



# Texas School for the Blind & Visually Impaired Outreach Programs

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## Thoughts on the Assessment of the Student with the Most Profound Disabilities

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*Note: This article first appeared in the Fall 1996 edition of SEE/HEAR newsletter published by Texas School for the Blind and Visually Impaired and Texas Commission for the Blind. It was developed in response to requests we have had from teachers who are working with children who have the most profound disabilities. Typical assessment information provided little for the teachers to use in developing programming for this type of child. Additional information has been included that was created by Stacy Shafer and Millie Smith. All content was updated and reformatted in September 2022.*

Since its inception of laws providing for the free and appropriate education for all students in this country our schools have seen a steady increase in the population of students who are considered to have the most profound disabilities. Although our willingness to serve these children is evident, our understanding of these students' educational needs, assessment and programming is still very much in its infancy. It is easy to feel we do not know what to do with these students. Developmental checklists and assessment tools used with other populations are not often sensitive enough to provide usable information to those charged with the instruction of this type of student.

The purpose of this article is to: (1) present basic user friendly assessment questions and background information which relates to this particular population, (2) acknowledge the individuality of each of these children by building a personal picture of how they learn, and provide useful information with which to develop programming. This is not intended to be a comprehensive assessment process but rather some questions and background information to consider when planning for this particular population.

### What Can Be Done to Gain and Hold This Child's Attention?

#### Attending and biobehavioral states

A typical nervous system exhibits a range of levels of arousal. In all of us there is a structure in the brain stem that controls levels of arousal (biobehavioral states). Some examples of these levels of arousal states are deep sleep, drowsiness, alertness, anxiousness, and agitation. (Guess, 1988). If our nervous systems are in the normal range, we spend our day shifting

across the states in a typical manner. We sleep at night, are alert and absorbed in a good book and drowsy after a big noon meal We may become very agitated when paying our bills or if a stray dog digs up the garden.

We are able to consciously control some of these arousal states. For example, if we find we are getting sleepy behind the wheel of a car, we stop to get a cup of coffee. We are calmer in a stressful situation if we bring along a friend or wear a favorite outfit. If something agitates or makes us anxious, we may engage in “self-talk” as a form of state management. For example, to calm down we might think to ourselves, “I’m not going to worry about it. It’s not that big of a deal. If worse comes to worse, I’ll just...”

For all of us, the only time we can learn new information is when we are able to achieve and maintain an alert state. This is why, after something traumatic throws you into an extremely agitated state, it is sometimes impossible to remember things that were said or to reconstruct a particular sequence of events. You may also find that, after a big lunch in a warm room, you become incredibly sleepy and have trouble reading a long memo from your boss. The ability to attain and maintain an alert state is essential for understanding and learning.

Children with profound disabilities may not exhibit the typical range of states. This is a characteristic of a number of students with profound disabilities. One student may always seem to be sleeping or drowsy. Another is chronically irritable or anxious, leaving adults fearful of interacting with her lest they “set the child off.” Many of these children may have brief cyclical periods of alertness, but seem unable to maintain this state long enough for typical instructional activities. Slightly over-stimulating this child can cause him / her to “shut down” to a sleep state.

Often these children have difficulty achieving and / or maintaining alert states. They may experience health setbacks that bring incredible drains on their energies and effectively prevent them from being able to respond to any environmental demands outside their bodies. In some students who are deafblind the lack of normal stimulation due to an extensive sensory loss causes them to spend much of their time in other than alert states. The key to instructing these children is to understand the internal influences on the child’s ability to attend to instruction.

There is a growing interest in the possibility that external factors can have impact on biobehavioral states in these children. During the assessments, we want to learn things about children that might help them develop better control of their states and maintain alert states for longer periods of time. The more adept they become to attending, the more opportunity they have for learning. Therefore, assessment should help determine the child’s current profile of states and what adaptations to the environment may assist the child in achieving and maintaining an alert state.

