New York Deaf-Blind Collaborative

A Tool for Identifying Vision and Hearing Loss in Children with Multiple Disabilities

[Funded by the U.S. Department of Education Office of Special Education Programs]



Queens College Powdermaker Hall 200 65-30 Kissena Blvd. Flushing, NY 11367-1597 www.qc.cuny.edu/nydbc nydbc@qc.cuny.edu

PURPOSE

This tool was created to assist classroom teachers, therapists, school nurses, and parents in identifying sensory impairments in children with multiple disabilities.

INTRODUCTION

Children with sensory impairments and multiple disabilities are a population that is challenging to educate and serve. Most learning comes through visual and auditory channels and when these avenues are impaired incidental and direct learning is reduced. While the impact of the sensory impairment may not always be the primary impediment to learning it is a factor that has significant impact on a child's ability to learn by affecting their access to the physical, social, and instructional environment. Use of appropriate modifications and instructional strategies can significantly increase access and, ultimately, development and achievement. A number of studies demonstrate that sensory impairments (hearing and vision losses) are significantly under-identified in children with multiple disabilities as well as in populations of people with developmental and intellectual disabilities.

A recent study from 2009 of adults with intellectual disabilities in an institutionalized population documents the percentage of those with sensory impairments as follows:

Hearing Impairment 46.0% Vision Impairment 38.4% Deafblindness 21.4%

(J. Fellinger, D. Holzinger, A. Dirmhirn, J. van Dijk, & D. Goldberg . 2009)

Based on national statistics of students with combined hearing and vision loss, the incidence of concomitant disabilities is also quite common. Some estimates of the occurrence of additional disabilities in children with hearing impairments are as high as 35% and vary between 40% and 70% for those with vision impairments alone (Chen, D. 2000). The complexities within this population make identification of sensory impairments, and, most notably dual sensory impairment (deaf-blindness), particularly challenging.

INSTRUCTIONS

This identification tool relies on three sources of data in determining if referral for a medical evaluation for hearing and/or vision loss is necessary:

- A. Observation
- B: Available medical information
- C. Parent Interview

A transdisciplinary team approach and inclusion of the parent in the process to the greatest extent possible are other critical features of this tool. The process is divided into 6 steps each with instructions on how they should be completed. The result of the tool is not a score but instead a set of facts about the child which assists you in making decisions that will affect the educational programming and overall service delivery for the child.

STEP 1: OBSERVE VISUAL AND AUDITORY BEHAVIORS

Behaviors that suggest Vision or Hearing Loss

If you suspect that your student has vision or hearing loss you should document those behaviors that lead you to believe that this is true. Below is a list of behaviors or characteristics typical of children who have vision and hearing loss. Check off those behaviors that are suspect, describe them if you think further explanation is needed and add any information you think pertinent to their sensory functioning and behaviors.

A. Vision			
	Appearance of the Eyes	Yes	No
Ι.	Atypical appearance of the eyes including eye alignment(crossed or turned eye)		
2.	Unusual eye movements (nystagmus)		
3.	Visible irregularities (sagging eye lids, shape, size, structure)		
4.	Tearing, redness of eye or eyelid		
5.	Absence of a clear black pupil, or pupil that is excessively large or small		
	Behaviors of the Student	Yes	No
Ι.	Unusual eye gaze or head position		
2.	Absence of visually directed behaviors that are expected for developmental		
	level		
3.	Lacks interest in visual materials		
4.	Poor reaching behaviors with under or over shooting of target		
5.	Squinting, tearing, frequently closes eyes		
6.	Turning away from light (photophobia)		
7.	Difficulty adapting to changes in lighting		
8.	Does not see as well in dim light		
9.	Does not look at faces		
10.	Pokes, presses or rubs eyes frequently		
П.	Holds visual materials close to face or at an atypical angle		
12.	Does not track moving objects		
13.	Does not visually inspects item being held		

