Young Children with Blindness/Visual Impairment and Additional Disabilities: Moving with Meaning

Presented by,
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Look for O&M Clues....
Wanda Jean is a 4 year-old with places to go and people to see! She uses an adapted mobility device to move within her classroom, school building, and the community with her family. She recognizes some letters and know that W is the first letter of her name. She likes the letter W so much that her parents suggested she name her new pet bunny Won-derful Wabbit and helped her make a sign with two brailled Ws on his cage. Her parents have read to her since birth and one of her favorite things do is to listen to stories that go along with the props in each story box at home and at school.
All three of the children in Wanda Jean’s family have two daily chores on list posted on the family’s refrigerator. Glued next to Wanda Jean’s braille name are two alfalfa pellets to remind her that it is her job after dinner to go to the pantry where the bunny’s food is stored on a lower shelf, put two scoops of the pellets into a plastic bucket, and walk to the nearby sunroom to fill Wonderful Wabbit’s bowl of food. This is a new chore and Wanda Jean’s older sister often helps her with each of the steps, but Wanda Jean takes great delight in feeling her rabbit eat his pellets as they fall from her hand into the bowl.

Simple Truths
- Children with BVI and additional developmental disabilities (ADD) are more like children without disabilities than they are different.
- Fundamental to all children: social emotional support, meaningful relationships, opportunities to communicate preferences / needs / choices, and ideas; opportunities to be physically active, and ongoing occasions for developmentally appropriate / age respectful experiences.

What Do We Need to Know?
- O&M Fundamentals
- Impact of VI on Development
- Impact of Other Disabilities
- Developmentally Appropriate Practices
- Child Specific Abilities and Interests
- Routines / Context

ORIENTATION AND MOBILITY FUNDAMENTALS

Definition: ORIENTATION - Orientation can be defined as “knowing oneself as a separate being, where one is in space, where one wants to move in space, and how to get to that place.” It is the “cognitive” component to travel. For young children, it means using their senses to learn (map) their bodies, immediate and distance spaces, and establishing object permanence, causality, means end, and increasing memory for locations. (Anthony, 1993, p. 116)

Definition: MOBILITY - “Mobility refers to motor development, including the normal integration of reflexes, acquisition of motor milestones, refinement of quality-of-
movement skills, and purposeful, self-initiated movement.” For young children it is involves master of volitional movement with increasing intent for mobility. (Anthony et al., 2002, p.328).

**Stages of Motor Development**

Birth to 3 months: Prone, lifts head
2 months to 4 months: Prone, lifts chest with arm support
2 ½ months to 4 ½ months: Rolls over
4 ½ months to 7 ½ months: Sits without support
5 months to 10 months: Stands with support
6 months to 10 months: Pulls self to stand
7 ½ months to 12 ½ months: Walks holding onto furniture
10 months to 12 months: Crawls
10 months to 14 months: Stands alone well
11 months to 14 ½ months: Walks alone well

**Components of Early O&M** - Developmental O&M programs for very young children should include the following components: Sensory skill development, concept development, and motor development (including purposeful and self-initiated movement). Additional components for preschoolers include environment and community awareness and formal orientation and mobility skills.

**Impact of BVI on Development - What Does Vision Provide?** Information – Nonverbal Communication / Social Connection / Near and Far / Detail (Part) and Global (Whole) / Abstract / Incidental / Imitation / Security / Danger / Travel Routes / Recreation

**Early Onset VIB: O&M Impact**
- Developmentally Appropriate Localization
- Dev Appropriate Cognitive Connection for Movement
- Impact of Incidental Learning
- Hypotonia

**Sequence of Auditory Localization:** We need to be aware of where we present sound sources. (1) sounds presented directly at ear level; (2) sounds presented at ear level and downward; (3) sounds presented at ear level and upward; (4) sounds presented directly upward, and (5) sounds presented in front of child’s body and at almost any other angle

**Object Permanence:** A huge marker for purposeful movement… the child remembers where people / items are located that are not within view. It is a anchor for memory across locations and time.

