

Parent Center Guide to Deafblindness: Educational Service Guidelines

Helping Families of Children and Youth with Deaf-Blindness in the Evaluation, IEP, and Transition to Adult Life Processes



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in collaboration with the Perkins School for the Blind
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Dear Parent Center:

Parents of children with deaf-blindness face many challenges every day. They have hopes and dreams for their children, and they want their children's 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.

The Guidelines 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, an IEP Meeting Checklist, and this guide for parent centers. You can access all of 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 your staff help parents of children with deaf-blindness maximize their children's education and development on these websites.

The authors of the series of parent resources based on the Guidelines would like to thank the Conrad N. Hilton Foundation for funding their development.

We would also like to thank the New York and New Jersey deaf-blind projects for their assistance in facilitating parent focus groups; the many representatives of state deaf-blind projects 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.

If you would like assistance in using this guide, the Guidelines, or the parent resources, please feel free to contact the Statewide Parent Advocacy Network. Contact us at (973) 642-8100 or span@spannj.org.

Introduction

Deafblindness: Educational Service

Guidelines¹ (the Guidelines) were written by a team of specialists in the field of deaf-blindness, including representatives from state deaf-blind projects, University deaf-blind training programs, direct service providers, the National Consortium on Deaf-Blindness staff, and families of children and youth with deaf-blindness. They represent the “best thinking,” and in some areas, evidence-based research, on what works for infants, toddlers, children and youth with deaf-blindness.

The Guidelines have several purposes. They can help state early intervention (EI) and special education lead agencies develop systems of support and effective approaches to meeting the needs of infants, toddlers, children and youth with deaf-blindness at the policy level. They can also help EI, district and school administrators, educators, and paraprofessionals who work with students who are deaf-blind, and their families, more effectively evaluate students who are deaf-blind, develop appropriate Individualized Education Programs (IEPs) and transition plans, and implement “best practices” so that students who are deaf-blind can receive appropriate early intervention services and a free, appropriate public education in the least restrictive environment that meets their needs.

Parent Training and Information Centers and Community Parent Resource Centers (parent centers) offer invaluable support to all families of children with disabilities, but especially to families of children with the most significant disabilities, including deaf-blindness. Families of children with deaf-blindness are important in the education of their children because:

- Families are the constant from birth to adult life in their child’s educational and life experience.

- Children with deaf-blindness often communicate in unique ways that are understood best by their family members.
- Families are most aware of the priorities that must be addressed for their child to fully participate in the flow of daily life at home and in the community.
- Families must reinforce the concepts and skills learned at school so that those concepts and skills can be used meaningfully and equally in their communities.
- The child’s development is linked to their family’s cultural background and life priorities, and it is only the family who can share those values with the professionals who work with their child.

Because of the critical importance of families of children with deaf-blindness in the education of their children, and the critical importance of parent centers in helping families of children with disabilities fulfill their roles, this guide has been developed to help parent centers help parents. In this guide, we will address how you can provide effective technical assistance on topics such as:

- Who are children with deaf-blindness?
- What kind of special training is needed by professionals to work with such students?
- What is different about the evaluation of a child with deaf-blindness, and who should be part of the evaluation team?
- What IEP services are important for children with deaf-blindness?
- What are the considerations regarding placement options for a child with deaf-blindness?
- What kinds of supports are available in your state and how do you reach them?

Who are children with deaf-blindness?

The educational rights of children with disabilities 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 Under IDEA, deaf-blindness is defined as “auditory and visual impairments, the combination of which creates such severe communication and other developmental and learning needs, that they cannot be appropriately educated in special education programs solely for children and youth with hearing impairments, visual impairments, or severe disabilities, without supplementary assistance to address their educational needs due to these dual concurrent disabilities.” ³⁴ *CFR, Part 300, Subpart A, §300.7(c)(2)*

Children may be classified as “deaf-blind” based on significant hearing and vision loss even if they have some vision and hearing. Many children with deaf-blindness are not classified as “deaf-blind,” but instead are classified under other eligibility categories such as intellectual disability, deaf or blind (depending on which of these senses are most impaired), or multiply disabled, among others. The Guidelines can help guide evaluation, IEP development, instruction, and transition for students who are both visually and hearing impaired, regardless of classification.

There are also infants and toddlers who are eligible for early intervention services due to deaf-blindness because they are “infants and toddlers with disabilities,” defined in IDEA as children “from birth through age two who need early intervention services because they are experiencing developmental delays... in one or more of the following areas: cognitive development; physical development, including vision and hearing; communication development; social or emotional development; adaptive development, or have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay.”ⁱⁱⁱ ³⁴ *CFR, Part 303, Subpart A, §303.16*

Children with deaf-blindness may be born with deaf-blindness or develop deaf-blindness as a result of disease or injury. Some of the conditions that may lead to deaf-blindness include CHARGE Syndrome, Usher syndrome, Leber’s amaurosis, and Down syndrome. Children may also have deaf-blindness because of pre- or post-natal complications, complications related to prematurity, infections such as meningitis, etc.

Risk factors for hearing loss include family history, maternal infection, prematurity, hypoxia, cleft palate, various syndromes, hyperbilirubin, Apgar score of 3 or less, ototoxic medication, prolonged ventilation, and infection (such as meningitis). Risk factors for vision loss include family history, prenatal infection, prematurity, hypoxia, various syndromes, and cerebral palsy.

