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The Evaluation of Children with Deaf-Blindness: A Parent Mini-Guide



Developed by the Statewide Parent Advocacy Network
in collaboration with the Perkins School for the Blind
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Dear parent of a child with deaf-blindness:

As the parent of a child with deaf-blindness, you face many challenges every day. You have hopes and dreams for your child, and you want their educational services to help them develop and learn.

In 2008, the Perkins School for the Blind worked with experts in deaf-blindness, including state deaf-blind projects, to develop Deafblindness: Educational Service Guidelines (the Guidelines). These guidelines provide state and local education agencies a framework to support the development of meaningful, appropriate programming for students with deaf-blindness. They also identify the knowledge and skills educators need to help their students who are deaf-blind reach their full potential and become successful, contributing members of our society.

In 2010-2011, the Perkins School for the Blind collaborated with the Statewide Parent Advocacy Network (SPAN), state deaf-blind projects, and families of children with deaf-blindness, to develop resource materials for families of children with deaf-blindness based on the Guidelines. The resource materials include fact sheets, mini-guides, and an IEP Meeting Checklist. You can access the resource materials and the Guidelines on the websites of SPAN (www.spannj.org), the Perkins School for the Blind (www.perkins.org), and the National Consortium on Deaf-Blindness (www.nationaldb.org). You can also find many other resources that will help you maximize your child's education and development on these websites. For additional assistance in advocating for your child with deaf-blindness in the education system, contact your state Parent Training and Information Center (PTI). You can find contact information for your PTI at www.parentcenternetwork.org. For additional assistance in advocating for your child with deaf-blindness in the healthcare system, contact your state Family to Family Health Information Center (F2F). You can find contact information for your F2F at www.familyvoices.org.

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The Evaluation of Children with Deaf-Blindness: Educational Service Guidelines

This mini-guide has been developed to guide you through the evaluation process of your child with deaf-blindness. It is based on the recommendations in Deafblindness: Educational Service Guidelines (the Guidelines).ⁱ



Federal Law: IDEA

If you are the parent of a child with deaf-blindness, your child's educational rights are protected by the Individuals with Disabilities Education Act (IDEA). IDEA guarantees the right to a "free, appropriate public education" to all children with covered disabilities from age 3 to 21. Deaf-blindness is a "covered disability" under IDEA.ⁱⁱ

Your school district must have written policies and procedures in place to ensure that they identify each potentially eligible child. Those policies and procedures must allow you to refer your child. Once you or a professional refers your child, you and a team from your district decide whether or not your child will be evaluated. If your district wishes to evaluate, they must obtain your informed, written consent to conduct an evaluation. If you do not want your child to be evaluated, and the district wants to evaluate, they must request and prevail at a due process hearing to move forward without your consent. If your child is determined to be eligible for special education, you must give informed, written consent for special education services to be provided. Your child must also be evaluated at least once every three years to determine continuing eligibility and needs.

Non-Discriminatory Evaluation

Once it's determined that there will be an evaluation, a decision must be made about the assessments that will be conducted as part of that evaluation. The assessments must be provided in the language used by your child and family. The evaluation must be "multi-disciplinary" (at least two professionals with different expertise). No single test can be used to determine if your child is eligible. At least one team member must be knowledgeable in the area of your child's suspected disability.

The evaluation reviews how your child is performing compared to peers and the general curriculum. The evaluation must identify all areas of suspected disability, and the impact of the disability on all education areas (including academic, behavioral, social-emotional, functional, etc.). It must consider your child's *strengths* as well as *needs*, and your concerns for enhancing your child's education.

The professionals who conduct your child's evaluation must have appropriate qualifications and credentials.

The evaluation also includes an interview with you and your child's teacher(s), a review of your child's developmental/educational history, a review of what works and what doesn't work in educating your child, and one or more "informal measures." The focus must be on enabling your child *to be involved in and progress in the curriculum all children are learning*.

Evaluating Your Child with Deaf-Blindness

Evaluating a child with deaf-blindness to identify their strengths and needs can be complicated. There are no standardized tools developed specifically for students with deaf-blindness. It is often more difficult for evaluators to identify what your child knows and can do, and not just the impact of their disability. Every child has a different combination of sensory losses, as well as possible cognitive, physical, and emotional challenges. There may be significant health/ medical issues. The Guidelines provide important information for you and the rest of the team to consider in the evaluation process: Who should be involved in the evaluation? What knowledge and expertise is important for evaluators? What tools should be used in the evaluation? What types of evaluation should be done? What information should be collected, and how? What is your role in your child's evaluation?

