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What Does "Follow the Child" Mean?

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Assessment woes

Why is it so difficult to assess children with deaf-blindness successfully? Many different people in the education/psychology field assess these children for many different reasons in many different ways, but very often the children end up being (usually) wildly under-estimated or (sometimes) just as wildly over-estimated. Clinical assessment approaches, medical, psychological, and educational have a part to play but may yield a very misleading view of the child's current abilities and developmental potential. Many people are familiar with the declaration that a child is untestable, or is too disabled or too non-compliant for any useful assessment data to be obtained, but this is the fault of the assessment approach being used rather than any failing on the child's part of course. Why is it thought preferable to make a child fit an assessment procedure rather than make the assessment procedure fit the child? Jan van Dijk has always made it very clear that we must alter our attitudes and approaches on every level when working with this population:

> "The multi-sensory impaired person is a unique human being with a unique line of development, who is more dependent on the professional's willingness to accept this and act accordingly than any other group of disabled persons," (van Dijk, 2001).

What goes wrong?

The problems encountered by children and families in their dealings with assessors are legion, and it is not hard to identify the mistakes that are commonly made by people who are supposed to and assumed to be trained and skilled in conducting an assessment:

- people use inappropriate assessment tools
- they ignore the child's motivators and use materials and activities which have no meaning for the child
- they fail to adapt to the child's needs for individualized pacing and physical positioning and support
- they repeatedly attempt to assess the wrong things
- they attend only to the part of the child that they are aiming to assess (e.g. eyes, ears, hands, and so on) as if the rest of the child has no relevance
- they focus on only a single sensory channel and ignore all the other senses, as if each sense works in isolation from all the others

- they approach the child already knowing what it is that they want to see, so that the child is expected to perform to order
- they bring a 'pass or fail' mentality to the task
- they communicate with the child in meaningless and inappropriate ways
- they look for inappropriate responses and ignore the responses that the child does make
- they misinterpret the child's behaviors
- they come to the assessment with their opinions already formed in advance, and then engineer the assessment process to prove their preconceptions correct

While there is general agreement that the assessment process is especially challenging with this population, many people have no problem with committing all or most of the errors listed above and then basing crucially important decisions about school placement, support services, and educational approaches on very faulty information. We also notice that people seem to be searching constantly for the ideal assessment tool, the binder or DVD or checklist that will guide them through a straightforward and fairly quick and easy procedure that will result in a successful indepth picture of the child. This tool does not exist of course. There are helpful assessment materials which have been designed or adapted to be used with children with sensory impairments including deaf-blindness, but the growing diversity and complexity of the population means that even these materials need to be used with care and caution, and can only ever be one part of the comprehensive assessment process. A very helpful booklet from Design to Learn Projects (Chen, Mar, Rowland, & Stillman, 2010) gives helpful advice on how to approach the issues of assessment, and also reviews twelve instruments that are commonly used to assess children with deaf-blindness in the US. Unfortunately there are many more assessment tools out there that have not been designed or adapted for this population at all, and these are often used because the assessors have no knowledge of anything more appropriate. Staff training in appropriate assessment approaches is also extremely scarce.

Follow the child

The idea that, rather than starting our assessment with a published instrument or a fixed set of questions in our mind, we should 'follow the child' has become a well-known concept in the field of deaf-blindness. For almost 5 decades Jan van Dijk has been suggesting that we should follow the child (van Dijk, Oster, & McDonnell, 2009), and in 2001 I wrote an article called 'Follow the Child – Approaches to Assessing the Functional Vision and Hearing of Young Children with Congenital Deaf-Blindness' (Brown, 2001), which attempted to explain just how helpful this approach could be. A seminal article by Robbie Blaha also offers invaluable advice for working successfully with this population of 'untestable' children through careful observation (Blaha, 1996). Unfortunately, this idea still seems to generate concern and misunderstanding and suspicion, so it seems a good idea to re-visit it and try to clarify what it means and exactly why it can be such a successful approach.

In view of critical responses that I have often received after talking about this approach, it might be helpful first if we think about what 'follow the child' does not mean, just to clear up mistaken assumptions and misunderstandings. It is not a recommendation that a child be left to do whatever they like all day without any adult intervention and interaction.