It is important for parent centers, parents, and the professionals who work with children with deaf-blindness to understand that:^{iv}

- An adequate basis for communication and an understanding of the environment are essential.
- The use of any residual hearing, vision and other senses is central to learning.
- The child must have an environment s/he can predict and control.
- Parent involvement is critical at all stages.

What kind of special training is needed for professionals in this field?

Deaf-blindness is “a unique, low-incidence disability, and students [] require a team of highly trained professionals and paraprofessionals to ensure that they receive the same access to an education as every other student.”^v Children with deaf-blindness need a bridge to connect them to people, the social environment, their physical environment, and all learning. Thus, professionals who work with children with deaf-blindness should:

- Have an in-depth understanding of different communication modes, from earliest communication through symbolic communication (spoken, written, and signed language);
- Know how to build communication abilities in children with sensory deficits;
- Be aware of the impact that sensory and cognitive impairments have on learning;
- Have knowledge of alternative and augmentative systems of communication;
- Know how to teach strategies to children who cannot physically access their learning environment;
- Create real life-learning opportunities;
- Have the ability to integrate information from and assist other professionals in meeting the needs of children who are challenged in processing sensory information and communication from others; and
- Employ a family-friendly approach including the family in all planning.

These are the knowledge, skills, and strategies that will enable the professionals to help students with deaf-blindness access the curriculum and become full participants in home, school, and community life.

How to Help Families Use the Guidelines and Resource materials

Parent Centers provide information, training, technical assistance, and support to families of children birth to 26 with disabilities, including deaf-blindness. Parent Centers have resource material for families on evaluation, IFSP and IEP, natural environments and least restrictive environment (LRE), participation in assessment, and transition to preschool and adult life, among other topics. All families of children with disabilities need information about special services. Families of children with deaf-blindness also need *specific* information about each of these processes for children with deaf-blindness.

The Guidelines and accompanying resource materials that have been specifically developed for families will help your staff and the families you serve use the Guidelines for positive outcomes for infants, toddlers, children and youth with deaf-blindness.

Technical Assistance

To prepare your staff to be ready to help parents of children with deaf-blindness in the IFSP and/or IEP process, and throughout their early intervention and educational experience, share with them this Parent Center Guide as well as the fact sheet series that links directly to the Guidelines. There is also a power-point presentation that you can use to help educate your staff so they have the knowledge and expertise to help families of children with deaf-blindness.^{vi}

It is important to prepare your staff, because deaf-blindness is a very low-incidence disability. If you have parents on your staff with direct experience and expertise with this disability, it will be invaluable to include them in the process of staff education, so that they can share their experience and expertise. However, there have been many recent developments in the field of deaf-blind education, so you will want to make sure that your staff development is up-to-date. (For example, 20 years ago, many children with deaf-blindness would have been placed in institutions, whereas today almost all children with deaf-blindness live with their families at home.) Once your staff is trained, you are ready to welcome parents of children with deaf-blindness to obtain effective technical assistance (TA)!

When a parent of a child with deaf-blindness contacts your parent center for TA, your staff will find out the stage of the process (evaluation/assessment, IFSP/IEP development, IFSP/IEP implementation, transition to preschool or adult life) in which the family is currently engaged.

At that point, your staff can share a copy of the relevant fact sheet with the family. Each fact sheet addresses a particular stage of the process, and links directly to the relevant sections of the Guidelines that are available on-line.^{vii} Each fact sheet is available in English and Spanish. Remember that IEPs should contain services that are research-based to the extent practicable. The Guidelines are based on the best available research, and thus families can advocate for the recommendations contained in the Guidelines to be incorporated into their IEP.

Your staff should also refer the family to your state deaf-blind project.^{viii} Each state has a deaf-blind project that is charged with supporting children with deaf-blindness in the early intervention and special education systems; they have a wide array of resources and supports available on-line or in person.

Technical assistance regarding the evaluation process

The Guidelines address seven main points regarding the evaluation process.

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."^{ix}

What is different about the evaluation of a child with deaf-blindness?

A parent of a child with deaf-blindness needs to know the general requirements for evaluation (timelines, requirement that it be multi-disciplinary, language protections, notice and other procedural safeguards, the role of families in providing information to guide the process, etc.) In addition, parents should understand specific components and professionals who should be involved in the evaluation process for a child with deaf-blindness.

In evaluating a child with deaf-blindness, it is critical to determine:

- What can s/he see and hear (degree of hearing loss, visual acuity, visual field)?
- How quickly can s/he learn new concepts and skills, and what is her/his learning style? Determining an appropriate pace for material to be presented that allows the child to tactilely explore materials or process information is critical.
- How does s/he communicate with others, and how do we need to communicate with him/her for us to be understood?
- What teaching strategies work best?

Multi-disciplinary initial and ongoing assessments may include:

- Communication, including pre-linguistic communication
- Sensory (vision, hearing, balance, smell)
- Social, leisure and recreation
- Motor, including orientation and mobility
- Compensatory mechanisms used
- Independent living
- Career
- Self-determination.

Students with deaf-blindness often have health and medical complexities in addition to the vision and hearing loss that can be best explained by their medical specialists. These factors can impact their academic and overall cognitive functioning as well as their ability to function in the school environment.

