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Developing an Effective IEP for Children with Deaf-Blindness: A Parent Mini-Guide



Developed by the SPAN 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.spanadvocacy.org), the Perkins School for the Blind (www.perkins.org), and the National Center 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 Parent Center at www.parentcenterhub.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.

We would like to thank the Conrad N. Hilton Foundation for funding these resources. We would also like to thank the New York and New Jersey deaf-blind projects for their assistance in facilitating parent focus groups; the state deaf-blind project staff and parents of children with deaf-blindness who participated in focus groups and provided feedback on the resources; and the Perkins School for the Blind for their ongoing support.

Developing an IEP for Children with Deaf-Blindness: Educational Service Guidelines

This mini-guide will help you work with your child's team to develop a plan for services, an *Individualized Education Program (IEP)*, for your child. The IEP is the road-map for your child's future!

Developing a Plan for Services

Once your child with deaf-blindness has been determined eligible for special education services under the Individuals with Disabilities Education Act (IDEA), the federal special education law, an IEP must be developed by you and other members of the IEP team. This team must include:

- ♦ You and any one else you would like to participate (other family members, friends, advocates, your child's doctors and specialists);
- ♦ Your child's general education teacher, if your child is or may be participating in general education. The general educator must participate in all decisions affecting general education;
- ♦ An individual qualified to provide or supervise special education;
- ♦ Someone who can interpret evaluations; and
- ♦ A district representative authorized to make commitments/decisions.

At least one member of the team should be someone with expertise in deaf-blindness, including

- ♦ The diversity and unique needs of students who are deaf-blind;ⁱ
- ♦ The importance of and strategies to strengthen communication skills who are deaf-blind;ⁱⁱ
- ♦ Appropriate service options and supports needed for students who are deaf-blind;ⁱⁱⁱ
- ♦ How to teach literacy and numeracy for students with deaf-blindness;^{iv}
- ♦ Appropriate assistive devices and technology;^v and
- ♦ The legislation and state and federal resources that support the education of students who are deaf-blind,^{vi} including state deaf-blind projects.)

Team members must also value your knowledge about how your child behaves and learns and your input into the process.^{vii} You are a valuable member of the team who has the best knowledge and understanding of your child across areas of communication and learning.

The IEP must contain information on your child's primary and any secondary disabilities, including your child's "classification." Your child's specific needs, not classification, should drive IEP decisions. The IEP includes:

Present levels of educational performance, including how your child's deaf-blindness and other disabilities affect her/his academics, social and emotional development, behavior, functional life skills, self-awareness, and ability to communicate needs, emotions, and knowledge. This must include strengths as well as needs, and the impact of their combined vision and hearing loss.

Measurable annual goals and short-term objectives or benchmarks, related to meeting your child's needs and to enable your child to be involved in and progress in the general curriculum. There must be at least one goal for each identified need. If your child will be taking the alternate proficiency assessment, there must also be short-term objectives or benchmarks for each goal.^{viii} Make sure that there is specific communication, literacy (reading and writing) and numeracy (math), social relationship, and expanded curriculum goals addressed to their individual needs.^{ix} *It is vital that you and the team focus on your child's potential and not just his/her limits.*

Specific special education (specially designed instruction) and *related services* (services your child needs to benefit from his/her education). Make sure that the team considers services to foster peer-to-peer, student-teacher, and student-parent communication, literacy and numeracy, development of social skills, and ability to use assistive technology.^x

Related services that may be appropriate for your child and that are available as part of the IEP if needed include:

- ♦ Speech language pathology and audiology services
- ♦ Interpreting services
- ♦ Psychological services
- ♦ Physical and occupational therapy
- ♦ Recreation, including therapeutic recreation
- ♦ Counseling services, including rehabilitation services
- ♦ Orientation and mobility services
- ♦ Medical services for diagnostic or evaluation purposes
- ♦ School health services and school nurse services
- ♦ Social work services in schools
- ♦ Parent counseling and training, if needed to ensure that your child benefits from their special education and related services.^{xi}

The IEP must also specify the types of professionals who should be involved in educating your child, as well as the types of specialized knowledge and expertise those professionals should have to address your child's needs.

