

Bridging Early Identification of Deaf-Blindness to Effective Intervention

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- National Deaf-Blind Child Count (Census)

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Moving from Early Identification to Early Intervention with Children with Deaf-Blindness

Susan M. Bashinski

March 3, 2022

**For the Montana Deaf-Blind Project
Rural Institute, University of Montana**

A Note re: the February 3rd Webinar

- One topic covered in the 02/03 early identification webinar was **newborn hearing screenings**
- In my haste to answer a question re: the **relative benefits and accuracy of the two types of tests** used in these screenings, I feel I might not have provided a sufficient amount of info.
- I have created a **detailed, supplementary handout** re: the characteristics and benefits of the AABR and OAE screening procedures
- Folks from the MT DB Project have **posted this info alongside other handouts from the 02/03 session**

Action Plan

Please record your thoughts, regarding how you *might* incorporate information from today's webinar in your family life / daily practice.

Thank you!

Launch poll #1 – Who is here today?

Agenda

- Criticality of early identification—and rationale
- Legal requirements for intervention with young children suspected of experiencing dual sensory loss
- Recommended practices, *and priorities*, for each of three primary environments in which early intervention with a young child with DB might occur
- Recommended practices for each environment will be organized according to a four category approach—which *almost adheres to an easy mnemonic!*
- The over-arching importance of routines

Criticality of Early Intervention

- Experiences “during the earliest years of life have a profound influence on a child's ability to learn, move, and interact with others”
- This is especially true for young children who experience deaf-blindness because “physical, communication, cognitive, social, and emotional developmental domains are deeply intertwined” (NCDB, 2019)
- Deaf-blindness is especially impactful because of the ways in which these limit accessibility to the environment **and access is foundational to learning!**

Criticality of Early Intervention

- In a young child with deaf-blindness, two of her three distance senses (i.e., vision and hearing) are impacted. This means the child must use her contact senses (e.g., taste and touch) to learn about the world!
- Early identification is positively correlated with a reduction in the negative impacts of combined sensory loss on future development, because when combined with early intervention, gathering environmental information can be enhanced.
- **Learning is all about information gathering!**

Legal Requirements

- **Children birth to age 3** | Very young children (birth up to age 3) who are deaf-blind are typically eligible for **early intervention services** under Part C of the Infants and Toddlers with Disabilities program of IDEA
- When children with DB reach the age of 3 years, they transition into **special education services** under Part B of IDEA. Special education services must be provided free-of-charge through the public school system—regardless of whether the child attends an on-site program or not.

Early Intervention with a Child Who Experiences Deaf-Blindness

- Children with deaf-blindness are identified at many, many different ages
- Because this session is focused on early intervention, we shall examine three primary environments:
 - Neonatal intensive care unit (NICU)
 - In-home interventions
 - On-site, preschool environments

Early Intervention with a Child Who Experiences Deaf-Blindness

- Regarding each of these three environments young children with DB often encounter, we'll examine elements of intervention in four categories:
 - **Touch**
 - **Talk**
 - **Transport (i.e., "Movement")**
 - **Tangibles**

Early Intervention with a Child Who Experiences Deaf-Blindness

- Involves partnering with that child
and
- **INVITING THE CHILD “OUT,”** (of his / her own body) to join you in the world, to interact with the environment, and to build levels of connections
- Regardless of the environment in which early interactions occur, it is critical to remember this reality!

NICU Interventions

Touch, Talk, Transport, Tangibles

Priorities for Intervention in the NICU

- Above all else, keeping the baby alive! Medical concerns **must** take priority over developmental ones
- Assisting the baby to gain weight
- Supporting the baby's family to deal with:
 - emotion and information overload
 - difficulty bonding with their baby
 - management of employment and other family responsibilities
- When considering developmental milestones, **calculate the true birth age, not "day born" in the case of a little baby born very prematurely**

Touch

(NICU Intervention)

- Babies born early, especially those born “extremely preterm” (i.e., less than 28 weeks) are at higher risk for sensory loss—and *the auditory and visual sensory systems are the last to fully mature*
- The tactile system is typically the first sensory system to mature...**so we need to take advantage of touching!**
- The tactile system interacts with—and impacts—every other sensory system!
- REMEMBER: Some premature babies will demonstrate tactile defensiveness

Touch (NICU Intervention)

- Even if the baby is in an incubator, touch as often as possible—but be sensitive to the baby's response (and provide frequent “breaks”)
- Many very premature babies will have extremely delicate skin—touch gently!