B. HEARING

	Appearance of the Ears	Yes	No
Τ.	Cleft lip or palate		
2.	Malformations of head and neck		
3.	Malformations of ears		
4.	Frequent ear aches or infection		
5.	Discharge from ears		
	Behaviors of the Student	Yes	No
Ι.	Makes few or inconsistent responses to sound		
2.	Does not look at visual materials when asked to by someone		
3.	Does not startle or react to unexpected or new sounds		
4.	Does not respond to caregiver's calling name/not soothed by caregiver's voice		
5.	Shows a preference for certain types of sound (high or low frequency, louder or softer sounds)		
6.	Has limited vocalizations does not try to imitate		
7.	Has difficulty attending to auditory stimuli for a reasonable length of time		
8.	Does not turn to or localize voices or sounds		
9.	Abnormalities in voice, intonation, articulation		
10.	Pulls on or covers ears		
11.	Breathes through mouth		
12.	Angles head to one side so as to favor one ear		

Additional Information		

STEP 2: REVIEWING MEDICAL RECORDS

In reviewing a student's medical and educational records you should be looking for two main sources of information, first if there is any information, regardless of how old, that pertains to vision or hearing loss. This could be in medical or educational reports or IEP's. Secondly, look for conditions that are considered risk factors and that are associated with and have a high probability of either vision or hearing loss.

The following are known risk factors for vision and hearing loss. Look for these terms when reviewing medical records and document which ones are present:

RISK FACTORS FOR VISION AND HEARING IMPAIRMENT

Hereditary Syndromes and disorders

Syndrome/Condition	Vision/Hearing	Date of Document	Type of Document
 CHARGE Syndrome/Association 			
2. Down Syndrome			
3. Trisomy 13			
4. Usher Syndrome			
5. Alstrom Syndrome			
6. Goldenhar, Hurler, Norrie, Waardenburg			
Syndromes			
7. Other genetic syndromes or defects			

Prenatal History

History of maternal infection/exposure during pregnancy	Vision /Hearing	Date of Document	Type of Document
1. Rubella			
2. CMV (cytomegalovirus)			
3. Toxoplasmosis			
4. Herpes			
5. Syphilis			
Prenatal infant exposure to drugs or alcohol			
7. Cleft Lip or Palate			

Perinatal History

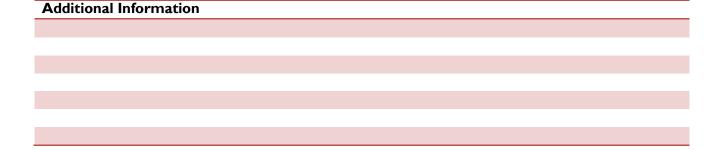
	Prematurity/Low Apgar	Vision Hearing	Date of Document	Type of Document
1.	Birthweight < than 1500 grams (3.3lbs)			
2.	Retinopathy or prematurity			
3.	Preterm birth, exposed to oxygen			
4.	On ventilator longer than 5 days			
5.	Elevated bilirubin requiring transfusion			
6.	Low Apgar scores (1-4 at 1 minute or 0-6			
	at 5 minutes)			

Post Natal History

	Prematurity/Low Apgar	Vision Hearing	Date of Document	Type of Document
1.	Meningitis or encephalitis			
2.	Hydrocephalus/hydrocephaly			
3.	Cerebral palsy or other neurological			
	disorders			
4.	Brain disorders, brain tumors or			
	malformations of the brain such as			
	Dandy Walker			
5.	Loss of oxygen to the brain			
6.	Severe head trauma			
7.	Prolonged fever			
8.	Child received "mycin" or other known			
	ototoxic medications			

"Red" Flag Terms

Medical Terms associated with Vision & Hearing Loss	Vision Hearing	Date of Document	Type of Document
1. Anoxia, asphyxia, hypoxia			
2. Atresia			
3. Cerebral hemhorrage			
4. Cerebral palsy			
5. Ischemia			
6. Meningitis			
7. Periventricular damage			
8. Fetal Alcohol Syndrome			



STEP 3: INTERVIEWING THE FAMILY

Families who have children with multiple disabilities are usually accurate reporters of their child's use of vision and hearing. They have more opportunities to see their child as well as a more diverse set of circumstances in which to see them. They also have the history of their child over the years in which to observe change. Interviewing parents with a set of discrete and open-ended questions will give a much broader view of the child and help to identify any issues with vision and hearing.