The questions related to biobehavioral states that should be answered during assessments are:

- What are the range of states the child exhibits across the day or week?
- What are the child’s most common states?
- Is this child able to reach the quiet alert or active alert state?
- Can he maintain it?
- What problems does the child have in shifting and maintaining states?
- What variables appear to effect state in the child (especially attending)?

There are a number of tools that can help in obtaining this information. These include:

- Assessment of Biobehavioral States and Analysis of Related Influences
- Appetite / Aversion Form
- Assessment of Voluntary Movement Component - Carolina Record of Individual Behavior (CRIB)
- Analyzing Behavior State and Learning Environments Profile (ABLE).
- The Key to Attending: The Orienting Reflex

People have a subconscious monitoring system that is working at all times. If this system detects something that needs our immediate attention, it pulls us to attention with the powerful orienting reflex. The orienting reflex is just that: a reflexive alerting to: significant things. It tells us when to pay strict attention so that we may make a decision whether or not to defend ourselves or to get more information. It alerts the senses to the fact that they need to pay attention, so that survival matters and novel things can be handled. (Silverrain, 1991)

All of us have orienting reflexes throughout the day. As an example, say that you are driving along listening to the afternoon news. The words roll by you until suddenly you hear your street address being said over the air. You snap to attention, lean forward, and turn up the dial to take in every word. You reflexively oriented to something that is important to you. The orienting reflex is powerful because it is the prerequisite to the alert state in the array of biobehavioral states. (Rainforth, 1982) It pulls you to an alert state from another state.

Parents use this reflex all the time. If you have a fussy (agitated state) child in the grocery store, you try to distract her so she will calm down. ("Do you see that man with the funny hat? What do you think his name is?"). What you are actually doing is trying to trigger the orienting reflex in the child so she will shift from an agitated state to a calm state.

In the area of attending, a critical component in both assessment and instruction is the orienting reflex. (van Dijk, 1985) It is important to consider because the orienting reflex can potentially be used to help the child who is usually in "other than alert states" shift into attending. The hope is that you can capture their attention on a reflexive level; then provide instruction. (See "associative learning" discussion.)

If the child shows an orienting reflex in response to a change in position, a particular scent, or colored lights, these materials or strategies can be embedded in the lessons to try to gain the child's attention and help him shift to an alert state. Once he makes that shift, you have a brief window of opportunity to provide further information and to attempt to extend the amount of time that he attends.

An important thing to note: There is a difference between the orienting reflex and a defensive startle. Overhearing your name in a conversation produces an orienting reflex. "The orienting reflex readies the nervous system for further learning." (Silverrain, 1991) The blare of a fire alarm typically produces a defensive startle. A startle indicates an overload of the nervous system, which is aversive rather than appealing. The result is not "attending," but rather physical agitation and / or disorientation and / or withdrawal. The child who experiences a defensive startle during an interaction with his instructors or his environment feels under assault rather

than invited to participate.

If the stimulus is perceived as aversive, you are less likely to attend and more likely to spend your energies trying to get away from the stimulus. Children who cannot physically get away from an aversive stimulus may literally shut down into sleep to escape. That is why it is critical to determine what the child tolerates or is attracted to (appetite) versus what repels the child (aversion). (van Dijk, 1985)

Families as well as other members of the child's team often have valuable pieces of information related to the things that seem to catch his attention or deeply bothers him. In the assessment process you need to identify things that elicit an orienting reflex so that you can embed those in your lesson to help the child maintain attending. You also need to assess what things are aversive to the child so you do NOT inadvertently include these things in lessons or social interactions with him and take away his ability to attend.

The questions related to orienting reflex that must be answered during assessment are:

- What does the orienting reflex look like in this child?
- What elicits an orienting reflex in this child?
- What does the defensive startle look like in this child? What elicits a defensive startle in this child?