Touch

(NICU Intervention)

- IF POSSIBLE...(and it *might not be possible*)... initiate the use of **touch cues** with the baby to identify key persons in her life

EXAMPLE:

KISSES – Mom – on right cheek

Daddy – tip of nose

Brother – back of hand

- This intervention strategy is called a **personal identifier**.

Talk

(NICU Intervention)

- Primarily, this refers to family and professionals *talking to the baby*, but professionals need to take care re: how they talk with the family, too...
- Babies who require NICU care are at a greater risk for hearing loss than babies who do not—but even so, hearing abilities are often uncertain *and / or inconsistent* for such babies. **Therefore, it is very important that family members talk to the baby!**

Talk

(NICU Intervention)

- Some key guidelines to keep in mind:
 - Especially try to talk with the baby when she *appears* to be in a calm behavioral state
 - Refrain from relying on talking to interact with the baby when she is particularly agitated; attempt to interact with **touch** instead (in this circumstance)
 - Avoid “verbal diarrhea;” use telegraphic language
 - Make an effort to use some key words consistently
 - Consider including melodic talk and / or music
 - Read very simple books to the baby

Transport (i.e., “Movement”)

(NICU Intervention)

- It needs to be expected that many times, babies in a NICU may not be removed from an incubator in order to participate in movement with a parent.
- IF the NICU staff approves, a parent might gain permission to gently move the incubator, itself, back and forth to create some movement for the baby
- Movement should always be paired with talk!

Transport (i.e., “Movement”)

(NICU Intervention)



- If the baby can be removed from the incubator, encourage the family to engage in gentle, rhythmic movements *while touching the baby* (e.g., rocking, swaying side to side, patting baby's bottom, cuddling)
- When picking baby up / putting baby down, do this in the same manner—and label the movement!

Tangibles

(NICU Intervention)

- It would not be unusual for a hospital to not allow tangibles to be introduced in the NICU environment or a baby's incubator
- In such instances, the family might inquire whether or not they might use a tangible (see next slide) during the time they are allowed to hold the infant

26 Tangibles

(NICU Intervention)

Provided the hospital will allow, parents might place:

- a small garment / fabric that has Mom's smell
- a soft, cuddle toy that might one day be used for comfort

in the incubator with the baby



Partner's Role

Deaf-blindness requires a learner's partners to take time to...

- plan how a learner will **RECEIVE** information in every activity
- plan what a learner will **DO** in every activity, to communicate **UNDERSTANDING**
- consider the **IMMEDIATE** physical, visual, and auditory **ENVIRONMENTAL CONTEXTS** of every activity in the assessment

Characteristics Relevant to Learning

It is important to remember that learners who have DB often:

- lack the ability to anticipate or predict events
- are deprived of many of the most basic extrinsic motivations (i.e., curiosity); sensory info is so distorted it is ineffective as a source of motivation to explore and interact with people and the environment
- will not benefit from being left alone, for long periods of time, with toys / materials

Home Interventions

Touch, Talk, Transport, Tangibles

Priorities for In-Home Intervention

- Promote the family's confidence and competence in their abilities to care for their child
- Support family functioning and strengthen family-child relationships by acting in ways that recognize and build on the family's strengths and capacities
- Work with the family to modify and adapt their home environment to promote the child's access to, and active participation in, potential learning experiences

Touch

(Home Intervention)

- It is critical to remember that for a young child who experiences deaf-blindness, his **hands** *might* be used **not only as tools**, but also as:
 - **eyes**
 - **ears**
 - **voice / communication**
 - **self-stimulation**
 - **OTHER** (e.g., self-protection, safety)

Touch

(Home Intervention)



- Assist families to develop touch cue systems (as explained previously)
- Use hand-under-hand strategies to gently guide the child's hands from underneath, thus allowing the child more freedom to:
 - actively participate
 - escape (if she wants)
 - explore
- Engage in joint tactile exploration—or “watch” the partner explore something

Touch

(Home Intervention)

- Body language is a two-way street...even very young infants and toddlers gain significant information when another person touches them:
 - texture of the skin
 - size of the other person's hands
 - temperature / muscle tone of the other's hands
 - amount and type of pressure applied
- Always show **respect** in the manner in which a young child's body is touched!