Who should be involved in the evaluation? What knowledge and expertise is important for evaluators? The professionals who evaluate your child with deaf-blindness must understand the impact of combined vision and hearing losses and be able to communicate effectively with your child.ⁱⁱⁱ IDEA requires that the evaluation be conducted in the language most likely to collect the needed information about your child's strengths and needs. So if your child uses sign-language, the evaluators must be able to communicate in sign language. If your child speaks Spanish, the evaluation should be in Spanish. The evaluation team should either be composed of individuals with expertise in deaf-blindness, or at least include a deaf-blind specialist to work with the other team members. Evaluators with expertise in deaf-blindness will understand that your child's combined sensory impairments are their primary disability even if they have other disabilities. They will be able to conduct and interpret functional vision and hearing assessments. They will help ensure that your child is not misdiagnosed and placed in inappropriate programs for children with physical or cognitive (intellectual) impairments if these are not the right setting for your child.

What tools should be used in the evaluation? What types of evaluation should be done? The evaluation must identify your child's current levels of functioning in all areas of development. As a starting point, your child should have an ophthalmological (vision), audiological (hearing), and neurological evaluation. These assessments will help identify your child's sensory and cognitive strengths and needs. If your child has physical/ motor limitations, the evaluation must also include an assessment of your child's fine and gross motor skills.

Identifying how your child communicates is at the core of the evaluation. Children with deaf-blindness usually face great challenges in communication even if they have some vision and hearing. They are often cut off from what others are saying, doing and feeling, and from what is happening around them. Communication is how people connect with others, and learn. Developing your child's "receptive" and "expressive" communication abilities is the most important way to improve their quality of life.



Because there are no formal assessments standardized for children with deaf-blindness, more informal and functional types of evaluation should be used for your child. For example, evaluators should observe your child in a variety of settings to see how s/he interacts and communicates with others. How your child uses other senses – especially touch – should be determined.

Functional assessments focus on functional vision and hearing, communication, academics, social competence, daily living skills, leisure and recreation, use of technology, motor skills, orientation and mobility, and vocational skills and interests. For your child with deaf-blindness, functional assessments provide a clearer, more accurate picture of your child's abilities than clinical assessments. *Curriculum-based assessments, interviews, and portfolio assessments* (reviewing your child's homework and classwork) are also valuable tools. *Ecological assessments* look at your child's strengths and needs to determine the adaptations, supports and accommodations important for them to be successful in a variety of settings. Tools such as the Learning Media Assessment can help determine the best learning media to use.^{iv}

Your child's evaluation should include assessments of your child's *literacy* and *numeracy* abilities.

Literacy: Reading and writing allow people to send and receive information. Your child with deaf-blindness should be exposed to a "literacy-rich" environment and have their literacy abilities measured. S/he may be able to see regular-sized print with magnification, large print, or read Braille, and become a reader! The evaluators must consider how much exposure your child has had to words in print or Braille as well as other types of language. As part of the evaluation, the evaluator should also expose your child to higher levels of literacy to encourage literacy development and evaluate their ability to move to higher levels of literacy. The Guidelines include important questions for evaluators to ask about literacy.^v

Numeracy: It is important that your child have the experience of using concrete objects for counting in everyday environments. These experiences are the foundations for math skills, or "numeracy." With effective teaching, your child with deaf-blindness may learn basic math or even college-level math concepts in the future.

The National Consortium on Deaf-Blindness has helpful information about assessments that may be appropriate to use in your child's evaluation.^{vi}

What is your role in your child's evaluation? Parental input must be considered in the evaluation of every child with a disability, but it is particularly important in the case of a child with deaf-blindness. You have valuable information that is essential in determining your child's strengths and needs. You share information with the evaluation team about your child's strengths; their medical, educational, and other history; important people in your child's life; what your child likes and dislikes; how you and your child communicate; your child's daily routines; and your hopes and dreams for your child. You also share the results of any outside evaluations, including medical information; your child's strengths, needs, preferences, and learning styles; and samples of your child's school and home work, and videos of your child in a variety of settings.^{vii}

Tips for Parents in the Evaluation Process

In preparation for the evaluation, ask questions!