**The Eyes Usually Lead the Hand**
Visual Tracking/ Visually directed reach/ Visually directed grasp = typical precursors to demonstrate continuum of OP with sighted infants

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**Confounding Factors:** Sound is not a substitute for sight in the first many months. Delays in searching for a dropped object. Poor understanding of spatial environment. The Fairy Godmother Provides (though in a different location than the dropped object)

**Reach to Sound Cues Alone:** Conceptual challenge first noted by Fraiberg. One study done in 2011 with 37 subjects (13 with ADD). Subjects who were blind – 12 months; other studies found that blind babies reached for unknown sounding objects by 11 months. Subjects with ADD – 36 months

**Object Permanence Strategies:** Meaningful tactile experiences. To increase the meaningfulness of sound: (a) Sound in space must be continuous; (b) the child has already achieved the skill of recognizing the sound with the presented object (sound/object association; (c) can determine the source of its direction when the sound ceases. Sound paired with tactile exploration – then sound can serve as an invitation to move to distant space

**DEVELOPMENTAL IMPACT OF OTHER DISABILITIES**

**Our Population:** Pediatric blindness/visual impairment is a low incidence disability. Low incidence with great diversity and complexity. Within the population, at least 60% have additional disabilities.

**Leading U.S. Causes of Pediatric Blindness/Visual Impairment**
1) Cortical Visual Impairment (Cvi)
2) Retinopathy Of Prematurity (ROP)
3) Optic Nerve Hypoplasia (ONH)
4) Retinal Diseases (Albinism, Lebers)

**Cortical /Cerebral Visual Impairment** - Leading cause of pediatric visual impairment. Affects how a child responds to visual information. Of the three top causes of pediatric BVI, it is often the latest to be diagnosed. (7.6 months – 2013). The cause onto itself means neurological damage. Concomitant diagnoses may include seizures, cerebral palsy, intellectual disability, and health concerns.

**Retinopathy of Prematurity** - First or second leading cause of pediatric ocular blindness/visual impairment. Often an early diagnosis 3.4 months (2013). Prevalence has decreased, but AD has increased. Often the most smallest and most compromised of premature infants. > 1,000 grams (2.2 lbs) = < risk for visual challenges

**Retinopathy of Prematurity** - Risk factor is intracranial hemorrhage – which can lead to neurological compromise (CVI). Concomitant disabilities may include: seizures, cerebral palsy, other health impairments, and intellectual disabilities. Hearing loss may also be a concern – especially with the administration of ototoxic drugs. (15 out of 100)
**Optic Nerve Hypoplasia** - First or second leading cause of ocular visual impairment - probably number one. Mean age of identification in one database study – 4.2 months of age. May occur in isolation or with other functional and anatomic CNS anomalies, including growth hormone deficiency.

**Optic Nerve Hypoplasia: A Spectrum Condition**
- Varying results of visual impairment
- Abnormal rest activity / sleep deficits
- High thirst / poor appetite / later risk for obesity
- Gastrointestinal challenges / Poor temperature regulation
- Cortisol problems – energy, reaction to stress, maintains blood sugar and blood pressure
- General developmental delay -brain malformations
- Cognitive impairment more noted with hypothyroidism
- ASD behaviors noted – rigidity, dependence on routines, perservativeness, auditory / tactile defensiveness

**Additional Diagnoses with BVI and ADD**
- S(TO)RCH / ZIKA Prenatal Viral Infections / Postnatal Infections
- Exposure to Toxins such as alcohol, prescription and illegal drugs
- Syndromes - involve a constellation of conditions

**Autism Spectrum Disorder**: Developmental disability with challenges affecting: verbal / non-verbal social communication skills, and social interaction skills. Other characteristics often associated with ASD:
- repetitive activities / stereotyped movements
- resistance to environmental / daily routine changes
- unusual responses to sensory experiences.

**Developmental Milestones (months)**

- **Reaches/Touches Object (Normal)**
  - 5.4 Months / (VI Only) 8.1 Months / (VI/ASD) 10.6 Months

- **Sits Alone (Normal)**
  - 6.6 Months / (VI Only) 9.2 Months / (VI/ASD) 11.9 Months

- **Crawls Three Feet (Normal)**
  - 9 Months / (VI Only) 11.4 Months / (VI/ASD) 18.3 Months

- **Plays Interactive Game (Normal)**
  - 9.7 Months / (VI Only) 9.3 Months / (VI/ASD) 13.1 Months

- **Walks without Support (Normal)**
  - 13 Months / (VI Only) 19 Months / (VI/ASD) 26.6 Months

- **Follows New Direction (Normal)**
  - 20.9 Months / (VI Only) 19.3 Months / (VI/ASD) 25 Months

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Deaf-Blindness
- **Hearing Impairment, Including Deafness:** challenges with detection / interpretation of voice and/or environmental sounds; understanding verbal communication –need for sign language
- **Deaf-Blind:** challenges to communication and concept development; vestibular concerns

Deaf-Blindness: O&M Needs
- Attention to communication methods. Need to understand both impact and methodology for meaningful receptive / expressive communication.
- Adaptations to travel techniques to accommodate hearing loss. Need to address possible balance issues, use of tactile cue, longer cane, preference for constant contact)
- Consideration of the child’s conceptual understanding of travel environments. Need to be deliberate in providing information (in context) to the child about his or her environment.