Appendix A and B are questions to ask parents about their child's vision and hearing. These questions are best asked face to face but, if not possible, then a telephone interview will suffice. These questions should not be treated as a form to send home as the impersonal nature of this approach will not yield useful information.

STEP 4: MEETING WITH THE FAMILY

If through the first three steps of the identification process it becomes likely that your student may have a vision or hearing impairment a meeting with the family should be requested to discuss the results of your observations and investigation.

There is no cut and dry threshold of determination but if both the educational team and the parent have suspicions, and the student's behavior and medical history support this, then a referral to the appropriate medical professional should be made.

The meeting to review this tool should include a discussion of your findings and thoughts as well as helping the parents find medical professionals they can access to have their child tested and, if appropriate, diagnosed. For students for whom you suspect a vision impairment, a referral to an ophthalmologist or low vision optometrist should be made. For students suspected of having a hearing loss, a referral to an Audiologist is in order (see Appendix of hearing and vision resources).

STEP 5: REFERRAL FOR MEDICAL FOLLOW-UP

Medical appointments are not always an easy experience for parents and helping them to prepare for the appointment will make it more productive for them and ultimately for the educational team, as there is a better chance of getting information that is useful in diagnosing and serving the child.

Giving the parents questions to ask the doctor can be extremely helpful in preparing the parents. Appendix C and D have questions for ophthalmologists and audiologists. These, as well as specific questions the parents or team have, should be formulated beforehand so the parent has them on hand for the medical appointment.

STEP 6: FOLLOW-UP MEETING TO DISCUSS MEDICAL FINDINGS

After the child has gone to their medical appointment for vision and/or hearing a follow-up meeting should be scheduled to assist the parents in understanding the results. If a vision or hearing impairment has been identified the next step is to make a referral for an evaluation by a teacher of the visually impaired and/or a teacher of the deaf and hard of hearing. These individuals will evaluate the child and make a recommendation for services that will be put on the IEP with appropriate goals and accommodations.

APPENDIX A

QUESTIONS TO ASK THE FAMILY ABOUT THEIR C	HILD'S VISION
Question	Comments/Observations
1. What have you been told by medical professionals (such as the	
pediatrician or family care physician) about your child's vision?	
2. Is your child taking any medications? What medical issues might affect	
your child's ability to learn to use vision?	
3. Do your child's eyes look typical (similar to other family members)?	
4. Have you noticed if one of the child's eyes turns inward, outward,	
upward, or downward? If so, when does this occur?	
5. Does anyone in the family have a vision problem, such as amblyopia, or	
"lazy eye"; farsightedness, nearsightedness, astigmatism, or color	
deficiency?	
6. What is your impression of your child's vision?	
7. What does your child like to look at?	
8. What kinds of things do you think your child sees, and in what activities	
does he/she use their vision?	
9. Does your child seem to respond to your face or to brightly colored toys?	
If so, how far away, or how close and in what positions does he/she notice	
them?	
10. Does your child use both eyes to look at objects or at your face when	
close to him/her (about 4 inches away)?	
11. What does your child do when you look at him/her from about 8 – 12	
inches?	
12. What toys/games does your child prefer? Toys that make sounds? Toys	
that are bright and colorful? Shiny toys?	
16. Does your child recognize people when they enter a room, when no	
auditory cue is given? How far away is the person when the child visually	
recognizes his/her presence?	
18. Have you noticed your child squinting when playing in bright sunlight?	
What is his/her reaction to an outside source of light or from lighting	
provided in an indoor environment?	
20. Have you noticed your child holding his/her hands near or against	
his/her eyes in usual ways, such as waving in front of or pressing the eyes?	
If so, when and how often?	
21. Does your child appear to tilt his/her head in an unusual way to look at	
things?	
23. Does your child watch TV or the computer? If so, where does he/she	
prefer to sit (distance from TV/computer, type of chair, angle of seat, etc.)? 24. How does your child locate things on the floor if they are dropped?	
, , , , , , , , , , , , , , , , , , , ,	
Does the child seem to use his/her vision to locate the items? If so, how? Additional Comments:	
Additional Comments.	