Ensuring that health professionals (primary care providers and specialists) share up-to-date and comprehensive information with the evaluation team will enable the team to include and consider medical/health factors in the evaluation process so that all of the student's complex learning, therapeutic, health and educational needs are identified in the evaluation and addressed in the IEP. Support groups for specific conditions (e.g., CHARGE syndrome) often have valuable information available at their web sites.

Who should be part of the evaluation team and what knowledge and expertise should they have?

Assessments should be performed by a team whose members have knowledge and skills in deaf-blindness and who:

- Understand the impact of combined vision and hearing losses on development;
- Are able to communicate easily (and interpret communication of the child who is deaf-blind);
- Have the confidence to welcome family members into the assessment process and respect the critical information they have to share with the team;

- Have the ability to conduct, interpret or support low vision and functional vision assessments, audiology and functional auditory assessments, and assistive technology assessments, and
- Have the ability to work together with all team members, especially family members, to set meaningful educational priorities and determine the best strategies and environmental adaptations for learning.

The professionals who evaluate a child with deaf-blindness must be able to communicate using the child's forms of communication.^x IDEA requires that the evaluation be conducted in the language most likely to collect the needed information about the child's strengths and needs. So if the child uses sign-language, the evaluators must be able to communicate in sign language. 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. Such evaluators will understand that the child's combined sensory impairments are their primary disability even if they have other disabilities. They will help ensure that the child is not misdiagnosed and placed in inappropriate programs for children with physical or cognitive impairments.

How can we ensure that the evaluation is non-discriminatory?

When a child is going to be evaluated by the school district, 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 the child and family (including sign language if appropriate). The evaluation must be "multi-disciplinary" (at least two professionals with different expertise). No single test can be used to determine if a child is eligible. At least one team member must be knowledgeable in the area of the child's suspected disability.

The participation of an evaluator knowledgeable about deafness/hearing loss, blindness/vision loss, and the unique aspects of the combination of these two disabilities, is both essential and required.

IDEA requires that the professionals who conduct evaluations have appropriate qualifications and credentials. Parents should inquire about evaluation team members' qualifications and credentials in working with children with deaf-blindness.

The evaluation reviews how the child is performing compared to peers and the general curriculum. The evaluation must identify all areas of suspected disability. It must consider the child's *strengths* as well as *needs*, and parental concerns for enhancing their child's education. In working with the parent, parent centers can help direct the parents' attention to their child's strengths and can help the parent identify what they know about how their child learns.

Evaluating a child with deaf-blindness to identify 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 children with deaf-blindness know and can do, and not just the impact of their disability. Every child has a different combination of sensory deficits, as well as possible cognitive, physical, and emotional challenges. The Guidelines provide important information for all team members to consider in the evaluation process.

What tools should be used in the evaluation? What types of evaluation should be done?

The evaluation must identify the child's current levels of functioning and impact of the disability in all areas of development (academic, behavioral, social-emotional, functional, etc.). As a starting point, a child with suspected deaf-blindness should have

ophthalmology (vision), audiology (hearing), and neurological evaluations. These assessments will help identify the child's sensory and cognitive strengths and needs. If the child has physical/motor limitations, the evaluation must also include an assessment of the child's fine and gross motor skills.

Identifying how a child with deaf-blindness communicates is 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 is essential to learning. Developing the child's "receptive" and "expressive" communication abilities is the most important way to improve their quality of life and ability to learn.

There are no formal assessments standardized for children with deaf-blindness. Therefore, more informal and functional types of evaluation, such as Home Talk: A Family Assessment of Children who are Deaf-Blind or the Callier Azusa Scale, should be used.^{xi} Evaluators should observe the child in a variety of settings to see how s/he interacts and communicates with others. Functional assessments focus on functional aspects of 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 a child with deaf-blindness, functional assessments provide a clearer, more accurate picture of their abilities than clinical assessments. Curriculum-based assessments, interviews, and portfolio assessments (reviewing homework and classwork) are also valuable tools. Ecological assessments look at the child's strengths and needs to determine the adaptations, accommodations, and supports needed to be successful in different situations.

Contrary to the stereotypes about children with deaf-blindness, the evaluation of a child with deaf-blindness *should* include assessments of *literacy* and *numeracy* abilities.

Literacy: Reading and writing allow people to send and receive information. A 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 the 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 the child with deaf-blindness 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.^{xiii}

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

What is the parents’ role in the evaluation of their child with deaf-blindness?

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. Parents have valuable information that is essential in determining their child’s strengths and needs. Parents share useful information with the evaluation team about their child’s strengths; their medical, educational, and other history; important people in their child’s life; their child’s likes and dislikes; how they and their child communicate; their child’s daily routine; and their hopes and dreams for their child.^{xiii}

Tips for Parents of Children with Deaf-Blindness in the Evaluation Process

Parent centers should encourage parents of children with deaf-blindness to share information with the evaluation team that will help them conduct a thorough, comprehensive, accurate assessment:

- Results of any outside evaluation as well as information from health professionals (primary care providers and specialists)
- A list of their child’s strengths, needs, preferences, learning style(s)
- Samples of their child’s work, at school and at home
- Videos of their child
- If there is a specific diagnosis, information on the condition (e.g., CHARGE).

Parent centers should also encourage parents of children with deaf-blindness to learn more about the process and to ask questions:

- What questions are we looking to answer?
- Who will be conducting the evaluation and in what settings?
- What is their training and experience?
- 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 the child’s suspected disability? Does it need to be in sign language, or another language?