**Intellectual Disability:** Challenges to: concept development /abstract concepts / concept and skill generalization / memory recall / problem solving / gap skills / adaptive skills

**Intellectual Disability Strategies:** Time Considerations / Task Analysis / Sequenced Instruction / Prompting / Meaningful repetition

**Orthopedic Impairment** - Challenges to: strength, ambulation, coordination, quality of movement Symptoms may include fluctuation or constant:* Joint stiffness / Pain / Restricted movement * Temperature, over exercise, fatigue

**Orthopedic Impairment:** Neurological conditions possibly affecting bones, joints, muscles, lungs, heart, digestive system, and even skin. It is essential to understand a child’s medical conditions and its implications for O&M. Effects may be numbness, fatigue, weakness, asymmetry, poor balance, and lack of coordination.

Hypertonia Symptoms: Stiff limbs, high muscle tone, difficulty moving, muscle spasms
Hypotonia Symptoms: “floppy” limbs, low muscle tone, difficulty standing, instability

**Cerebral Palsy** - Defined as the loss or impairment of motor function caused by brain damage. Every case is unique to the individual. Incurable, but not progressive Affects: Body movement Muscle control Muscle coordination Muscle tone Reflexes Posture and balance Fine motor skills Gross motor skills Oral motor functioning Vision skills

**Types of Cerebral Palsy:** Monoplegia: Affects one limb, usually and arm / Hemiplegia: Affects one side of the body; leg, trunk and face / Diplegia: Affects either both arms or both legs / Quadriplegia: Affects all four limbs of the body
**Conditions of Cerebral Palsy:** Spastic: tense, contracted muscles (most common type of CP) / Ataxic: poor sense of balance, often causing falls and stumbles / Athetoid: constant, uncontrolled motion of limbs, head, and eyes / Rigidity: tight muscles that resist effort to make them move / Tremor: uncontrollable shaking, interfering with coordination

**Possible Sensory Effects of Cerebral Palsy**
- Loss of tactile / proprioceptive sensation / touch awareness / discrimination / temperature awareness / pain awareness / awareness/ identification of objects in hand
- Cortical / Cerebral Visual Impairment / Strabismus / Amblyopia / Visual field Loss

**Orthopedic Impairment—O&M Techniques:** PT and OT consultation / built up cane grip / lighter cane / two handed AMD / AMD with weight/ cold weather protection / shorter lessons / breaks

**Other Health Impairment:** Challenge to strength / vitality (endurance) / alertness
Effects can include: Poor circulation / Poor respiration / shortness of breath / Fatigue / Reduced Stamina or Endurance / Sensitivity to temperature conditions

**Epilepsy:** There are different types of seizures, as such effects are different. In general, the child will have affected attention and processing. Will experience missed information and fatigue.

**Anticonvulsants and Side Effects**
- **Phenobarbital:** photophobia, constriction /convergence problems
- **Dilantin:** convergence problems, focus problems, esotropia
- **Clonopin:** abnormal eye movement, diplopia, nystagmus, glassy eyed appearance
- **Tegretol:** photosensitivity, blurred vision, visual hallucinations, oculomotor disturbances, nystagmus, conjunctivitis

**SED / SLI**
- **Serious Emotional Disability:** Challenges to mental health, ability to build or maintain interpersonal relationships; general and pervasive mood of unhappiness or depression; in appropriate types of behavior under normal circumstances
- **Speech or Language Impairment:** challenges with receptive / expressive communication; difficulty with intelligibility; auditory processing / perception

**Use of Calendar Box / Schedule:** Organizes the events of the day / Symbols used are meaningful to the child because they are customized to the child’s sensory / conceptual abilities.

