

**Doctors' Presentation Discussion Summary**  
ADVISOR Workshop  
14 March 2005

**Moderator: Luisa Mayer**

- If the doctors don't have information about the previous history of a patient (typically for children who are further along the process), then they are really at a loss.
- Measuring vision is really important (and not just for the doctors). It is also very important to recognize the strengths and weaknesses of the different ways of measuring vision.
- Theme: **What's it all worth?**
  - How do we convey worthwhile information to each other?

**Discussion/Comments/Suggestions:**

1. Doctors should take the lead from the TVI, in terms of how much information to provide, and how much time they spend with a patient. If the TVI is informed and knowledgeable, then the info provided should be short and direct. If the TVI is not as informed, then more detailed reports should be written.
2. It is extremely helpful for the TVI's to come to the evaluations, at least on occasion. This allows the doctors to understand what's going on in the classroom, which in turn allows them to make the appropriate recommendations, thus helping get the TVI's what they need. This way, the TVI's can have the doctor's backing if they need to go to the school system and ask for more resources for a specific student. Even email is good, if the TVI can't make it to the appointment.
3. Services are continuously hard to get. There is a national TVI shortage. MA and the region have taken steps to address it, but the need for more TVI's remains.
4. Two ways a doctor would get new patients: via reference from a TVI, or having families sent directly to them. If a TVI refers a student, the doctor has a framework of what the patient's questions might be. But if there's no TVI reference, the doctor is not sure what the background of the patient is. Usually, new patients are referred because the doctors need to assess if there is a service needed, and how much of it is needed. **To the doctors: Indicate concerns NOT educational prescriptions.** (In terms of determining the TVI time a child needs, doctors should stay away from specific hourly prescriptions, for instance, because they might not be certain of the TVI availability from state to state.)

5. ADVISOR needs to focus on how to increase the dialogue between teachers and doctors.
6. Parents do not generally recognize their power. For instance, they might not even know that their child has a TVI. Worst case scenario: parents don't get along with the TVI.
7. **Question:** What happens if there is a doctor's assessment and then services are not available (shortage of funds at school districts, etc.)?
  - o **Answer:** The School District can never legally say that they can not afford it. You can take them to court if they refuse. **Doctors, teachers, and parents need to fight for those services.**
8. Some parents don't realize the power that they have, and may be very passive. When parents come to you, they are looking for guidance. Giving them resources that they can look at (books, web sites) is a good idea. This helps them get started, because the parent is the first teacher. **Your responsibility as a parent is to teach your children things without waiting for the TVI's**, especially if they might not be readily available right away. **But how do doctors and TVI's tell parents to do that?** In answer to that, a suggestion was made to set up a web site just for that: a list of books and resources.
9. Everyone should be careful when recommending things to parents. Make a personal connection with the parent and recommend an organization such as NAPVI. It is better if the recommendation is personal and not generic (i.e. from a web site).  
**Good Basic Book for Parents: "Children with Visual Impairments".**
10. It is helpful when doctors write down all the recommendations for the kids with field defects, especially if they have multiple handicaps (because they can't express that they have a visual defect, and it usually takes a long time before that visual defect is identified). Therefore, that student might not have a TVI, which needs to be amended right away.
11. It is helpful when more detailed info is provided by doctors. This is a huge benefit to the TVI's, especially when it comes time for the teachers to do their learning assessments.
12. An example was brought up where one parent sees that another parent's child just had an ERG, so they say: "Why didn't I get an ERG?" Point: Assessments are done on a case-by-case basis. It should be made clear to the parents that not every student will have the same type of testing or treatment.
13. Another concern is that some parents don't want to do tests, because they are scared to find out what exactly is wrong, or they just don't want to know.

14. Issue raised: VEP Acuity is better than 20/200 in terms of numbers, but functionally, the child is doing much worse – causes problems because it's difficult to get state resources if you go by the numbers. The reports by doctors need to be sensitive to that and indicate if the child is FUNCTIONALLY blind. The following phrase was suggested: "Functionally legally blind, and should be considered for the all the benefits therein." Even if the numbers aren't exactly qualifying, it needs to be made clear that this child needs services.

**Responses:**

- 20/200 is the legal definition for blind.
- Acuity is not 20 over anything. It's cycles per degree. (Common mistake).
- Certain forms and reports do not require numbers, while other do; depends on what you're applying for, or whom you are reporting to.
- Difficulty: families take those reports to get Medicaid, for instance, where you need to have numbers included in the report. If the numbers don't accurately represent the child's visual condition, these families can not access additional services.
- Comment by Children's Boston doctor: the doctors always try to document how they test for acuity. Then they also include their recommendation and state how the patient performs visually in relation to their real-life environment. Meaning, if the test done to evaluate acuity is not all that comprehensive, and the doctor knows that the child "functions by the definition of blindness," they make sure to state that. Also, it's OK to admit if you don't get an accurate measurements with your tests.
- **Important:** Include numbers AND recommendations in reports, so that the TVI's can use those numbers and/or statements depending on the situation. If a report/application gets denied based on the numbers, having an explanation statement saying that "the child is functioning on a level of blindness" helps the case's chance for appeal.