Parent centers can also encourage parents of children with deaf-blindness to 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 parents and the evaluation team that you can share with parents. You can find your state deaf-blind project by going to the website of the National Consortium on Deaf-Blindness at www.nationaldb.org and clicking on the link to state deaf-blind projects.

Technical Assistance regarding the IEP Development Process

A parent of a child with deaf-blindness needs to know the general requirements for IEP development (timelines, requirement for team membership, language protections, notice and other procedural safeguards, the role of families in providing information to guide the process, etc.) under IDEA and your state special education laws/rules.

In addition, parents should understand specific components or professionals who should be involved in the IEP development process for a child with deaf-blindness, described below.

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

Issue II. The educational 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.

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

Issue 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.

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

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

Issue VII. Educators must ensure that transition planning for students who are deafblind is collaborative and involves all appropriate adult service agencies.”^{xiv}

Technical Assistance regarding IEP/ITP Implementation & Provision of Supports

A parent of a child with deaf-blindness needs to know the general requirements for IEP implementation and provision of supports. In addition, parents should understand specific components or professionals who should be involved in the IEP/ITP implementation process and provision for supports for a child with deaf-blindness. The Guidelines address a variety of main points regarding the IEP/ITP implementation process and provision of instructional and support services. These points are contained in several sections, including Foundations, Educational Personnel,^{xv} and Supportive Structure and Administration^{xvi}.

“Educational personnel:

Issue I. Educational personnel should have the specialized knowledge and skills, and commitment to meet the educational and communication requirements of students who are deafblind, as stipulated in their individualized education programs (IEPs).

Issue II. Educational personnel should have the knowledge and skills to foster communication development including proficiency in the communication forms of students who are deafblind that will facilitate access to all aspects of the learning environment.

Issue III. Educational personnel should work collaboratively with professionals and other members of students’ communities.

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

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

Issue VI. Specialized personnel should be hired to provide direct and/or support services specified in students' IEPs.

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.

Issue 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."

Supportive Structure and Administration:

Issue II. State and local education agencies (SEAs and LEAs) should ensure that every student who is deafblind is served by a well-coordinated educational team with the specialized knowledge and skills to fulfill its responsibilities for developing and meeting the requirements of the Individualized Education Program or Individualized Transition Plan (IEP/ITP).

Issue IV. State and local education agencies (SEAs and LEAs) should identify and use specialized resources to meet the needs of students who are deafblind and their families.

Issue VII. State and local educational agencies (SEAs and LEAs) must ensure the availability of a full array of appropriate services that meet the unique needs of students who are deafblind.

Issue VIII. State and local education agencies (SEAs and LEAs) should ensure that students who are deafblind receive instructional materials, adequate resources, and appropriate reading media on schedule with their sighted-hearing peers.

Issue IX. State and local education agencies (SEAs and LEAs) should ensure that instruction for students who are deafblind will extend beyond the boundaries of the school and the school day."

The Guidelines address "best practices" for children with deaf-blindness in terms of instruction and support services in Chapter I, Foundations^{xvii}:

- "How to help students build personal, trusting relationships with family members, peers, and other significant people in their lives?"
- How to provide predictable routines that will develop anticipation and stimulate communication?
- How to develop the student's ability to use a variety of communication forms or methods (e.g., gestures, objects, pictures, signs, speech) that they can understand and that can be understood by others?
- How to create learning environments that foster the desire to communicate and develop and expand the student's interests?
- How to foster development of concepts that lead toward social, academic, and functional abilities?
- How to help the student to build and sustain social relationships?
- How to help the student understand the organization of physical environments?
- How to assist the student in moving safely and confidently through different physical environments?
- How to stimulate the student's curiosity and problem solving abilities?
- How to provide real-life learning experiences?

- How to prepare the student for the transition from school to adult life?
- How to support the student so he or she may live a meaningful and happy life?"

Developing a Plan for Services

Once a child with deaf-blindness has been determined eligible for special education services, an IEP must be developed by the parent(s) and other members of the IEP team. At least one member of the team should have expertise in deaf-blindness. This includes:

- Understanding the diversity of students who are deaf-blind and their unique educational needs;^{xxviii}
- The importance of and strategies to strengthen communication skills of students who are deaf-blind;^{xix}
- Appropriate service options and supports needed by students who are deaf-blind;^{xx}
- How to teach literacy and numeracy for students with deaf-blindness;^{xxi}
- Assistive devices and technology appropriate for students who are deaf-blind;^{xxii} and
- The legislation and state and federal resources that support the education of students who are deaf-blind,^{xxiii} including state deaf-blind projects.

Team members must also value parents' knowledge about how their child behaves and learns and their input into the process.^{xxiv} For students with special healthcare needs, input from healthcare providers such as primary care physicians, specialists, and/or school nurses is vital. Information from healthcare providers should be included in the IEP, which may also include an Individualized Health Plan (IHP).

The IEP must contain:

Present levels of educational performance. This must address both the child's strengths and specific needs. It should include how the child's deaf-blindness and other disabilities affect

academics, social and emotional development, behavior, life skills, self-awareness, and communication of needs, emotion, and knowledge, including the impact of their child's combined vision and hearing losses.