Talk

(Home Intervention)

- Develop supports for increasing the young child's ability to **receive** communicative input
- Engage in “nontraditional” conversations (through co-active strategies-upcoming)
- If hearing ability remains uncertain, or the infant / toddler has been diagnosed with a hearing loss, it is critical to **supplement talking with gestures and / or manual signing**, as well as other forms of communication

Talk

(Home Intervention)

- Create a signal / gestural dictionary for ALL partners to use when interacting with the young child
- This will promote consistency in interactions
- This sort of dictionary has been shown to facilitate **expressive** communication development

Each time _ Susan _ DOES this....	It will be interpreted to MEAN this....	_ Susan's _ partner will DO this...	_ Susan's _ partner will SAY this...	How _ Susan's _ partners will shape behavior
Physically pulls person in the direction of an object or activity	"Please interact with me; I want you to do something with me / for me!"	Give Susan attention; attempt to show her the object or activity she wants	"You want to look at / touch something"	Demo / prompt more conventional gesture (eventually, to shape a point)
When in her carrier, kicks legs frontwards and backwards	"I want out of this carrier!"	Go to Susan, from the front, and begin to unfasten safety belt	"You want OUT—you want me to hold you!"	Provide touch cues to both elbows, moving them up
Smacks at own face or body	"NO! I don't want you to do that to me!"	IF <u>optional</u> , move away; IF <u>not</u> <u>optional</u> , break for 10 seconds	IF <u>optional</u> , "You want something else" IF <u>not</u> <u>optional</u> , break	Hand-under- hand movement to push away (to side of body)

Transport (i.e., “Movement”)

(Home Intervention)

- Assist family members to “read” the infant’s various movement and body signals, including:
 - heart rate / muscle tone
 - respiration rate
 - gagging
 - hyperextension, flailing, yawning
 - body position
 - facial expressions
- Recognize the young child’s overt behaviors as communication signals!

Transport (i.e., “Movement”)

(Home Intervention)

- It is critical to remember that many of the earliest memories of a child who experiences deaf-blindness are those associated with **movement** and **touch**
- Remember: for young children who experience DB, they frequently are not motivated by curiosity or interesting things or persons in the environment!
- A child's own body awareness might be limited
- Spatial awareness, the development of reaching, and independently moving in the environment can all be very challenging—and will likely require nurturing

38 Transport (i.e., “Movement”) (Home Intervention)

- Van Dijk proposed **co-active strategies**, which include not only the frequent use of touch, but also joint motor activities between parent and child
- Co-active movements develop a child’s security, help build relationships with others, and assist them in interpreting environmental cues



Tangibles

(Home Intervention)

- Provide infants and toddlers with novel, interesting objects to explore
- Encourage young children to try new things, as well as repeating her favorite activities with her
- Facilitate reaching, moving, tasting, smelling, touching, etc.
- Ensure the environment is familiar, safe, and that the infant / toddler feels as secure as possible

Tangibles

(Home Intervention)

- ▶ Develop supports for maximizing the young child's ability to use the remaining auditory and / or visual skills she has—by expanding touch to include **purposefully chosen tangible objects**
- ▶ Portions of favored objects may be used as **object cues**



On-Site Preschool Interventions

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Touch, Talk, Transport, Tangibles

Priorities for On-Site Preschool Interventions

- Work collaboratively with the family and all other professionals on the child's team to develop an "Individual Family Service Plan" (IFSP)
- Actively solicit information from, **and share information with**, family members (and / or other key care providers)
- Create environments that provide opportunities for movement and regular physical activity to maintain or improve fitness, wellness and development across domains

Priorities for On-Site Preschool Interventions

- Identify each child's strengths, preferences, and interests to engage the child in active learning
- Expand the young child's world, to include new environments and a greater number of communication partners
- Provide opportunities for the young child to interact with peers
- Begin to build a broader foundation for literacy and academic development

Touch

(On-Site Preschool Intervention)

- Become aware of the learner's skin and muscle tone—and note what form(s) of touch she uses
- Determine how the learner uses her hands and for what purposes
- Create a physical environment that includes a variety of interesting textures and tactile features
- Use touch to encourage the young child to engage with a partner and “come out into the world and *join* the partner” in varied activities

