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Follow the Child – Approaches to Assessing the Functional Vision and Hearing of Young Children with Congenital Deaf-Blindness

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California Deaf-Blind Services (CDBS) serves a population of children and young people that covers a very wide spectrum of ability and disability. Even within the group who were born deaf-blind there is a huge variation in the severity and type of vision and hearing impairments, and many children have neurological damage that results in cortical visual impairment and central auditory dysfunction even though their eyes and ears appear to be intact and working. Increasingly these children have many other problems alongside those associated only with vision and hearing. Severe orthopedic impairments, seizure disorders, heart defects, and breathing and swallowing difficulties are becoming more common, and many of these children also exhibit other sensory problems that affect the touch, taste, smell, movement, balance, and pressure senses. Because of this broad and complex spectrum of difficulties, it is very likely that some of a child's sensory problems will go undiagnosed and unsuspected, and the significance and implications of the sensory problems, both individually and as a whole, will be overlooked in favor of a "global delay" view of the child.

These children present formidable challenges for assessment, and working with them often seems to produce no clear-cut answers but many paradoxes and contradictions:

- Good, up-to-date clinical assessment information is crucially important but this information is often

bewilderingly at odds with the child's observed functioning; children who should not be able to see or hear may do either or both of those things surprisingly well—yet those for whom the visual and auditory prognosis seems very good may not appear to see or hear at all.

- A classic "hands-on" approach may seem to be essential to guide and direct the child, but for many children in this population—for a considerable time—"hands-off" may be the only approach which is acceptable.
- A distraction-free environment is essential for successful assessment, yet many of these children function and learn much better when there is a comforting and familiar "buzz" of background noise or movement.
- Children should be assessed when they are well rested and alert, yet sometimes an assessment may be much more successful if the child is quiet, or even very tired when their sensory priorities have altered.
- Standardized assessment procedures assume adult direction in carefully planned and controlled situations, but many children respond very negatively to this kind of direction and control and under-function as a result.

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There is increasing awareness that even children with the most profound disabilities may have usable vision and hearing that they can be helped to use more effectively, and, given the limitations of clinical assessment approaches, more emphasis is being placed upon family members, early intervention and school staff as potential assessors. Even so, for these people lack of success often results from trying to copy aspects of standardized clinical assessment procedures that may be inappropriate and counter-productive. Examples of these include:

- Insisting that the child is sitting upright for the assessment regardless of their postural preferences;
- Using specific, standardized materials for the assessment which may be of no interest at all to the child;
- Setting too brief and inflexible a timescale for the activity—the adult’s timescale rather than the child’s;
- Eliminating most or all of the play element because of the “serious” nature of the activity;
- Approaching the activity with predetermined ideas about what the child must do in order to be considered to have succeeded.

Basing the assessment approach on the child’s curiosity and personal satisfaction, on current abilities and interests rather than on current deficits, on function rather than on structure, on motivated behavior rather than on sterile performance, is now seen as a legitimate and effective way of beginning the process. The approach needs to be individualized and holistic, so that every aspect of the child is taken into consideration even if only one sensory or skill area is being assessed. The emotional needs of the children will exert a direct and powerful influence on their ability to function, so that serious consideration of questions like “How do you feel?” “What do you like?” and “What do you want?” will provide the best basis for successful assessment. People often think that “What can you do?” is the key question to pose to any child during an assessment, but with this group a better question to begin with would be “What do you do?”

When assessing visual and auditory responses in this population it is important to know about the development of vision and hearing skills, and the

possible implications of clinical findings. It may also be important to know about the implications for vision and hearing of other conditions like cerebral palsy and epilepsy (CDBS staff can help with all this). General suggestions that can prove helpful include the following:

Consult those who know the child better than you or who have a distinctly different viewpoint

Initially it may be helpful to spend a considerable amount of “assessment” time in interviews with family members, early intervention/school staff, etc. in order to gain insights. It is a good idea to organize your questions to make certain that everything is covered. People who know the child well may not realize how much they know nor how important it is, so the interview can serve the extra and very valuable purpose of making them more aware of the insights they already have, where previously they may have been feeling very de-skilled. It is important to record that information gained in this way has not been verified through direct observation, and also to remember that the people being interviewed may not say exactly what they mean, so that careful interpretation and further questioning will be needed.