There are a number of tools that can help in obtaining this information. These include:

- Assessment of Biobehavioral States and Analysis of Related Influences,
- Appetite / Aversion Form,
- Assessment of Voluntary Movement Component

## **How Does the Child Take in Information?**

### **Preferred sensory modalities**

We all use our senses to gather information from our environment. These senses include: visual, auditory, vestibular (related to movement and spatial orientation sensed through muscles, tendons, joints, and the inner ear) kinesthetic (related to bodily position, weight, or movement sensed through the muscles, tendons, and joints, olfactory (smell), and gustatory (taste).

We also have preferred senses for taking in information which impacts how we best learn. Some of us learn new material best by listening, others prefer to read the information, and others may need to write new information down. It is important to determine which sensory channel (s) the child with profound disabilities prefers to use and then provide instructional activities and information through those preferred channels. For example, a child may alert to a change in lighting. She may attend longer if there is some music involved in the lesson. She will accept certain types of tactual input in the palm of the hands but never on her mouth. Looking at the self-stimulatory behaviors (i.e. rocking, flicking, etc.) can also give you some information about which sensory systems have value to the child. (Moss & Blaha, 1993)

It is helpful to systematically test across all sensory channels with tools like Every Move Counts and to compile and analyze anecdotal information from families and staff who have daily

interactions with the child. These observations contain clues about sensory things involving water. You observe that the one sound that seems to “tune him up” (bring him to attending) is the sound of water running from a faucet. That piece of information tells you that the child recognizes a consistent and a distinct auditory cue and associates it with something that he really enjoys.

The strategy of “multi-sensory approach” is sometimes recommended for this population. There seem to be different working definitions for this term. This approach is sometimes perceived as stimulating all the child’s senses at the same time with the same level of intensity. This version of multi-sensory approach assumes a couple of things:

All senses are triggered in pleasant ways. This may not be true for these children. A child may orient to music through the auditory channel but find tactile information through his hands frightening. Combining these with equal intensity in a lesson may throw the child for a loop. The child can combine completely different sensory input into a meaningful whole. This may not be possible for all children. For example, some students may need to focus on one channel at a time to understand what is happening. It may be better to pace the lesson so the child can have a longer time to look at or touch something before you start talking about it. You can relate to this need if you think of the times you have turned off your radio when you were looking for a freeway exit in a large unfamiliar city.

The questions that should be considered in assessment related to sensory channels are:

- What sensory channels are most effective for gaining the child’s attention?
- What sensory channels are important for conveying reliable information to the child?
- What degree of sensory information or pacing of presentation of information helps the child shift his state to attending?
- What channels are associated with orienting reflexes?

Assessment tools that help to provide this information include:

- Learning Media Assessment (LMA),
- Every Move Counts,
- Appetite / Aversion Form,
- Functional Scheme – Visual Perception, Auditory Perception, Tactual Perception, Olfactory Perception, Gustatory Perception, Developmentally Impeding Functions.

## **Does the Child Remember and Learn?**

Any type of learning has to do with memory. The following are indicators that a child is remembering specific sensory information.

### **Habituation as an indicator of memory**

When I first moved to Austin I rented a home near the airport. It was a great house but unfortunately stood under the flight path. Incoming flights woke me up at night and interrupted phone conversations for the first few days. After a time, however, I tuned it out and stopped noticing the noise. When my sister came for a visit she asked me, “How can you stand it?” I honestly had no idea what she was talking about. I had gotten used to the sounds and had

stopped hearing them. This is an example of habituation. Our minds unconsciously sort through incoming information. Habituation is an indication of memory because you only get used to things that your system is able to remember. Habituation decides what we should ignore or notice and is characterized by a lack of response. This is very important as it allows the nervous system to focus on relevant events and not be overwhelmed by all the trivial types of stimulation occurring around us all the time.

Watching for signs of habituation in a child is important because it tells you he is remembering. Many times you hear comments like, "He used to really jump when the intercom came on, but now he doesn't seem to notice it. I don't know if he can still hear it." Or "This used to be her favorite tape, but now she doesn't seem to respond to it." These could be indicators of habituation which signifies that the child views the information as "old news."