**Traumatic Brain Injury:** challenges with cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech.
**Multiple Disability:** two or more areas of significant impairment creating a unique condition that is evidenced through a multiplicity of severe educational needs

**DEVELOPMENTALLY APPROPRIATE PRACTICES**

**Family-Centered Practices:** In order for early intervention to be as effective as possible, families must be involved. Families contribute unique information about their children’s development, preferences, and needs. Developmentally appropriate and family-centered practices embrace diversity, use a transdisciplinary model of intervention, and value natural learning opportunities. (Hatton, McWilliam, & Winton, 2003)

**Natural Learning Opportunities:** Orientation and mobility intervention for young children should be embedded into the family’s daily routines and activities. Family routines are valuable natural learning opportunities that promote the attainment of functional outcomes. Functional outcomes (desired goals based on family priorities) enhance children’s development and improve the quality of life for children and families. (Hatton et al., 2003)

**Developmental O&M:** A developmental approach to O&M is based on the premise that the foundation for O&M skills is built during infancy and early childhood. O&M concepts and skills are developed in the child’s home environment and community. COMSs need a solid understanding of early childhood development. (Anthony et al., 2002)

**Babies Are Not Little Adults:** Infancy is a time of constant change / Infancy is a unique period of its own. Early learning is based on senses / actions (observing, touching, doing). The preoperational years move the child toward more abstract thinking, including more deliberate trial and error.

**Young Children Learn Best:** Though hands-on opportunities / Self-discovery / Play experiences. / Practice / Meaningful repetition. When others model higher level concepts and skills with social support from others.

**Getting Focused on our Role of Supporting learning** - Creating learning environments / providing opportunities for learning. Recognizing individual differences and experience. Guiding and not teaching.

**CHILD SPECIFIC ABILITIES AND INTERESTS**

**Interview Strategies:** Sensitive information gained during the interview should remain confidential. Exchanges should be conversational in nature. Open-ended questions, such as asking caregivers to describe a typical day for their child, may elicit more detailed information. What is the best part of the day, what is the most difficult part of the day? Family members must have opportunities to ask questions, not just respond to
questions. Interviews should be conducted in a culturally-sensitive manner. Also, be thinking of individual learning style.

Example: Parent Assessment of Needs (PAN)
- The PAN provides a framework for assessment of children’s development and families’ priorities and concerns.
- The PAN includes sections on home routines (e.g., meal time, dressing, bath time, toileting, bedtime), family activities, community activities, and communication.
- The PAN can help the team to identify and select appropriate assessment measures.
- The PAN can be ordered through the American Printing House for the Blind. *Chen, Calvello, and Friedman, 2015*

First Step: Access - sensory / physical / cognitive / communicative

We need to know:
- Availability for learning (states)
- Sensory abilities, preferences, and needs (1st)
- Range of motion, volitional movement, and endurance, and needs
- Curiosity, orienting, anticipation, memory, concepts, and needs
- Level of communicative intent, mode(s), receptive, and expressive abilities, and needs

Descriptions of the States of Arousal:
State 1 – **Deep sleep**, eyes closed, regular aspiration, no movements
State 2 – **Intermediate sleep**, eyes closed, few minor facial, body and/or mouth movements, and respiration is periodic, alternate periods of shallow and deep breathing
State 3- **Active sleep**, eyes closed, irregular respiration, some gross motor activity (stirring, writhing, grimacing, mouthing, or other facial expression).
State 4- **Drowsiness**, eyes open and closed intermittently, fluttering eyelids, eyes having glassy appearance, frequent relaxation followed by sudden jerks.
State 5- **Quiet awake**, relatively inactive, eyes open and appear bright and shiny, respiration regular.
State 6- **Active awake**, eyes open, diffuse motor activity of limbs or whole body, vocalizations of a content nature.
State 7 - **Fussy awake**, eyes open, irregular respirations, diffuse motor activity, vocalizations of fussy, cranky variety.
State 8- **Mild agitation**, eyes open, diffuse motor activity, moderate crying, tears may or may not be present.
State 9- **Marked uncontrollable agitation**, screaming, eyes open or closed, tears may or may not be present.

Examples of comments: be sure to record significant events or intervention which cause a change in the states: *medication (new, changes); *tried intervention (e.g., communication activity); *seizure; *changed positioning; *had tantrum because …
Learning to Read Signals - The learner’s body communicates: understimulation / overstimulation. Homeostases: The ability or tendency of an organism or cell to maintain internal equilibrium by adjusting its physiological processes. We want to introduce enough information to alert the interest of the learner, but not so much that we over-stimulate him or her.