Measurable annual goals and short term objectives or benchmarks, related to meeting the child's needs as well as making it possible for the child to be involved in and progress in the general curriculum. There must be at least one goal stated for each identified need. If the child with deaf-blindness will be taking the alternate proficiency assessment, which is likely for many students with deaf-blindness, there must also be short-term objectives or benchmarks for each goal.^{xxv}

Because of the stereotypes about the limited ability of students with deaf-blindness, Parent Centers must support parental efforts to make sure that there are specific communication, literacy (reading and writing) and numeracy (math), social relationship, and expanded curriculum goals addressed to the individual needs of their child with deaf-blindness.^{xxvi} *It is vital that they and the rest of the team focus on the child's potential and not just his/her limits.*

The IEP must include specific *special education* (specially designed instruction) and *related services* (services the child with deaf-blindness needs to benefit from his/her education). Work with the parent to identify how to ensure 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.^{xxvii} The IEP should also specify the types of professionals who should be involved in educating the child with deaf-blindness, as well as the types of specialized knowledge and expertise those professionals should have to address their needs. Personnel to consider in the IEP to provide direct and/or support services include:^{xxviii}

- ***Deaf-Blind (DB) Specialist:*** A DB specialist may provide direct services to the child or consultation/training to teachers and support staff. DB specialists understand 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 a child with deaf-blindness use optical (low vision) and non-optical devices (e.g., reading stands); identify appropriate visual materials; make modifications to visual materials (e.g., large print); and acquire materials from the American Printing House for the Blind (APH).
- ***Teacher of the Deaf/Hard of Hearing:*** A child with deaf-blindness may need direct or consultant services from a teacher who can help in the use of appropriate communication and assisted listening devices, and address literacy issues related to hearing loss.
- ***Orientation and Mobility (O&M) Specialist:*** Orientation and mobility instruction will help the child with deaf-blindness develop skills to understand and navigate his/her environment, including developing independent travel skills. The O&M specialist must be able to communicate with the child in his/her primary mode of communication (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 and emotional well-being.
- ***Paraprofessionals:*** One-on-one paraprofessionals, also known as instructional aides or assistants, will likely

be needed to provide support for communication, sensory access, movement, delivery of direct instruction, and/or personal care. The IEP should specify whether the child requires one or more paraprofessionals throughout the entire day or for particular classes or transitions, and the knowledge, expertise and training needed, including training 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 the paraprofessionals.

- ***Interpreter:*** If the child with deaf-blindness uses sign language as his/her primary language, s/he will require the services of a trained interpreter whose services are tailored to his/her specific needs. If the child also requires tactile (touch) interpretation, 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 the child with deaf-blindness to help her/him attain the goals and be involved in and progress in the general curriculum and participate in extra-curricular activities.

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.

For each service in the IEP, the following must be specified: the *name of the person responsible for implementation*, and *start date, frequency, duration, and location of services*. This is particularly important for students with deaf-blindness, as there will likely be multiple professionals involved in their education and

support services, and there must be effective allocation of responsibility, identification of the appropriate qualifications for personnel responsible to carry out each function, and coordination among all professionals.

The methods that will be used to *determine progress toward the goals* for the child with deaf-blindness: Parents must receive a report on their child's progress at least as often as reports are provided to parents of children without disabilities. This is critical for children with deaf-blindness as traditional methods used to determine and report on progress may not be appropriate given their unique combination of disabilities.

The extent of the *participation of the child with deaf-blindness in state and district-wide assessments*, and any *modifications or accommodations to be made*: Decisions to exclude a child from assessments must be justified in writing, and the IEP must describe alternate ways to measure progress.

The *child's placement*, which should be in the regular classroom to the maximum extent appropriate: The team should consider the full range of placements, and the types of supports that might be needed to make less restrictive, more inclusive settings work for the child with deaf-blindness. The National Consortium on Deaf-Blindness has useful information on inclusion.^{xxix}

Needed personnel development: The IEP must specify the training needed to ensure that all of the child's teachers, related services providers, and aides are qualified and knowledgeable. This should include general information about effective practices for educating children with deaf-blindness. Additional professional development may be needed for personnel to be able to meet each child's specialized, individualized needs, including creating an environment where the child with deaf-blindness feels comfortable and accepted, and where his/her curiosity and problem-solving skills are stimulated.

Considering 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. These special circumstances are of vital importance for children with deaf-blindness, who will likely need services in each of these areas:

Behavior needs: Functional behavior assessment and positive behavior support plans must be included for students with challenging behaviors that interfere with their or other students' ability to learn.

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

Communication mode: It is vital that the communication modality used by and/or taught to the student also be taught to their family so that they may support their child in the community and carry over academic instruction from school to home.

Assistive technology: Computers, tape recorders, communication devices, etc., needed for school and home use must be included in the IEP.

Extended school year: If the child needs year-round services to maintain progress toward goals, these must be included. Decisions about eligibility for, and length of time and contents of, extended school year (ESY) services, must be individualized.

Transition to adult life services, starting with the IEP for the school year in which the child will turn 16,^{xxx} or earlier if appropriate, as will almost always be the case for students with deaf-blindness. This must include teaching the child/youth self-advocacy and independent living skills such as mobility, self-care skills, employability skills, etc.

Technical Assistance regarding Transition

The Guidelines address transition to adult life in Chapters 1, 4, and 5.