### **Building associations as an indicator of memory**

Building associations between two events is a type of learning and remembering. Linking a new fact with a familiar one (associative learning) is one way we grow to understand the things around us. Before we talk about ourselves, however, let's talk about less complex life forms and what they have shown us about associative learning.

"Snails, believe it or not, demonstrate simple associative learning. Recent studies show the effects of learning on the nervous systems of snails. Large groups of sea snails are given a fast spin (simulating the roll of a wave) which makes them contract. Each spin is preceded by a burst of bright light. Bursts of bright light alone have no effect on snails. After a while, the snails will contract when the light is shone on them, as if a spin were imminent. Researchers have shown that during this learning, new nerve connections have grown that did not exist before. The snails began to react or anticipate the spin simply by association with the burst of light."

"You might find it interesting to know that new born human infants have also shown the ability to associate a preceding event with one that follows. A hungry, crying baby will become quiet when she hears her parent's footsteps approaching in the night because she anticipates the bottle. We know that the human nervous system is capable of making associations between two events when the final event in the chain relates to basic survival or pleasure needs."  
(Silverrain, 1991)

A child who dearly loves the taste of pudding initially shows no recognition of a spoon. However, over time, you may see him develop the same level of enthusiasm for a spoon as the pudding because you repeatedly paired the spoon with the pleasure of eating pudding. The ability to make an association between the spoon and the pudding is an example of associative learning. (Note: We have learned from early studies that present the spoon immediately before he tastes the pudding is the way to help the child make the connection.) By building these meaningful pairs in a child's life you are expanding his understanding of the world. Noting any associations that child may have already is important assessment information.

### **Anticipation as an indicator of memory**

Anticipation should be considered an indication of learning and memory. When a child feels his bib go about his neck and begins to open and close his mouth, he is anticipating the next step. He is showing us that he remembers. Unlike habituation that is characterized by a lack of

response, anticipation is characterized by a “tuning up” of the system and some action on the part of the child that says “Oh yeah, I remember this!” Anticipation tells you that you have been successful in developing associative learning. You have built an association between bib and eating.

Anticipation of an upcoming event can “rev you up” to maintain an attending state. For example, a person is on a road trip and knows that the exit he must take will be a few miles past a factory on the left. This guy may drive along lost in his own thoughts for thirty minutes or so until suddenly, the factory appears on the left and triggers an orienting reflex. He shifts into the alert state and begins to anticipate the exit. Because he anticipates the exit, he stays alert for a short period of time and looks closely for the sign. Using cues with children helps them anticipate and pull to attending so they can learn.

### **Surprise as an indicator of memory**

Building in a surprise or what has been called a mismatch of expectations (van Dijk, 1985) is a test for memory and learning. A mismatch occurs for the child when he anticipates his mother picking him up and playing a particular swinging game, but is treated to this same game by this father. The child registers his surprise by fluttering his eye lids and breathing more rapidly. The surprise elicits an intense alert state in which associations previously learned are reviewed and compared with the new experience important learning has taken place for him. A child responds to a mismatch of expectations only because he remembers what should have happened.

Questions to ask related to assessing cognition (habituation, anticipation) include:

- Are there things the child used to orient and respond to that he now seems to notice?
- Does he stop responding after 2-3 times?
- Does he seem to pair things, events, and/or people together?
- Does the child show anticipation of what is about to happen?
- Does the child register surprise when there is a change in a familiar routine?
- Does the child seem to know familiar versus unfamiliar people?

As assessment tool that helps to provide this information is Every Move Counts.

### **What Can This Child Do to Impact His Environment?**

Since learning is something the child does with you and not something you do to him, it is critical to determine the easiest way for the child to respond so that he is able to successfully participate. Possible responses that these children might make are changes in affect, vocalizations, gaze shift, and body movements. (Korsten, 1993) Even if these responses are not intentional, you should identify a particular response he gives and try to shape it into a purposeful response. Systematically testing for these responses is an important part of assessment.