Neither does it mean that potentially damaging self-injurious behaviors should be ignored and tolerated. It does not mean that adults should have no preconceived ideas of what they could be doing with the child and should just allow the child to determine the entire course of all their interactions. It also does not mean that the child should be left to self-stimulate all day, although self-stimulation behaviors should be respected as a valuable source of useful assessment data for us. The 'follow the child' approach is primarily concerned with finding out, as quickly as possible, who the child is and how they operate, and in the process starting to build a relationship with them with minimal aversive episodes. The relationship you build is the essential component that should enable the child, one day, to follow you.

Assessment questions

I like to think of assessment as a process of getting to know the child, and if done correctly that should also result in the child beginning to get to know me too. We assess because there are things that we don't know but we want to find out. As a result we have certain questions in our minds to which we want to find the answer, and having the right questions in mind will usually guide us to some helpful answers, even if the answers to our much bigger questions may still remain to be explored. I also like to think of assessment, and the process of getting to know a child, as asking a series of questions about the child to obtain information that I want to know but don't have at the moment. I may ask the parents and others who know the child better than me, and their information will form a major part of my assessment findings. Pediatric Ophthalmologist Dr. Gordon Dutton recently told me that his initial interview with a parent can provide up to 90% of the information that he needs to carry out an assessment. I may not ask the child these questions directly, but they will be in my mind as crucially important things that I wish to discover, and they will guide and color my behavior in a way that I hope will show the child that I am interested in these questions that demonstrate my respect for them. These would not be any of the obvious big questions that are often the sole focus of people's assessment procedures, questions like "What can you see?", "What are your hearing thresholds?", "How many manual signs do you recognize and understand?", "How many steps can you walk unsupported?", "Can you stack three one-inch cubes?", and so on.

The First Questions

Before we begin to address any of these specific questions about the child's precise, measurable skills we could usefully occupy our minds with a much more personal set of questions. In an article published in 2001, Nelson & va Dijk suggest four key steps to beginning an assessment:

- Make the child at ease
- Determine the child's bio-behavioral state
- Determine the child's interest
- Follow the child's interest

In my article, also published in 2001, I suggested a similar approach but in a rather different way:

> "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?'" (Brown, 2001, p. 2)

My first four questions are important in providing a good basis for successful relationship building, and they match the 4 key steps of van Dijk & Nelson well. Although I refer to them as 'first' questions I think they should be in your mind all the time in all interactions with the child, not just as your starting point. They are not age-specific but apply to all chronological ages and developmental levels. I have seen teachers use these four questions to structure their observations and their preliminary guessed interpretations, and from this get a fairly quick and useful idea about who the child is and how they function.

How do you feel?

'Make the child at ease' and 'Determine the child's bio-behavioral state' are both obviously included in my very first question 'How do you feel?'. This is a population particularly likely to show good days and bad days, even good moments and bad moments, and we have known for many years that extreme variability of functioning and attention is a characteristic of most younger children with deaf-blindness. Issues of poor self-regulation, rapid changes in arousal levels, complex health issues, pain, physical discomfort, neurological involvement that results in

variability of sensory perception and processing, are all likely to be at work here. How can we deal with this in an effective and reasonably well-informed way? Knowing the child is the only thing that helps as far as I know, or relying upon guidance from those who know the child well.

What do you like?

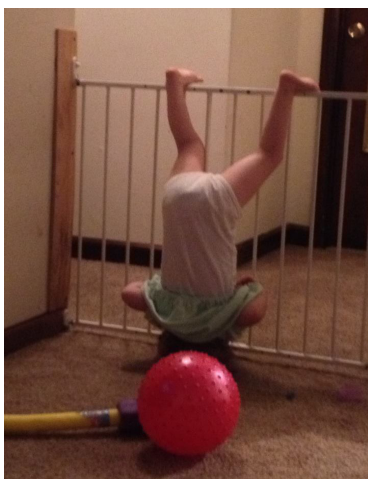
'Determine the child's interest' is clearly a main feature of the question 'What do you like?'. I have written at length about the crucial importance of motivators for learning, and the fact that it is motivation that makes brains grow and develop (Brown, 2009). Of course, once motivators have been identified they have to be used in creative ways appropriate for the individual child.

What do you want?

The next question 'What do you want?' takes us directly to the child's already existing expressive behaviors and immediately credits them with the ability to indicate their feelings and desires to those who bother to observe and get to know them, even though this may not be being done intentionally by the child in the early stages of development. Eye pointing, toe wiggling, hyperventilating, rhythmic grunting, and freezing like a statue can all indicate very specific feelings and wishes in certain contexts once you really know the child.