Consider the following possible personnel to include in the IEP:^{xii}

- ♦ **Deaf-Blind Specialist:** A deaf-blind specialist can provide direct services to your child, or consultation to teachers and support staff, and understands the unique effects of combined vision and hearing loss in communication, learning, orientation and mobility, social skills, etc.
- ♦ **Teacher of Students with Visual Impairments (TVIs):** TVIs can help your child use optical (low vision) and non-optical devices (e.g., reading stands); identify and/or modify visual materials (e.g., large print); and acquire materials from the American Printing House for the Blind.
- ♦ **Teacher of the Deaf/Hard of Hearing:** This teacher can help with communication and assisted listening devices, and address hearing-related literacy issues.
- ♦ **Orientation and Mobility Specialist:** Orientation and mobility instruction will give your child skills to understand and navigate his/her environment, including developing independent travel skills. The orientation and mobility specialist must be able to communicate with your child in his/her primary mode of communication such as sign language, touch or object cues, or alternate communication forms.
- ♦ **Intervener:** An intervener, a one-to-one service provider with training and specialized skills in deaf-blindness, facilitates access to environmental information usually gained through vision and hearing; the development and use of receptive and expressive communication skills; and positive relationships to promote social-emotional well-being.
- ♦ **Paraprofessionals:** One-on-one instructional aides or assistants provide support for communication, sensory access, movement, delivery of direct instruction, and personal care for your child with deaf-blindness. The IEP should specify whether your child requires one or more paraprofessionals throughout the entire day or for particular classes or transitions, and the knowledge, expertise and training they need, including being trained in deaf-blindness and having access to modeling, coaching, and monitoring by professionals with expertise in deaf-blindness. The IEP should provide a clear description of their responsibilities, and specify the educator who will supervise them.
- ♦ **Interpreter:** If your child uses sign language as his/her primary language, s/he will require the services of a trained interpreter whose services should be tailored to your child's specific needs. If your child also requires tactile (touch) communication, the interpreter must have specialized training in interpreting for students who are deaf-blind.

Supplementary aids and supports that will be provided to or on behalf of your child to help her/him attain the goals and be involved in and progress in the general curriculum and participate in extra-curricular activities.



Examples of supplementary aids and supports highlighted on the website of the National Dissemination Center for Children with Disabilities include^{xiii}:

- ♦ “*Supports to address environmental needs* (preferential seating; planned seating on the bus, in the classroom, at lunch, in the auditorium, and in other locations; altered physical room arrangement);
- ♦ *Levels of staff support needed* (e.g., consultation, stop-in support, classroom companion, one-on-one assistance; type of personnel support; behavior specialist, health care assistant, instructional support assistant);
- ♦ *Planning time* for collaboration needed by staff;
- ♦ *Child’s specialized equipment needs* (e.g., wheelchair, computer, software, voice synthesizer, augmentative communication device, utensils/cups/plates, restroom equipment);
- ♦ *Pacing of instruction* needed (e.g., breaks, more time, home set of materials);
- ♦ *Presentation of subject matter* needed (e.g., taped lectures, sign language, primary language, paired reading and writing);
- ♦ *Materials* needed (e.g., scanned tests and notes into computer, shared note-taking, large print or Braille, assistive technology);
- ♦ *Assignment modification* needed (e.g., shorter assignments, taped lessons, instructions broken down into steps, allow student to record or type assignment);
- ♦ *Self-management and/or follow-through* needed (e.g., calendars, teach study skills);
- ♦ *Testing adaptations* needed (e.g., read test to child, modify format, extend time, use Braille);
- ♦ *Social interaction support* needed (e.g., provide Circle of Friends, use cooperative learning groups, teach social skills);
- ♦ *Training* needed for personnel.”

The IEP must also include the *projected date for beginning of services; the frequency, duration and location of services; and who will be responsible for implementing each service.*

Other topics that must be addressed in the IEP include:

Equal program access: Access to the same educational and extra-curricular and non-academic services and activities available to children without disabilities, with needed accommodations. This includes before- and after-school programs, clubs, and other activities. If your child is being educated out of district, you may want to discuss having the district transport your child back to their neighborhood school to participate in after-school activities to support the development of friendships and social skills.