“Chapter 1 Foundations:

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

Chapter 4 Services and Placement Options:

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

Issue 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.

Issue VII. Educators must ensure that transition planning for students who are deafblind is collaborative and involves all appropriate adult service agencies.

Chapter 5 Supportive Structures and Administration:

Issue II. State and local education agencies (SEAs and LEAs) should ensure that every student who is deafblind is served by a well-coordinated educational team with the specialized knowledge and skills to fulfill its responsibilities for developing and meeting the requirements of the Individualized Education Program or Individualized Transition Plan (IEP/ITP).

Issue VI. State and local education agencies (SEAs and LEAs) should implement planning strategies for the important transitions that students who are deafblind will experience throughout their education.”

IDEA ensures “*that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living.*”

Without effective transition, too many youth with deaf-blindness leave school with little chance for employment or community living. The Guidelines^{xxxv} recommendations will help parents and their youth with deaf-blindness prepare for transition and adulthood.

Parents of youth with deaf-blindness must be aware of their rights and the rights of their youth in the IEP and transition processes. Particular areas of importance include the fact that youth must be invited to the IEP meeting whenever transition is being discussed, and that any accommodations needed for their meaningful participation (interpreters, etc.) must be provided.^{xxxii} The transition plan must reflect the reality that deaf-blindness impacts children’s social and communicative connections and ability to develop as a person. The youth with deaf-blindness needs to learn about his/her disability, accommodation needs, and how to articulate what s/he needs before leaving high school. Attending and participating in transition planning is a vital part of this process.

The IEP of a youth with deaf-blindness should address assessments to determine appropriate postsecondary outcomes. These may include vocational evaluations, interest inventories, and independent living assessments as well as psychological and educational testing. Person-centered planning strategies can help parents, the youth, and the school identify strengths, preferences, and specific skills needed for successful transition.^{xxxiii} Independent living assessments help identify the supports youth with deaf-blindness will need to live and work in their community, including communication support service providers, interpreters, or augmentative communication systems.^{xxxiv}

The IEP must include appropriate measurable postsecondary goals based on age-appropriate transition assessments. Age appropriate assessments might include interest inventories or community-based vocational assessments that help youth with deaf-blindness identify career interests. The IEP for youth with deaf-blindness in transition should be driven by these postsecondary goals.

The transition IEP must address whether consultation from adult agencies such as vocational rehabilitation, developmental disabilities, or agencies serving adults with deafness/hearing loss or blindness/vision loss is needed, and how it will be obtained. Often, there is no one service agency that assumes responsibility for adults with deaf-blindness and the other disabilities that often accompany the conditions that lead to deaf-blindness (such as cognitive and physical disabilities).^{xxxv} More than one adult-serving agency may need to be involved in the transition process of youth with deaf-blindness. The school may need to establish interagency agreements with these providers.

Parents of youth with deaf-blindness need to consider four important domains when thinking about life after high school:

Post secondary education. What kind of post secondary education is realistic and appropriate? What skills are necessary to be successful? The IEP should identify and implement steps to make sure that when college is identified as the appropriate post secondary goal, the student has taken courses in high school that will help secure choices of college. Is the youth expected to pass the high school graduation test? Will s/he be taking the S.A.T. or A.C.T? Will s/he need accommodations under Section 504 of the Vocational Rehabilitation Act (Section 504) or the Americans with Disabilities Act (ADA) to have equal access to these assessments, or to participate in postsecondary education?

Employment. Does the IEP discuss career goals? Will the youth need to develop skills for a specific career? Career and vocational education and exploration are critical. Preparation for employment may include career awareness activities, job sampling, attendance at career seminars or conferences, and contact with adults with deaf-blindness who can serve as positive role models and enhance expectations for youth.^{xxxvi} The IEP should also address vocational skills that will deal with the youth's ability to complete a job application, handle a job interview, and to know where to begin to find an available job. Vocational evaluations help determine career interests and capabilities so can be an appropriate request in transition planning.

Independent living. To maximize the possibility of independent living, youth with deaf-blindness must learn concepts and skills in natural settings beyond the school building, the school day, and the school year. Will s/he have to take public transportation for work? Does she need direct instruction to learn how to use it? Is accessible transportation needed? How will s/he get needed orientation and mobility training in current and future environments? As s/he progresses, orientation and mobility classes will take more of his/her time, so these classes should be offered during both daylight and evening hours. Youth with deaf-blindness may have night blindness, and may need opportunities to learn additional skills to safely navigate when it's dark.^{xxxvii} Does s/he need direct instruction in meal planning or food shopping, using money/ making change, or personal hygiene? Are there social skills needed so s/he can function within the community? Will s/he eventually be able to live independently, or will s/he need a group home or other type of residential support? If s/he is eligible for support from other agencies, the IEP plan should address how the district will help the parents to apply for and access those services.

Health. Lack of attention to health needs and health management can jeopardize the goals of youth with deaf-blindness for learning, working, and living safely in the community. Health needs to consider as part of transition planning include appropriate nutrition; proper hygiene; importance of exercise as a life skill; effects of adverse chemicals (alcohol, tobacco, other substances); and sexuality and reproductive education. If the youth has more specialized health care needs, this area of transition planning is even more critical. Transferring responsibility for self-care to the youth requires consideration of factors such as complexity of health needs, physical and intellectual abilities of the youth, cultural values, health care practices, and beliefs about disability. It is also important to address how the youth will transition from pediatric to adult healthcare providers.