Learning Style Assessment: This includes the following: interests, motivation, preferences, dislikes, processing time, self-regulation, exploratory strategies, and attention to activities. The team can learn about children’s learning styles from observations and interviews. Observe the child in a variety of different places, times, activities and with different caregivers. This is a good place to test your hypotheses based on (a) diagnosis of BVI and (b) other diagnoses.

Likes and Dislikes Form: This tool was developed by Kathee Keller Scoggin. It should be filled out with the input of the people who know the child best – parents and early intervention / school personnel. The goal is to record the child’s preferences and aversions for people, foods, movement, etc. As the tool is populated, it will provide insights into the child’s sensory abilities and preferences. This information can be used to capture motivators for communication, book topics, and movement.

Appetite/Aversion Form: Fill one sheet out for each child. Over a period of time through listening to stories from others and through observation of the child, simply list things the child likes and doesn’t like. We all enjoy things that we are good at and that we understand. The child’s “Likes” will be his areas of strength and indicates sensory channels that are working. His “Dislikes” will be areas of weakness and indicates sensory channels that may not be working efficiently. The information gathered on this form will give you underlying themes that you can use for adaptations, teaching strategies, topics for communication, and activities. Summary Information: (a) What sensory channels is the child using the most? Vestibular, kinesthetic; (b) What are possible topics for communication? Things that vibrate, food, rocking; (c) What are some activities that the child might find aversive? Fire drills, large group activities in noisy places, people touching her face. and (d) What other adaptations or strategies are suggested by the above information? Include movement or vibration during activities

Assess Child Preferences
- What motivates the child? This becomes the topic for the child’s interactions.
- What kinds of toys or objects does the child enjoy?
- How kind of “games” does the child enjoy?
- Does the child have a favorite toy or game?
- Are there toys or games the child does not enjoy?
- What does the child show the greatest reaction to?
- Is there a clear difference in the child’s behavior when you pause the interaction? Does it suggest like or dislike of that interaction?
**Sensory Stimulation Behavior:** Repetitive, Stereotypical, and functionally autonomous

**Self Injurious Behavior:** Injurious – persistent self-inflicted

The Big Question is WHY? – using EMC2, MAS; The next question is NOW WHAT? Research notes - do not provide passive stimulation to decrease the behavior, but provide the child with active control. And for the child to more appropriately communicate the intended message (what is accomplished by the SSB or SIB). Can use an inventory of self-behaviors.

**O&M Assessment Tools**
- *Individual Sensory Learning Profile Interview* or ISLPI (Anthony, 2003a)
- *Oregon Project for BVI Preschool Children* or OR Project (Anderson, Boigon, & Davis, 1991)
- *O&M Assessment: Early Years of Birth Through Three Years* (Anthony, 2004b)
- *New Mexico School for the VI – O&M*
- *TAPS*
- *Inventory of Purposeful Movement* (Anthony, 2004a)
- *Volitional Movements*

**DAILY ROUTINES AND ENVIRONMENTAL CONTEXT**

**Routines / Activity Based**
- Daily routines provide meaningful contexts because they are predictable, functional, and occur numerous times throughout the day.
- When the child is familiar with the routine, the intervention / instruction can focus on scaffolding new and more complex learning.
- Interventions can be integrated into play, caregiving, and other activity-based routines.

**Questions to Consider**
- With infants and toddlers, the focus is on the routine of the family. Not the routine suggested by the professional.
- Is the activity enjoyable to the child? Does it engage the child based on identified interests?

**Examples of Routines / Activity Based:** Caregiving Routines - Diaper Changing / Toileting, Washing Hands / Bath Time
- Transition Routines: Select a book for reading aloud time, Seek or Put away Toys, Move from one preschool center to the next, Coming into the building / leaving the building / Move from one preschool room to the next /

**Key Components; Self Initiated Movement / Purposeful Movement / Movement for Meaning / Variety**

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Self-Initiation / Purposeful: “One way to describe the essence of active movement is when children are free to move when and where they want. The can be done when children monitor their own movement. Monitoring their own movement occurs when children decide when and where to move and when to start and stop their own movement. When the purposeful thought for movement comes from the child, this is one way to describe “active movement and when we do the movement for children by manipulating their bodies, this is one way to describe passive movement. Blind children are vulnerable to experience more than their share of passive. For example, when blind children are manipulated manually by adults, what they experience is passive movement and not their own active movement. This is not the way to learn about the world (Cutter, 2007 p. 19)

Practice Examples