The extent of your child's *participation in state and district-wide assessments*, and any *modifications or accommodations*. Decisions to exclude your child from assessments must be justified in writing, and the IEP must describe alternate ways to measure your child's progress. The National Consortium on Deaf-Blindness has information on testing modifications and accommodations for children with deaf-blindness, as well as information on alternate assessment for children with deaf-blindness.

Your *child's placement*, which should be in the regular classroom to the maximum extent appropriate. You and the team should consider the full range of placements, and the types of supports that might be needed to make more inclusive settings work for your child with deaf-blindness.

Needed personnel development, to ensure that all your child's teachers, related services providers, and aides are qualified, and are knowledgeable about and know how to use effective practices for educating children with deaf-blindness in general, and meeting your child's specialized, individualized needs, including how to create an environment where your child feels comfortable and accepted, and where your child's curiosity and problem-solving skills are stimulated.

The methods that will be used to *determine your child's progress toward the goals*. You must receive a report on your child's progress at least as often as reports are provided to parents of children without disabilities.

Special Circumstances:

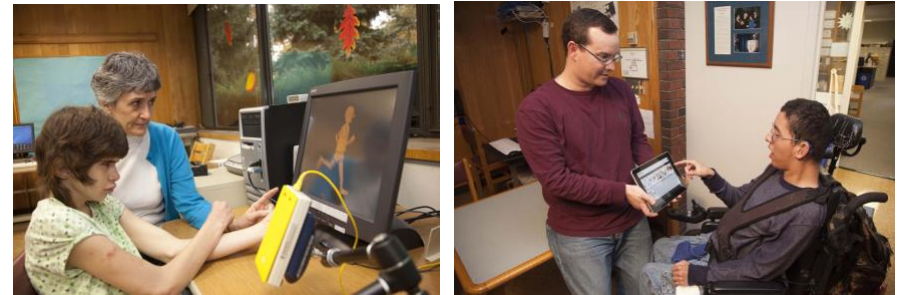
Under the IDEA, there are special issues that must also be discussed at *every* IEP meeting, and if needs are identified, they must be addressed. Your child with deaf-blindness will likely need services in each of these areas.

Need to communicate with peers, teachers, and you, in their mode (method) of communication.

Need for extended school year (services over the summer, if your child needs year-round services to maintain progress toward goals). Extended school year (ESY) services must be individualized.

Need for students who are blind to learn Braille (any decision not to teach a student with blindness Braille must be justified).

Need for assistive technology (computers, tape recorders, communication devices, slant board, pencil grip, etc., for school and home use if necessary).



Behavior needs (functional behavior assessment and positive behavior support plans for students with challenging behaviors that interfere with their or other students' ability to learn).

Transition to adult life services, starting no later than the school year in which your child will turn 16, including teaching your child self-advocacy and independent living skills. Some states begin the transition to adult life process at age 14. You can get information about state-specific transition requirements from your state PTI at www.parentcenterhub.org.

Tips for Parents of Children with Deaf-Blindness: The IEP Meeting

Before the meeting, write a list of concerns or issues that you feel are important to discuss. Ask to see your child's school folder and any reports or evaluations prior to the meeting. (You have the right to see your child's records and any information that will be discussed at the IEP meeting in advance of the meeting under FERPA, the Family Educational Rights and Privacy Act, also known as Buckley Amendment).^{xiv}

Talk to your child's teacher(s), related services providers, communication specialists, and other professionals who work with your child. Discuss any questions or concerns you have prior to the meeting so meeting time can be used productively to formally develop the plan. Request that a team member with expertise in deaf-blindness participate, in writing.

Remember that you are an expert on your child. Be prepared to share your observations of your child's functioning in all areas, as well as your expectations and vision for the future. If your child already has an IEP, familiarize yourself with the current IEP. Are current services effective? Are additional services needed? Are some current services not needed? If your child is not yet receiving services, talk to other parents of children with deaf-blindness about services and supports that have worked for their children.