### **Systematic inventory of voluntary movements**

It is important to systematically observe the child in all the positions typically used with him and inventory the voluntary movements he can make. Some of these children are said to have no



voluntary movements to use for instructional purposes. Typically, this is not the case. When a child is observed in a variety of positions he may show a surprising number of movements. From this inventory of voluntary movements, the team can target a particular response(s) which will allow the child to participate in an activity.

Many children can make a particular movement easily in one position but not in another. Some positions are more stimulating or relaxing for a child and this effects their ability to attend. (“As soon as we put him in side-lying, he stops fussing.”).

Additionally, some children, when moved from one position to another, experience a significant change in their biobehavioral state. They may find the experience frightening and need a period of time to recover before they can attend. These children could benefit from strategies to make the transition less aversive (e.g., touch cues which signal that they are about to be taken from their travel chair or slowing down the pace of the transition). Other children may be at their most alert following a change in position. It is an individual thing.

Questions related to voluntary movement that can be addressed in assessment include:

- What specific voluntary movements does the child exhibit across positions?
- How do different positions affect the child’s level of arousal or bioheaviorial states?
- Does transition from on position to another cause a significant change in the child’s biobehavioral state?

Assessment tools that help to provide this information include:

- Every Move Counts - Assessment of Voluntary Movement Component
- Functional Scheme – Gross Movement, Fine Movement
- Physical Therapy Assessment
- Occupational Therapy Assessment

## Using the Assessment Information in Developing Programming

### Programming Strategies

Once this assessment information has been compiled the educational team should be able to draw on it in developing their program. Ann Silverrain suggested some strategies to follow in her 1991 article. These include:

- **Use assessment data to determine learning media that provides the appropriate level of stimulation**---enough to be alert and not enough to cause withdrawal. We must forget about stimulation for the sake of stimulation. “Tolerating stimulation: is not an appropriate goal. Damaged nervous systems need the appropriate type and amount of stimulation; they do not need to be bombarded.
- **Develop activity routines which have a predictable sequence of steps, objects, or actions** that evoke the orienting reflex to reengage the child throughout the activity and provide opportunities for the child to respond or take a turn.



Remember pacing is critical in getting child response.

- **Use familiar objects and people in daily routines as a basis for instruction.** Evaluate anticipatory responses to sensory cues to determine the appropriateness of the materials or actions used for cuing. As you cue the child, look for orienting reflexes to occur. Remember that you want to get an orienting reflex, follow with an activity of high interest or one that comforts or meets a basic need as a way of rewarding the child's response. Over time we should begin to see the child show signs of anticipation. All things we want the child to respond to should be real things or actions that are used by or with the child in everyday routines.
- **Design a daily schedule of predictable and pleasurable events or routines.** With any activity, if we want to see an anticipatory response (evidence that the child remembers) the activity must have a strong emotional appeal for the child. When we see the child anticipate events and show some awareness of the functional use of objects, then primitive communication choice systems can be used. When a child does such things as gaze at a preferred item then at you; tactually explores two objects and picks the relevant one in context; pushes an object toward you; pulls or pushes your body in a way that says "I want you to do this with me". Then you are beginning to move into the realm of intentional conversation.
- When the child is consistently anticipating a particular object or action in a routine, toss in a mismatch to test awareness and communication. This check can only occur within the context of a stable routine. For example, the child is routinely expecting to have you present her red bib before meal time, but instead you put a hairbrush in front of her and her bib off to one side. Will she realize there is a problem and try to communicate that to you? Will she try to get your assistance in resolving the problem? These are indicators of a readiness for more complex learning.

## Conclusion

As the family and the other members of the educational team work together they become better at recognizing and respecting the skills and strong personal preferences that children with the most profound disabilities show us. All the children have ways of showing us what they want more of and what they would like to avoid. It is our responsibility to develop the assessment expertise needed to be aware of those messages and to use them to build better learning environments for the child.

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