- What questions do we hope will be answered by the evaluation?
- Who will be conducting the evaluation? What is their training and experience?
- In what settings will the evaluation be conducted?
- What areas will be evaluated?
- What specific tests or portions of tests will be used and why?
- Does the evaluation need to be adapted to compensate for my child's suspected disability? Does it need to be in sign or another language?

Ask for any written information on the evaluation process. Talk with other experienced parents, school representatives, or outside professionals about the evaluation process. Contact your state deaf-blind project to find out more information about evaluations for children with deaf-blindness and tools for you and the evaluation team. You can find your state deaf-blind project by going to the website of the National Consortium on Deaf-Blindness at <http://nationaldb.org> and clicking on your state, or call 800-438-9376.

For more information about or help with the referral and evaluation process, you should contact your state Parent Training and Information Center (PTI). You can find your state's PTI at <http://www.parentcenternetwork.org>.

For more detailed information about evaluation and other educational services for children with deaf-blindness, go to <http://www.perkins.org/resources/educational-publications/deafblindness-educational-service-guidelines> to access Deafblindness: Educational Service Guidelines. In terms of evaluation, these guidelines include:

Chapter 1 Foundations

Issue IV. Educational professionals who provide assessments of students who are deafblind should understand the impact of combined vision and hearing losses and be able to communicate using students' forms of communication.

Issue V. Educators should value family members as equal partners in educational planning for students who are deafblind.

Chapter 2 Education Personnel

Issue VII. Educational personnel should ensure appropriate participation of communication support personnel in all facets of the educational process for students who are deafblind.

Issue VIII. Educational personnel should be knowledgeable about assistive devices and technology appropriate for students who are deafblind.

Chapter 3 Assessment

Issue I. Assessors/evaluators should have knowledge of the impact of deafblindness on learning and have the expertise to select, administer, and interpret a variety of assessment approaches and data.

Issue II. Assessors/evaluators should understand and use a variety of communication forms. They should have the ability to interpret and respond to students' forms, reasons and meanings of communication.

Issue III. Assessment and evaluation of students who are deafblind should be a collaborative, comprehensive, and ongoing process that includes authentic assessments.

Issue IV. Assessments and evaluations should occur across a variety of natural environments (home, community, school) to determine students' functional abilities (communication, self-care, vision and hearing, orientation and mobility).

Issue V. Evaluation of literacy and numeracy abilities should be included in the assessment process.

Issue VI. Assessors/evaluators should actively involve families in the assessment process and give consideration to family cultures and values.

Issue VII. Assessment/evaluation should lead to ongoing planning and implementation of the individualized education program.

Chapter 5 Supportive Structure and Administration

Issue V. State and local education agencies (SEAs and LEAs) should ensure that students receive ongoing and appropriate assessments that will enable educational teams to develop and implement individualized education programs.

Conclusion

The evaluation of your child with deaf-blindness for special education, if it is done well, will give you and the school team the information you need to develop an appropriate plan for services that builds on your child's strengths to address their needs. The National Dissemination Center for Children with Disabilities (NICHCY) has more information on the evaluation of children with disabilities.^{viii} CADRE, the National Center on Dispute Resolution in Special Education, has resources that can help you work more effectively with your child's school, and prevent or resolve disputes.^{ix}

ⁱ Deafblindness: Educational Service Guidelines,
<http://www.perkins.org/resources/educational-publications/deafblindness-educational-service-guidelines>

ⁱⁱ IDEA defines "deafblindness" as "concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness." Your child does not have to be totally deaf or totally blind to qualify.

ⁱⁱⁱ Deafblindness: Educational Service Guidelines, Chapter 1, Foundations, Issue IV.

^{iv} <http://www.perkins.org/resources/scout/literacy-and-braille/learning-media-assessment.html>

^v Deafblindness: Educational Services Guidelines, Chapter 3, Assessment, Issue V.

^{vi} <http://nationaldb.org/ISSelectedTopics.php?topicCatID=792>

^{vii} Deafblindness: Educational Service Guidelines, Chapter 1, Foundations, Issue V; Chapter 3, Assessment, Issue VI.

^{viii} <http://www.nichcy.org/EducateChildren/evaluation>

^{ix} <http://www.directionservice.org/cadre/>