Touch

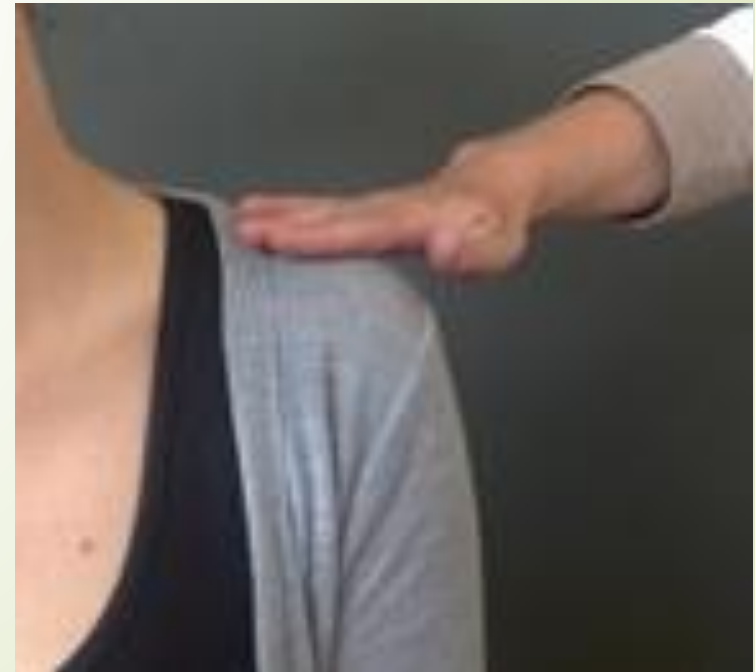
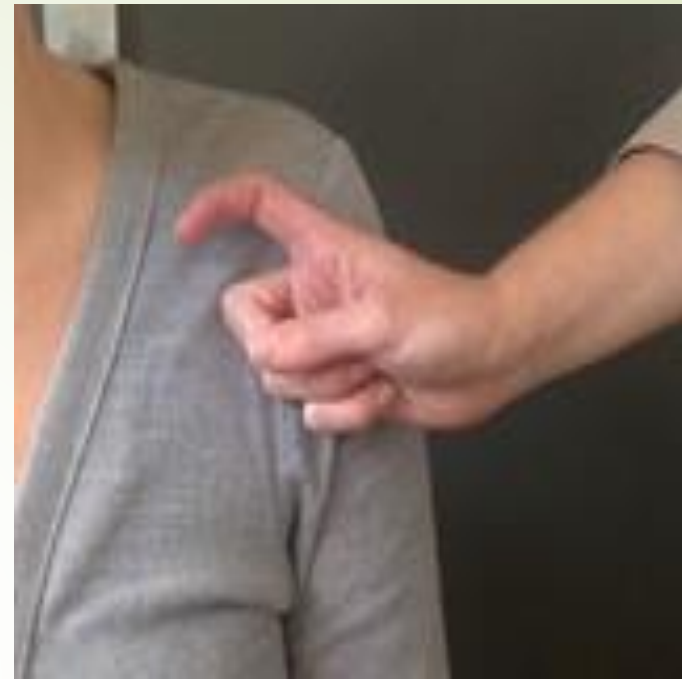
(On-Site Preschool Intervention)

- Create and implement consistent tactile means for:
 - securing the young child's attention
 - teaching differential responses to preferred and non-preferred activities / items
 - facilitating her discrimination skills
- Use touch as a formal cue (i.e., a **touch cue**) for understanding people and activities in her environment

Touch

(On-Site Preschool Intervention)

- A **TOUCH CUE** consists of tactile contact, made in a consistent manner, directly on the learner's body, to communicate with her
- The purpose of a touch cue is to communicate a variety of a partner's intents
- The use of touch cues may reduce a learner's startle, or challenging behaviors, by helping her anticipate what is going to occur



Talk

(On-Site Preschool Intervention)

- If hearing ability remains uncertain, or the infant / toddler has been diagnosed with a hearing loss, it is critical to implement inter-professionally guided multi-modal communication instruction—**vocal, unaided (i.e., gesture, manual sign, tactile sign),** and **aided communication forms.**
- Model use of all these forms!

Talk

(On-Site Preschool Intervention)

**Gesture
Development:**

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9	Gives, shakes head
10	Reaches, raises arms
11	Shows, waves
12	Points with open hand, taps
13	Claps, blows a kiss
14	Points with index finger, gestures “shh”
15	Nods head, gives thumbs up
16	Other conventional gesture(s)

Talk

(On-Site Preschool Intervention)

- Allow the young child sufficient time to process information—wait...and slow down!
- Provide opportunities that allow the young child to *initiate* communication interactions, as well as *respond* to others
- Create and implement a signal / gestural dictionary (to enhance expressive communication) and pair this with an augmented input dictionary (to facilitate receptive communication development) for ALL partners to use when interacting with the child

Talk

(On-Site Preschool Intervention)

General guidelines for facilitating communication:

- Integrate communication into all activities
- “Talk” (in all forms) to provide meaning for actions
- Utilize the young child’s preferred communication mode(s)
- Use labels; introduce new vocabulary
- Teach concepts associated with common activities
- Provide turn-taking opportunities
- Offer choices and facilitate the child making these

Transport (i.e., “Movement”)

(On-Site Preschool Intervention)

- Van Dijk proposed a set of **co-active strategies**, which include not only the frequent use of touch, consistent verbal and nonverbal cues, but also joint motor activities
- **Resonance** requires close physical contact between the teacher and the young child, with the *teacher* initiating the movement (whole body, hand or limb, movement w/ objects)
 - resonance board
 - actions that affect the immediate environment

Transport (i.e., “Movement”)

(On-Site Preschool Intervention)

- **Co-active movement** is an expansion, as well as an extension, of resonance
 - Activities are sequenced to involve two or more components
 - Each activity has a definite starting and ending point
 - Gradually, physical distance increases between the teacher and the young child
 - EXAMPLE: Teacher and child picking up toys and putting them in a “finished box” at the same time

Transport (i.e., “Movement”)

(On-Site Preschool Intervention)

- Engineer the physical classroom environment in such a way as to reduce clutter and obstructions to movement
- Create designated spaces throughout the classroom for specific activities
- Use textures (e.g., various carpet squares, vinyl tiles on the floor) to guide the child's movement to key locations associated with the classroom space

Tangibles

(On-Site Preschool Intervention)

When considering “tangibles” for a preschool classroom, one important aspect is to provide **accommodations** that an individual child might require because of **visual** and **auditory** losses

➡ Auditory Accommodations

- Select positions for the teacher and child strategically
- Consider classroom acoustics
- Manage sound:noise ratio
- For child with pronounced vision loss, consider tactile and / or auditory cues as labels

Tangibles

(On-Site Preschool Intervention)

➤ Visual Accommodations

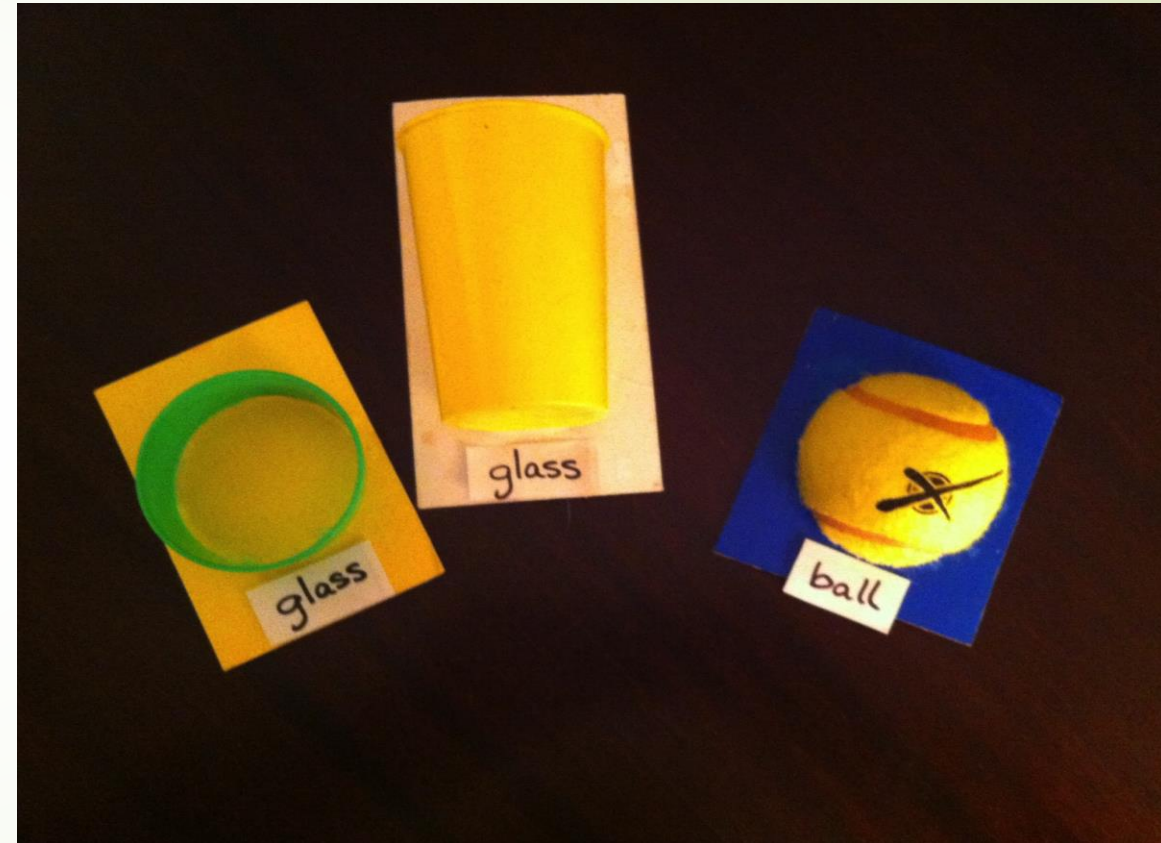
- Control classroom lighting: **Glare is an enemy!**
- **Contrast is a friend!**
- Consider color choices; especially for a young child with cortical vision impairment, color can make a significant difference
- Size of tangibles utilized is key
- Position, spacing, and arrangement of visual stimuli matter
- For child with pronounced hearing loss, consider tactile and / or visual cues as labels