Youth with deaf-blindness must also receive appropriate transition *services*. IDEA defines transition services as a coordinated set of activities designed within a results-oriented process, focused on improving youth's academic and functional achievement to facilitate their movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation, and based on each youth's needs, taking into account their strengths, preferences and interests.

Transition services include:

- *Instruction:* Courses of study and/or skills;
- *Related services:* Transportation, speech-language pathology and audiology services, interpreting services, psychological services, physical and occupational therapy, recreation, including therapeutic recreation, social work services, school nurse services, counseling services, including rehabilitation

- counseling, orientation and mobility services, and medical services for diagnostic and evaluation purposes only, required to assist youth to benefit from special education. However, the term does not include a medical device that is surgically implanted or its replacement;
- *Community experiences:* Provided outside the school or in the community, such as community work experiences/exploration, job site training, banking, shopping, transportation, counseling, recreation;
- *The development of employment and other post-school adult living objectives:* Services leading to a job/career or those that support activities such as registering to vote, filing taxes, renting a home, accessing medical services, filing for insurance or accessing adult services such as SSI; and
- *Acquisition of daily living skills:* Ability to do activities that adults do every day - preparing meals, paying bills, maintaining a home, grooming, caring for clothes.
- *Functional vocational evaluation:* Assessment process that provides information about job/career interests, aptitudes, and skills, gathered through situational assessment, observations or formal measures.

Transition services should be delivered through curricular and extracurricular activities across many settings – *in academic and vocational classrooms, at home, and throughout the community* – to practice and reinforce skills in real life situations.

As youth with deaf-blindness approach adult life, it is critical for them to be aware of their support needs. Youth must choose to identify that they need support, and must be able to articulate those needs based on disability. At age 18, “adult rights” pass to the youth, *even the youth with deaf-blindness*, and s/he will decide whether to disclose her/his disability. College, work, and community settings must provide accommodations *only* if they are made aware that they are needed.

The IEP team must provide information about the age of majority at least three years before youth turn 18. Parental rights regarding IEP decisions transfer to the youth when they turn 18, unless the parent or someone else is appointed as their young adult's legal guardian. This requirement in the law does not consider ability of the student. Thus, parents should think about full or partial guardianship before their youth turns 18. This "transfer of rights" does not mean that parents are no longer a part of any IEP team; the young adult with deaf-blindness can choose to actively invite their parent(s) to continue to help with decisions at the IEP meeting with a simple letter.

Last Evaluation. Each youth must be evaluated every three years to determine whether s/he continues to have a disability and whether strengths and needs have changed. If the parents and school agree that a reevaluation is unnecessary, the reevaluation may be waived. For students in transition, it is important to discuss and plan for a final evaluation to have current documentation of the youth's disability and levels of academic and functional performance. A reevaluation is not required before termination of eligibility due to graduation or exceeding age 21, unless it is written into the IEP. Parents should advocate to specify the timing for conducting the last evaluation as a transition strategy toward post secondary goals when their youth is 16 and beginning the transition process to help eliminate conflict during the last school year.

Summary of performance. IDEA requires that youth receive a Summary of Performance (SOP) (academic achievement and functional performance as well as recommendations on how to assist her/him to meet postsecondary goals) upon graduation or "aging out" (usually turning 21). The SOP can be part of the documentation required under Section 504 of the Rehabilitation Act and the Americans with Disabilities Act to help establish youth's eligibility for reasonable accommodations and

supports in post-high school settings. It is also useful for the Vocational Rehabilitation Comprehensive Assessment process. This information is intended to help employers, colleges, and others consider accommodations for access. Submission of the SOP does not automatically mean that youth will qualify for accommodations, as these decisions are made on a case-by-case basis, but it is helpful information. The National Secondary Transition Technical Assistance Center has a sample of a meaningful SOP at <http://www.nsttac.org>.

Other Roles for Parent Centers

Another critical role for parent centers in assisting children with deaf-blindness and their families is advocacy and collaboration at the state level to develop guidelines and structures to support districts and schools in educating students with deaf-blindness. Parent centers can advocate for the implementation of the recommendations in the Guidelines at the state and local level. This is important in part because parents of students with deaf-blindness represent a small constituency. The Guidelines' recommendations for state and local education agencies are contained in Chapter 5, Supportive Structure and Administration:^{xxxviii}

“Issue I. State education agencies (SEAs) should have designated personnel to ensure that policies related to students who are deafblind are implemented.

Issue II. State and local education agencies (SEAs and LEAs) should ensure that every student who is deafblind is served by a well-coordinated educational team with the specialized knowledge and skills to fulfill its responsibilities for developing and meeting the requirements of the Individualized Education Program or Individualized Transition Plan (IEP/ITP).

Issue III. State and local educational agencies should develop strategies to recruit and retain personnel who have the knowledge and skills to work with students who are deafblind.

Issue IV. State and local education agencies should identify and use specialized resources to meet the needs of students who are deafblind and their families.

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

Issue VI. State and local education agencies should implement planning strategies for the important transitions that students who are deafblind will experience throughout their education.

Issue VII. State and local educational agencies must ensure the availability of a full array of appropriate services that meet the unique needs of students who are deafblind.

