Supporting Availability for Learning: Student-Centered Biobehavioral Assessment and Intervention for Children and Youth with Deafblindness/Multiple Disabilities

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In an article titled "Thoughts on the Assessment of the Student with the Most Profound Disabilities," published in a 1996 issue of the SEE/HEAR Newsletter (Texas School for the Blind and Visually Impaired), Robbie Blaha wrote:

> 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.

Almost twenty-five years later, Blaha's words are poignant and relevant to our field. Students with deafblindness represent the lowest incidence in the population of students with disabilities, yet they are the students with the most extensive individualized support needs. Teachers and related service providers who work with these students require unique expertise to provide appropriate educational interventions, and the use of standardized assessments alone is insufficient in guiding meaningful instruction (Ferrell, Bruce, & Luckner, 2015).

Why is assessment of availability for learning a critical area of need for our students?

While the total number of children and youth (hereafter, "children") with combined vision and hearing loss has remained relatively static over the past two decades, the population has shifted significantly to reflect an increase in the presence of additional disabilities. The 2018 National Deaf-Blind Child Count (NCDB, 2019) indicated that between 2005-2018, the percentage of children with deafblindness having four or more additional disabilities increased from 13.1% to almost 42%. The most common additional disabilities for children on the Child Count from 2013-2018 were: orthopedic/physical disabilities (59-61%),

intellectual/cognitive disabilities (65-68%), and complex health care needs (51-53%) (NCDB, 2019).

Children with multiple disabilities often have complex physical, sensory, developmental and health challenges which can have a significant impact on their "availability for learning." This term may be used generally to describe readiness or attention, but specifically, it refers to the *biobehavioral states* that are necessary in order to process information and experiences. *Biobehavioral states* encompass the combination of internal and external factors that influence the condition of a person at any particular moment (also referred to as “arousal” or “alertness”).

Guess and colleagues (1988; 1990) addressed the subject of biobehavioral state assessment for students with the most profound multiple disabilities in over 10 research studies between 1988-1996. Their Behavioral State Observation Scale (1988; 1993), adapted in part from Brazelton’s (1978) Neonatal Behavioral Assessment Scale and Wolff’s (1959) observations on infant arousal states, used nine major behavior state codes: Asleep-Inactive, Asleep-Active, Drowsy, Daze, Awake Inactive-Alert, Awake Active-Alert, Awake-Active/Stereotypy, Crying/Agitated, and Seizures (Richards & Richards, 1997). Munde et al.’s literature review (2009) analyzed a number of studies addressing “alertness in individuals with profound intellectual and multiple disabilities.” This review shows many subsequent adaptations of Guess’ scale and coding system, as well as varied

applications of intervention, from the impact of alternative/augmentative communication switches to the effectiveness of Snoezelen rooms on moderating alertness (Munde et al., 2009).

Analyzing patterns of behavior states for students with multiple disabilities, Arthur (2004) wrote, "…it could be argued that to be involved in a CI [communicative interaction], a participant must be awake and actively involved" (p. 137). For students with the most complex needs who struggle to maintain equilibrium, who may spend a significant amount of time throughout the day in drowsy or asleep states, or post-seizure, who have limited or no voluntary motor control, and use unconventional forms of communication, the educational team and family may find themselves asking: How do I know if the child is *available for learning*? How can I tell if the child is alert, attending, responsive or responding, processing or retaining information?

First, we must address the question: *What is learning?* "Learning" is a broad and generic term, and a standard definition does not answer the more fundamental question: *How do we know if a student is learning?* Simply put, learning is physical change in the brain. We are learning when the synapses in our brain are active, strengthening pathways and making new neural connections (Gaddum, 1966). When we have the opportunity to develop consistency and anticipation through repeated experiences and routines, neuron pathways are used repeatedly,

and the myelin sheathing that coats and protects these neural "highways" are strengthened. Blaha (1996) presented concrete, observable examples of learning, including: *habituation* (getting used to something, for example, a sound that used to make you startle, but now you don't notice); *association* (demonstrating understanding of the connection between objects or experiences, for example, associating a spoon with pudding); and, *surprise* ("a mismatch in expectations," for example, if the spoon is presented with no pudding and the child reacts with frustration).

Children who have multiple disabilities and/or deafblindness may struggle to maintain alertness throughout the school day for a variety of ecological reasons, including both internal and external influences (NCDB, n.d.). **Internal influences** include biophysical factors**,** such as the specific implications of a child's etiology (for example, the proprioceptive and vestibular dysfunction often experienced by children with CHARGE Syndrome [Brown, 2011]), sleep disorders common to children with congenital visual impairment, the impact of seizures and medication, and the child's history of experiences with unanticipated touch and physical manipulation (hand over hand instruction). Children with complex health care needs including central nervous system impairments may also have difficulty regulating and maintaining equilibrium. **External influences** on learning may include such environmental and ambient conditions as the temperature of the room,

lighting, the extent and type of physical interaction, positioning, and visual/auditory clutter (NCDB, n.d.). For children with cortical visual impairment (CVI) – now the main cause of visual impairment in children in the U.S. (Hatton, Ivy, & Boyer, 2013), affecting at least 30% of students with deafblindness (NCDB, 2019) – the impact of multisensory complexity (Complexity of the Sensory Environment) on visual processing can have an overarching impact on availability for learning (Roman-Lantzy, 2018).

Green et al. (1994) surveyed a group of educators working with children with multiple disabilities about the levels of alertness of their students, and how student alertness impacted teaching. While the teachers indicated almost unanimously that they preferred to conduct training when the student was alert, almost 70% reported postponing teaching due to non-alertness. The authors pointed out a potentially significant issue in educational programs serving students with multiple disabilities: "withholding training due to lack of student alertness" (Green et al., p. 520). Rather than postponing training altogether, the study suggests a more productive path: what can the educational team do to **promote alertness** when the child is not alert?