What do you do?

The fourth and last question might be the most important of all since it leads us to the essence of the individual. Sometimes a person will claim that a child does nothing when they are left entirely alone, even though this is obviously unlikely to be true. We could categorize this as very careless observation, which tells us a lot about the person's attitudes and preconceptions (and their poor observational skills) rather than anything at all useful about the child. More often I am told that if left alone the child will only stim, 'stimming' being the disapproving abbreviation for self-stimulation, which is widely considered as a thoroughly bad thing, to be opposed and stopped as a first priority. For me a child's self-stimulation behaviors provide vital insights into who they are, what their sensory needs and preferences might be, and how they self-regulate to arouse or calm themselves. These are vitally important things to know about a child if successful interactions are to take place and if learning is to result from those interactions. I have outlined thoughts about this aspect of a child's behavior in two articles which are now available on-line (Brown, 2008; Brown, 2009), and a further article with a specific focus on self-stimulation will be available soon.



What can you do?

This is typically a teacher's question, to get an idea of the thresholds of the child's skills so that you have a good idea where to start teaching. Much of the information needed to answer this question will come from direct interaction with the child to try to elicit responses from them. It is an important and highly relevant question, but it needs to be posed after the first 4 described above.

So how do you 'follow the child'?

Leaving aside questions of attitude and expectations, which are the essential starting points, success in this form of assessment is based upon meticulously careful observation of the whole child, collaboration with others (including especially those who know the child better than you do), interpretation of your observations, testing of those interpretations, and amending things until you are fairly certain that you have got things right, at least for the time being.

This intensity of observation is a quiet and undemonstrative business—I sometimes observe a child intently for an hour or so and then get asked when I intend to start my assessment because people don't realize that I am already doing exactly that! It is exhausting work if done thoroughly for several hours—it is not unusual for me to leave a school visit tired and with my brain spinning with impressions and possible interpretations—but it can be done in short periods too, with your observations compared and consolidated over time. On occasion I can observe a child carefully for just 30 minutes and then feel confident enough to intervene, introduce myself, and make a success of the interaction. This approach works, and nobody has ever shown me a better way to start to prepare for effective intervention and teaching. It is also an honorable and valid way of assessing and working with children, and Jan van Dijk, more than anyone else, has provided this validation for us in his lifetime's work. Watch his webcast on 'Child Guided Assessment' (van Dijk, 2011) and see wisdom, respect, practicality, and genuine caring at work.

What are you observing for?

Blaha gives useful ideas on what we should be observing for. Again, van Dijk (Nelson & van Dijk, 2009) has given us useful information about where our focus should be rather than the narrow skills-based emphasis of most conventional assessment procedures. His short list follows this sequence:

- Ability to maintain & modulate state. How well does the child achieve and remain in a receptive state of arousal which promotes perception and attention and learning, how well can they increase or decrease their state of arousal to maintain attention, and what activities and sensory inputs facilitate these processes?

- Preferred learning channels. Is the child a visual, an auditory, a tactile, or a movement learner? Does this vary, and under what circumstances? How are their sensory hierarchies impacted by both internal and external environmental factors?

- Ability to learn, remember & anticipate routines. This is a fundamental feature of caregivers behavior with infants, even on the simplest level of playing peep-bo or tickling games, and routines are used extensively in the field of deaf-blind education going up to a very complex and sophisticated level.

- Accommodation of new experiences with existing schemes. Once a routine is memorized, and recognized, how does the child cope with unexpected changes in the routine? Do they even notice the change, and what problem solving abilities do they show?

- Problem solving approaches. What abilities does the child demonstrate to perceive a problem and then find a solution to it? Do they give up easily, do they experiment with alternatives to find a way through the problem, do they ask others for help, or do they react with frustration and episodes of greatly raised arousal?

- Ability to form social attachments and interact. This includes recognition of others, memory of previously established social interaction patterns, differentiated behaviors with different people, and expansion of the social circle from a single special partner to others.

- Communication modes. Use of a multi modal language and communication approach to identify 'the child's preferred modes' over time (remembering that the preferred mode for expressive communication might be different to the preferred mode for receptive communication).

To this list I would add the importance of observing the child's postural preferences and the way they transition from one posture to another, which can offer insights into their distractibility issues, sensory needs, and self-regulation strategies.

I hope that anyone with responsibility for assessing a child they do not know will consider following the child in the ways that I have described as a first step, before they intervene to elicit responses from the child.

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