Issue VIII. State and local education agencies should ensure that students who are deafblind receive instructional materials, adequate resources, and appropriate reading media on schedule with their sighted-hearing peers.

Issue IX. State and local education agencies should ensure that instruction for students who are deafblind will extend beyond the boundaries of the school and the school day.”

There are three critical actions that Parent Centers can take at the state level to implement these recommendations:

- Connect states, districts and schools with US Department of Education-funded resources such as the National Consortium on Deaf-Blindness and National Instructional Materials Accessibility Standards project;

- Work with the state to develop and widely disseminate (including through workshops and resource materials) state guidelines for the education of students with deaf-blindness, based on the Guidelines; and
- Convene representatives of the state education agency, deaf-blind project (many are housed at the state education agency), and deaf and blindness agencies; disability organizations focused on deafness/hearing loss, blindness/ vision loss, deaf-blindness, and the other disabilities often associated with deaf-blindness; advocacy and other interested organizations (Council on Developmental Disabilities, Protection and Advocacy, University Center of Excellence on Developmental Disabilities, etc.); and families, youth with deaf-blindness, and districts and schools, to develop strategies to overcome the barriers to effective education of students with deaf-blindness.

Fact Sheets and Other Resources for Families of Students with Deaf-Blindness

Through a partnership between the Statewide Parent Advocacy Network, New Jersey’s Parent Training and Information Center and home to the Region 1 Parent Technical Assistance Center (RPTAC), Perkins School for the Blind, professionals with expertise in deaf-blindness, and diverse parents of children and youth with deaf-blindness, a series of brief fact sheets and mini-guides have been developed for families of students with deaf-blindness to help guide them through the evaluation, IEP, and transition to adult life processes. These fact sheets, brochures and tools are available on the SPAN website at www.spannj.org and on the website of the Perkins School for the Blind at www.Perkins.org, in English and Spanish. Other resources include a model form addressing IEP Quality Indicators for Students with deaf-blindness that also refers to the Guidelines.^{xxxix}

Conclusion

Deaf-blindness is a very low incidence disability, with significant impacts on affected students and their families. Knowledgeable and committed parent centers can serve as a life-line for these families, making the difference between an effective education and an ineffective one for students with deaf-

blindness. Your state deaf-blind project, your Regional Parent Technical Assistance Center, and the National Consortium on Deaf-Blindness, want to help you make this difference for this small group of families and their children who *can* learn and *will* learn if the Deafblindness: Educational Service Guidelines are implemented in their education.

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.” A child does not have to be totally deaf and blind to qualify.

ⁱⁱⁱ Specific criteria for eligibility for early intervention varies greatly from state to state, especially under the “high probability” component of the EI definition.

^{iv} McInnes and Treffry, Deaf-blind Infants and Children, A Developmental Guide. 1982)

^v Joe McNulty, Deafblindness: Educational Service Guidelines, page xii.

^{vi} The powerpoint presentation is available on-line at www.spannj.org and can be downloaded and used at no charge.

^{vii} Perkins School for the Blind.

^{viii} National Consortium on Deaf-Blindness

^{ix} Educational Service Guidelines, Chapter 3 Assessment, Table of Contents page vi, Guide p. 35

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

^{xi} Families can find a summary of some relevant assessment tools at <http://www.tsbvi.edu/therapy/assessments.htm>

^{xii} Deafblindness; Educational Service Guidelines, Chapter 3, Assessment, Issue V.

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

^{xiv} Educational Service Guidelines, Chapter 4 Services and Placement Options Table of Contents p. vi, Guide p. 47

^{xv} Educational Service Guidelines, Chapter 2 Personnel, Table of Contents p. v, Guide p. 17

^{xvi} Educational Service Guidelines, Chapter 5 Supportive Structure, Table of Contents p. vii, Guide p. 57

^{xvii} Educational Service Guidelines, Chapter 1 Foundations

^{xviii} Chapter 1 Foundations Issue I

^{xix} Chapter 1 Foundations Issue III, IV

^{xx} Chapter 1 Foundations Issue VI

^{xxi} Chapter 2 Educational Personnel Issue V

^{xxii} Chapter 2 Educational Personnel Issue VIII

^{xxiii} Chapter 1 Foundations Issue VII

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

^{xxv} Some states require short-term objectives or benchmarks for all children.

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

^{xxvii} Chapter 4 Services & Placement Options Issues IV, VI

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

^{xxix} National Consortium on Deaf-Blindness, <http://nationaldb.org/ISSelectedTopics.php?topicCatID=779>

^{xxx} Some states start transition services at age 14.

^{xxxi} Deafblindness: Educational Service Guidelines

^{xxxii} Chapter 4 Services & Placement Options

^{xxxiii} For more information on person-centered planning, visit the Cornell University ILR School Employment and Disability Institute Person-Centered Planning Education Site at <http://www.ilr.cornell.edu/edi/pcp>

^{xxxiv} Chapter 4 Issue VII

^{xxxv} Chapter 4 Issue VII

^{xxxvi} Chapter 5 Issue VI

^{xxxvii} Chapter 5, Issue IX

^{xxxviii} Chapter 5, page 57

^{xxxix} IEP Quality Indicators for Students with Deaf-Blindness, developed by Texas Deaf-Blind Outreach, can be found at http://www.tsbvi.edu/attachments/1800_IEP_Indicators.pdf.