Identify motivators

This information may be gained from the initial interviews, but it should also be a goal of the first part of the assessment itself, so the motivators identified can then be used in more specific contexts for further assessment. It is important to consider all possible motivators for the child, not just those concerning vision or hearing.

Match several different sensory inputs if necessary

This approach must be noted in the assessment record, but it can be a very effective way of alerting a child to use their vision or hearing. One very effective idea might be to use vibro-tactile input, for example on a resonance board, to gain the child’s visual and/or auditory attention, or to use a purely visual or auditory signal to indicate that some vibro-tactile stimulation is coming. After a period of time it might be possible to

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remove the vibro-tactile input and observe purely visual or auditory responses from the child.

Relax or arouse the child

Many of the children in this population are generally very unresponsive to stimuli of all sorts and may need to be carefully aroused into a higher level of alertness to function at optimal level in a visual or auditory assessment. Arousal may be achieved through the careful use of activities involving vibro-tactile input, large rhythmic movements, or stimulating massage, for example. Other children may be over-reacting to certain stimuli and may benefit from activities that encourage relaxation such as a major reduction in environmental stimuli, a hydrotherapy session, or a relaxation massage. Only knowledge of each individual child, and close and careful observation, will enable the effective approaches to be identified on any particular day. By following this principle it may be possible to obtain stronger and more consistent visual and /or auditory responses from some children. A sensory integration dysfunction assessment by a specially trained Occupational Therapist is usually very pertinent to all the children in this population. Some children, when they are feeling alert and full of energy, will be very visual in their behaviors as they explore their surroundings and “turn off” their residual hearing, but when they are too tired to be looking and moving around they may be more receptive to sounds and show surprisingly good auditory behaviors. Observing for these things and then carefully choosing times and environments for the assessment may make a big difference to a child’s ability to concentrate on one particular sense.

Position the child to facilitate function

Sitting is not the only position in which we can and do use our vision and hearing, and for many of these children it is the least likely position in which they will use their eyes and ears. For children who have problems with balance, postural control, head control, or motor coordination, being supported in the upright position may mean that they have to attend to other urgent considerations rather than to information coming in through their eyes and ears. Only by tackling and minimizing these other considerations can we ever liberate them to concentrate on what they can see or hear. For some children, for example, being placed flat on their back may enable much better visual and auditory functioning, while for others this could be too difficult and challenging a position. Again, each child will have different

needs at different times on different days and at different stages in their development.

Allow the time necessary for the child to perceive the stimulus and respond

These children operate on a much more extended timescale than ours, and everything they do requires more time, energy, attention, and concentration than it does for us. Using vision and hearing is a very complex and sophisticated process, and each stage in this process (being aware that there is something to see or hear, attending to it and locating it, recognizing and attaching meaning to it, and then responding to it in some planned way) may need a considerable amount of time. Many of these children have never been allowed the necessary length of time to work through this whole process. As with everything else it is important to make a note in the assessment findings of the length of time it took the child to alert, attend, locate, or whatever.

Observe for any changes in behavior

It should also be remembered that there are all sorts of ways to respond to a visual or auditory stimulus apart from turning quickly and appropriately, which is often the only behavior that people look for when they are “assessing” a child’s functional vision and hearing. Many children may not turn and look but will show that they are aware of the stimulus by changing their breathing rate, or the tone of their muscles, or the rate at which they suck rhythmically on their pacifier, or the types of vocalizations they are making, or any one of many other changes in their behavior. Sometimes these changes may take a while to happen after the flashlight has been turned on or the music box has started to play or whatever, and sometimes the change in behavior will come only after the flashlight has gone out or the music has stopped. These responses may also occur only once or twice in any one session and the child will then seem to stop seeing or hearing until a considerable period of time has passed.

By following these suggestions it is usually possible to begin the difficult process of working out just what a child can see and hear, and how they see and hear. Recording what happened, and looking for consistent patterns of response even within the child’s apparently inconsistent behaviors, may be of great help to clinicians in piecing together the assessment jig-saw pattern.

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