Adapted from "Essential Elements in Early Intervention: Visual Impairment and Multiple Disabilities" by Deborah Chen

APPENDIX B

QUESTIONS TO ASK THE FAMILY ABOUT THEIR C	CHILD'S HEARING
Question	Comments/Observations
1. What have you been told by medical professionals (such as the	
pediatrician or family care physician) about your child's hearing?	
2. Has your child had ear infections, if so how often?	
3. Is your child frequently congested? Do they have frequent colds?	
5. 15 your child requestly confested. Bo they have request colds.	
4. What is your impression of your child's hearing?	
5. What sound's get your child's attention?	
6. What does your child do when you call their name?	
or tribe accopion cima do triber you can circin hame.	
7. How does your child react to sudden loud noises? (telephone,	
car, vacuum)	
O Miles I Color of the color of	
8. What kinds of things do you think your child sees, and in what activities does he/she use their vision?	
activities does ne/sne use their vision!	
9. Does your child seem to respond differently when the television	
or radio is on?	
10. Does your child appear to enjoy toys with sound/noise?	
11. Doos your child onlow you talking or singing to them?	
11. Does your child enjoy you talking or singing to them?	
12. What words does your child seem to understand?	
Additional Comments:	

Adapted from "Essential Elements in Early Intervention: Visual Impairment and Multiple Disabilities" by Deborah Chen

APPENDIX C

Q	UESTIONS FOR THE FAMILY TO ASK THE OPHTHA	MOLOGIST
Qu	estion	Comments/Observations
1.	What vision tests were conducted?	
2.	What were the results of those tests?	
3.	How did the tests go? How did my child react during the tests? How confident are you in the results (reliability)?	
4.	What do the results mean in terms of my child seeing clearly?	
5.	Would my child benefit from glasses and, if so, what would it help him/her to see?	
6.	Do you suspect that my child has a progressive loss? Will his vision be worse in the future?	
7.	Is my child's vision the same in both eyes? Is there a "better eye" that will assist him/her in accessing materials or things in his/her environment?	
8.	When does my child's prescription need to be rechecked?	
9.	How does the information from the test results help my child's educational team?	
10.	Are there other tests that my child needs?	
11.	When should my child be retested?	
	Are there other tests for a child with additional disabilities that are better?	
13.	How can I prepare my child for further testing?	
Otl	ner comments:	

Adapted from "Essential Elements in Early Intervention: Visual Impairment and Multiple Disabilities" by Deborah Chen

APPENDIX D

Q	UESTIONS FOR THE FAMILY TO ASK THE AUDIOL	OGIST
Qu	estion	Comments/Observations
1.	What kind of hearing tests were conducted?	
2.	What did the test results measure and what were the results?	
3.	How did the tests go? How did my child react? How confident are you in the results (reliability)?	
4.	When should my child be retested?	
5.	What do the results mean for my child's ability to discriminate sounds and understand speech?	
6.	Would my child benefit from amplification (hearing aids, FM unit, etc.)?	
7.	What would be the best way to get more information my child's hearing? What are my next steps?	
8.	Is my child's hearing equivalent in both ears? Is there a "better ear" that	
_	will assist him/her in accessing speech or environmental sounds better?	
9.	Do you suspect that my child has a progressive loss? Will his hearing be worse in the future?	
10.	Is it possible for us to listen to the sounds that my child hears?	
11.	If my child gets hearing aids what type is recommended? Why is that style better for him/her than others?	
12.	With hearing aids, when will he/she need to get new molds?	
13.	Is my child a candidate for a cochlear implant? Why or why not?	
14.	When should my child be retested?	
15.	How does the information from the test results help my child's educational team?	
Otl	ner Comments:	

Resources for Evaluating Vision and Hearing

This list of resources is not an endorsement of the providers named; it is simply a resource that can act as a starting point for families who require evaluation of their child's vision and/or hearing.