How do *you* moderate your biobehavioral state when you need to? Consider the experience of driving a car at night, and feeling drowsy**:** what do you do to make yourself more alert? You may roll the window down to let in the cool air

(tactile stimulation), or turn the radio up (auditory stimulation). Likely, the first thing you do, without even thinking about it, is to shift your position and sit up straight. Your ability to deliberately enact these changes helps to regulate your biobehavioral state. Students with multiple disabilities have significantly reduced ability to elicit or achieve the sensory input, environmental and physical conditions needed to calm themselves when agitated, or to alert themselves when drowsy. Figure 1 shows examples of alerting and calming stimuli for individuals with typically developing sensory channels and central nervous systems. It is important to recognize that children with multiple disabilities, depending on their etiologies and experiences, may have different responses to sensory input. See Morgan (2004; http://www.tc.columbia.edu/i/a/1719_NYSTAPResourceBioBehavioralStates.pdf) for more information on calming/alternating stimuli.

How can we support meaningful intervention to increase availability for our students?

Individualized assessment is the first step toward understanding the child's unique needs in promoting availability for learning. Figure 1 presents several assessments for gathering child-centered background information supporting biobehavioral assessment and intervention.

Figure 1. Assessments for Students with Multiple Disabilities/Deafblindness

Assessment	Domains and comments
The Communication Matrix (Rowland, 1996; Rev., 2004) www.communicationmatrix.org	Expressive communication development, from pre-intentional behaviors to language
Likes/Dislikes (WSDS, n.d.)	Detailed informal preferences assessment
Adapted Sensory Channel Form (Anthony, 1997)	Adapted version of Koenig and Holbrook's (1995) Sensory Channel Form, expands upon the practice of learning media assessment for students with multiple disabilities
Child-Guided Strategies: The van Dijk Approach to Assessment (Nelson et al., 2009)	Comprehensive framework for individualized assessment, including information on communication, sensory learning channels, and concept development
HomeTalk: A Family Assessment of Children who are Deafblind (Bringing It All Back Home Project, 2003)	Extensive guided template for a family-centered profile of the child, including information on preferences, sensory status and etiology, communication, habits and routines, and development across domains
CVI Range (Roman-Lantzy, 2007; Rev. 2018)	Comprehensive functional vision assessment for students with cortical visual impairment (CVI)
Informal Functional Hearing Evaluation (IFHE) (TSBVI, n.d.)	Detailed functional evaluation of the impact of hearing loss on access to educational environments and communication

Thorough biobehavioral state assessment, though partly integrated into other assessments, mostly remains a formal process given the Behavioral State Observation Scale (Guess et al., 1988; 1993), The Carolina Record of Individual Behavior (Simeonson et al, 1982), or Analyzing Behavior State and Learning Environment (Ault et al., 1995). In contrast, Smith and Shafer (n.d.) provided highly functional and user-friendly examples of the application of formal

biobehavioral assessment to an educational environment for the purpose of guiding collaborative team intervention for students with visual impairments and multiple disabilities.

Inspired by the model provided by Smith and Shafer, and the work of Blaha and others in asserting the critical importance of biobehavioral assessment on promoting availability for students with the most profound and complex disabilities, an updated assessment tool was created: "Assessment of Biobehavioral States: Supporting Availability for Learning for Students with Multiple Disabilities including Deafblindness & Profound Intellectual & Multiple Disabilities" (The full tool can be accessed at http://bit.ly/availabilityassessmenttool). This assessment is geared specifically toward supporting child-centered intervention for learners with deafblindness and/or profound multiple and intellectual disabilities who struggle to maintain availability for learning for a variety of reasons. The tool uses Guess et al.'s (1988; 1993) coding systems for behavioral states and environmental input partially adapted by Arthur (2004), with additions to the protocol including positioning and interactional considerations (for example, the use of *hand under hand* versus *hand over hand* interaction). Significantly, the tool includes detailed forms and resources for conducting the evaluation and using the results to guide intervention, and an expanded protocol designed to obtain information relevant to students with deafblindness and complex health care needs.

A primary aim of this tool is to connect the results of previous research on biobehavioral states with the myriad promising practices from the field of education for children and youth with deafblindness. The Guidelines for Recommendations page (Russell, p. 7) includes many areas to consider for potential intervention, from changes to the biophysical management plan and the student's schedule, to the use of specific communication techniques such as touch cues, name cues, tangible symbols, and strategies promoting active learning. In order for the results of biobehavioral assessment to effectively impact intervention, it is essential that the collaborative team possess a strong skill set in both responsiveness and affective involvement (Martens et al., 2014) and in the use of "shared forms of communication" between the communication partner and the student who uses unconventional or presymbolic forms of communication (Bruce, 2003).

All of these evolving approaches emphasize the critical need for ongoing training of educational teams, including paraprofessionals and interveners, in research-based and promising practices that may support a child's increased availability for learning. The Open Hands, Open Access (OHOA) Deaf-Blind Intervener Modules (NCDB, n.d) cover extensive content areas in deafblindness, and include an entire training module on Availability for Learning. Availability for Learning remains a critical area of need for students with multiple disabilities and

deafblindness, and this need is reinforced by trends in the population which continue to reflect an increase in prevalence and severity of multiple disabilities (NCDB, 2019). While the literature supporting communication practices is rich, there is a continued need for research connecting the implementation of assessments with the use of research-based and promising practices for intervention, and in effective practices for training collaborative teams.

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