Tangibles

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(On-Site Preschool Intervention)

- An **OBJECT CUE** is an object, or a part of an object, that is used to refer to a person, place, thing, or activity
- The purpose of an object cue is to provide a concrete means of supporting conversational interactions
- Use of object cues might facilitate the development of joint tactile attention



Tangibles

(On-Site Preschool Intervention)

Object cues are critical for **REFERING** to a particular person with whom the learner is working...

PERSONAL IDENTIFIER

Example:

- shown here, sequined bracelet for TVI (remember previous discussion re: touch cues as personal ID)



Tangibles

(On-Site Preschool Intervention)

- A calendar system (AKA anticipation schedule) can be especially helpful for young children with DB
- Such a system involves the manipulation of objects associated with activities, including a “finished box”
- Assists young children to develop skills of anticipation, learn predictability, and understand time passage



Routines

A structured routine that is targeted for instruction:

- ▶ helps to **organize** the world for a learner with DB
- ▶ provides a learner with necessary **supports** for learning and help to develop memory
- ▶ helps a learner to build **trust** in / with others

Routines are foundational to the development of a young child who experiences deaf-blindness!

Therefore, routines are appropriate for use in NICU, in home programs, and on-site preschool programs.

Routines

Definition of “routine”:

A related series of activities, organized into a **predictable** format

Consistent implementation of routines serves to organize a learner’s activities—and assists her to feel safe in the world!

A young child who experiences deaf-blindness needs to learn to anticipate!

Routines

Routines may be developed for:

- Home chores and responsibilities
- Free time activities
- Daily preschool events / activities
- Specifically targeted IFSP goals

Routines

To assist family members with increasing their child's participation in routines at home:

- ▶ Ask the family to rate the child's participation in terms of their own expectations:
 - **exceeds,**
 - **meets,**
 - **occasionally meets,**
 - **does not meet**
- ▶ Ask the family about their “satisfaction” with the routine

What Makes Up a Routine?

A given routine NEEDS to include:

- The same **number of steps**
- Implemented in the same **order**
- Implemented **consistently, each and every time** a learner is engaged in the activity (by *both* her school team and family, if at all possible)

Elements of a Scripted Routine

- **Touch** or object (i.e., **tangible**) cue
- **Verbal / Manual sign** cue
- Time delay (pause) AND
the learner's anticipated response to those cues
- Expected *initial* action (i.e., **movement**) from the learner

Routines

Partners need to organize and utilize a sequence of experiences, which include:

- Natural context
- Predictability
- Central (shared) focus / joint attention
- Turn-taking opportunities / reciprocal roles
- Repetition
- Small number of steps
- Clear transition points

Routines

KEY: Create predictability for the young child, through the incorporation of consistent structure!

MUST have a clear: Beginning, Middle, and End!

Utilizing Routines with a Team

- Collaborate with family about daily life activities and home routines
- Communicate with the family to identify motivating activities for the young child
- Brainstorm to identify the most reasonable response a learner will be expected to make to *actively* participate and be fully engaged at each step of routine

Utilizing Routines with a Team

- Begin with “now” and “later” boxes, along with a “finished” box, as a rudimentary daily schedule
- Develop “experience books” about the learner’s personal activities / experiences, using salient representations
- Create an interactive home – school journal to record a few daily events in which the learner participated (to support “memory thinking”)

Thank You!

I sincerely appreciate your participation today!
Please feel free to contact me with any
questions:

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