPLASIA DISEASE DISTRIBUTION SURVEY

http://www.thevisioncenteratchla.org/site

Drs. Mark Borchert, M.D. and Pamela Garcia-Filion, M.P.H.. are conducting a survey that needs your help. It is available on the link above (or by doing a search on Optic Nerve Hypoplasia Disease Distribution Survey.

Purpose
The survey is being used to gather information on how cases of optic nerve hypoplasia (ONH) are spread across the United States and to determine if there are unique distributions of this disease. Participation is available to families with a child diagnosed with ONH (or SOD) and is completely voluntary. This survey does not require that you identify yourself.

If you have any questions regarding this survey, you can contact us at (323) 361-2267 during the hours of 8 A.M. and 4 P.M. Monday through Friday. This study is approved by the Committee on Clinical Investigations - (323) 361-2265.
This project is supported by the U.S. Department of Education, Office of Special Education Programs (OSEP). Opinions expressed herein are those of the authors and do not necessarily represent the position of the U.S. Department of Education.