Think about whether your child should be included at the meeting and discuss this with your child's teacher and the IEP team. (You have the right to involve your child in any or all of the IEP meeting. At age 16, your youth has the right to participate in her/his IEP meeting). If your child will not be attending the IEP meeting, be sure to get their input in advance.

Be a good listener. If you do not understand, ask that it be restated. If there isn't enough time to discuss all of your important issues, don't feel rushed to agree to the IEP. When the time is up, let the rest of the team know that there are still issues to talk about, and ask when the IEP meeting can be continued. CADRE, the National Center on Dispute Resolution in Special Education, has useful resources on how to build a positive relationship with your IEP team and minimize or resolve conflict.^{xv}

For more information about the IEP process and your rights in that process, contact your state PTI. For general information about the IEP process under IDEA, go to <https://www.parentcenterhub.org/iep/>. For more specific information about IEP development for children with deaf-blindness, read the Guidelines^{xvi} or check out the [IEP Quality Indicators for Students with Deaf-Blindness](#).^{xvii} To find your state deaf-blind project, go to the website of the National Center on Deaf-Blindness at www.nationaldb.org and click on your state or call 800-438-9376.

ⁱ [Deafblindness: Educational Service Guidelines](#), Chapter 1 Foundations Issue I

ⁱⁱ Chapter 1 Foundations Issue III, IV

ⁱⁱⁱ Chapter 1 Foundations Issue VI

^{iv} Chapter 2 Educational Personnel Issue V

^v Chapter 2 Educational Personnel Issue VIII

^{vi} Chapter 1 Foundations Issue VII

^{vii} Chapter 1 Foundations Issue V; Chapter 2 Educational Personnel Issue IV; Chapter 4 Services & Placement Options Issue I

^{viii} Your state PTI can tell you if short-term objectives are required for all children.

^{ix} Chapter 4 Services & Placement Options Issues II, IV, V

^x Chapter 4 Services & Placement Options Issues IV, VI

^{xi} <https://www.parentcenterhub.org/iep-relatedservices/>

^{xii} Chapter 2 Educational Personnel Issue VI, VII

^{xiii} <https://www.parentcenterhub.org/iep-supplementary/>

^{xiv} www.wrightslaw.com/info/ferpa.index.htm

^{xv} <https://www.cadeworks.org/for-families>

^{xvi} **Deafblindness: Educational Service Guidelines IEP Development Guidelines:** https://www.nationaldb.org/media/doc/DESG_Final.pdf

Chapter 1 Foundations

I. Educators should be knowledgeable about the diversity of students who are deafblind and their unique educational needs.

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

VI. Educators should be knowledgeable about appropriate service options and supports needed by students who are deafblind throughout their education and transitions.

VII. Administrators, educators, and other team members should be knowledgeable about the legislation and state and federal resources that support the education of students who are deafblind.

Chapter 2 Educational Personnel

IV. Educational personnel should possess skills to promote full participation of families.

V. Educational personnel should be knowledgeable about teaching literacy and numeracy to students who are deafblind.

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

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

IX. Educational and related service personnel working with students who are deafblind should have a supportive network of and supervision by persons knowledgeable in the education of these students.

Chapter 4 Services and Placement Options

I. The educational team must fully include the family and student in developing the Individualized Education Program (IEP) and Individualized Transition Plan (ITP).

II. The team should consider how the student's combined vision and hearing losses may create a need for one-on-one support to access and participate in the life of the school.

III. The educational team should consider the challenges unique to the student who is deafblind to ensure appropriate educational services and placement decisions.

IV. The educational team should ensure that goals and objectives addressing the development of communication and social relationships are included in the IEP and ITP to meet the individual needs of the student who is deafblind.

V. The educational team should ensure that services address expanded curriculum areas to meet the unique needs of the student who is deafblind.

VI. Educators should ensure the availability and use of assistive technology for students who are deafblind.

^{xvii} www.tsbvi.edu/attachments/1800_IEP_Indicators.pdf