VISION

Medical professionals who evaluate vision in children with suspected vision impairments are of two basic types, Pediatric ophthamologists (MD) and low vision optometrists (There are also regular optometrists, but in these instances a low vision optometrist should be used.). This can be a good starting point if a child requires evaluation for a suspected visual impairment. If the low vision optometrist suspects a medical condition they may refer the child to a pediatric ophthalmologist for follow up. Most hospitals and medical centers have pediatric ophthalmologists. Listed below are resources for both

PEDIATRIC OPHTHAMOLOGY

Pediatric Ophthalmic Consultants 40 West 72nd Street, Lobby New York, New York 10023

Phone: 212-981-9800 Fax: 212-981-9818

http://www.pedseye.com/office information.htm

Columbia Ophthamology Consultants Edward S. Harkness Eye Institute Flanzer Eye Center 635 W. 165th Street, NYC, NY 212-305-9535

http://www.cumc.columbia.edu/dept/eye/doctors/doc_coc.html

New York Eye and Ear Infirmary 310 East 14th Street, New York, NY 10003

Main Number: 212-979-4000

http://www.nyee.edu/pediatric-ophthalmology-and-strabismus.html

Ophthamology and Visual Science Montefiore Hospital 4141 Carpenter Avenue Bronx, NY 10467 Phone: 718-920-9734

http://www.montefiore.org/services/coe/surgery/ophthalmology/

Pediatric Eye Center Maimonides Hospital 902 49th Street Brooklyn, NY 11219 (718) 283-8000

http://www.maimonidesmed.org/Main/ClinicalServices/OphthalmologyEye 23.aspx

LOW VISION OPTOMETRY

SUNY College of Optometry University Eye Center 33 West 42nd Street, New York, NY 10036 (212) 938-4000 1-888-277-5666

http://www.sunyopt.edu/uec/index.php/eyecare for children/low vision children

HEARING

If you suspect that your child has a hearing loss the first point of contact for evaluation should be an audiologist. If further medical follow up is required the audiologist will refer the child to an ENT to determine a course of treatment.

Lexington Hearing and Speech 30th Avenue and 75th Street Jackson Heights, NY 11370 718.350.3170

http://www.lexnyc.org/hearspeech.html

Pediatric Audiology Department
Laurence D. and Lori Weider Fink Children's Ambulatory Care Center
160 East 32nd Street
(between Lexington and Third Avenues)
New York, NY 10016
(212) 263-7349
Fax: (212) 263-2597

http://ent.med.nyu.edu/patient/audiology-fink

Division of Audiology and Speech Columbia University Medical Center 3959 Broadway, BHN 5th Floor New York, NY 10032 212-305-0029 http://www.entcolumbia.org/audspdiv.html

Communication Disorders and Children's Hearing Program Children's Evaluation and Rehabilitation Center Albert Einstein College of Medicine 1300 Morris Park Avenue Bronx, NY 10461 (718) 430-8500

Center for Hearing and Communication 50 Broadway, 6th Floor New York, NY 10004 Phone: 917-305-7700

http://www.chchearing.org/

References

Chen, D., (1999). Essential Elements in Early Intervention: Visual Impairment and Multiple Disabilities, AFB Press, New York.

Cunningham, M., Cox, E.O., (2003). Hearing Assessment in Infants and Children: Recommendations Beyond Neonatal Screening, American Academy of Pediatrics, New York.

Lipkin P., (2006). Screening Implementation: Referral and Follow Up. www.medicalhomeinfo.org/downloads/ppts/DPIPReferral.ppt - 2010-02-08, downloaded February 2nd, 2011.

Malloy, P., Stremel Thomas, K., Schalock, M., Davies, S., Purvis, B., Udell, T. (2009). Early Identification of Children Who Are Deaf-Blind, National Consortium on Deaf-Blindness, Monmouth, OR.

NCDB 2008 Early Childhood Needs Survey: Summary, (2008). National Consortium on Deaf-Blindness, Author.

National Institute on Deafness and Other Communication Disorders, Hearing Developmental Checklist, http://www.nidcd.nih.gov/health/hearing/silence.asp, downloaded January 6th 2011, Author.

Recommended Practices for Vision Screening of Children Ages Birth to Five Years, (2006). Early Intervention Training Center for Infants and Toddlers With Visual Impairments, Author.