

THE OHIO CENTER FOR



DEAFBLIND EDUCATION

**Parents and Families of
Children and Youth with Deafblindness:
*What You Should Know***



Ohio Center for Deafblind Education
2016

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About OCDBE

The Ohio Center for Deafblind Education (OCDBE) is a federally funded technical assistance and dissemination project designed to provide technical assistance, training and professional development, and consultation at no cost to improve results for children, birth through 21 years, with combined vision and hearing loss. OCDBE is also responsible for conducting an annual census of children with combined vision-hearing loss in Ohio. For more than 30 years, OCDBE has worked with local districts and their schools, state agency personnel responsible for IDEA Part B and Part C implementation, state and national parent and professional association representatives, and a variety of other partners committed to improving results for all children. For more information, contact OCDBE at 614.785.1163, or visit the OCDBE website at www.ohiodeafblind.org.

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WELCOME FROM THE OCDBE



One of the objectives of the Ohio Center for Deafblind Education (OCDBE) is to help families who are raising a child with combined hearing and vision loss. This brochure is designed to help you begin to make sense of the educational journey you and your child are setting out on together. It offers information about the next steps to take after finding that your child has combined vision and hearing loss, information about your child's learning needs, and information about resources that can help guide you and your child along that journey.

We hope it is reassuring for you to know there are many helpful resources across the state for families such as yours. Some information will be sent to your home by service agencies, while some will require active investigation on your part. Some parents who have children with deafblindness in Ohio say they find that the most meaningful advice comes from others who have children with vision and hearing losses. Taking time to attend a training or a retreat sponsored by the Ohio Center for Deafblind Education is one of the best ways to begin making connections with people who can share their insights and experiences.

SECTION I *Where can families begin learning about deafblindness?*

“Deafblind” can be a confusing term. Very few children are totally deaf and completely blind. Most often, the term describes a child who has some vision and hearing. In order to be considered deafblind, the combined losses have to be severe enough to require adaptations or supports that children without vision and hearing loss do not need. Like other disabilities, deafblindness varies from individual to individual. No matter what the degree of deafblindness, however, each child with significant loss of vision and hearing requires a unique approach to learning, an approach that is suited to the child's best ways to access information.



One of the most important things to keep in mind at the beginning of your journey is the knowledge that you are not alone! As Sections I through V show, there are many other families, medical professionals, and educators to help you.

A good place to begin to learn about deafblindness is with us—the **Ohio Center for Deafblind Education (OCDBE)**. OCDBE is a federally funded project that provides free technical assistance services to children, birth through 21 years of age, who have combined vision and hearing loss, and to the children’s parents. OCDBE technical assistance includes consultation; training and professional development; and information through OCDBE’s lending library, as well as other tools, products, and consultative services.

The first step in getting connected with our project is to register your child through our website at www.ohiodeafblind.org. Once registered, you are eligible for services and can begin building relationships with our project staff, consultants, education personnel, and other families of children with deafblindness. We encourage you to contact OCDBE. We want to be a part of your family’s journey.



SECTION II *What is “early intervention” for children with deafblindness?*

Very young children, birth to age 3, with deafblindness are eligible for early intervention services under the Infants and Toddlers with Disabilities program of the Individuals with Disabilities Education Act (IDEA). Early intervention services, designed to address the child’s developmental and learning needs, are extremely important to children with deafblindness and their families. Central to early intervention is the individualized family service plan (IFSP).

Through the IFSP, parents are involved in setting developmental goals for their child, choosing strategies to help meet those goals, and deciding what services are needed to help their child and the family meet the challenges of deafblindness. Family members and service providers work as a team to plan, implement, and evaluate services specific to the family’s concerns and priorities.

Finding early intervention services in Ohio can begin with contacting Ohio Help Me Grow (HMG) at (800) 755-GROW (4769). When you contact Help Me Grow, you will be asked to share general information about your family and your child. You should also mention any special concerns you have. A Help Me Grow service

coordinator will be assigned to help you access services and understand your rights. You can find the website at <http://www.helpmegrow.ohio.gov/en/early%20intervention/early%20intervention.aspx>.

There are also informational resources on the Center for Parent Information website at <http://www.parentcenterhub.org/repository/deafblindness/#early>. Below are two examples of information linked to the site:

Early Interactions with Children Who are Deaf-Blind.

<https://nationaldb.org/library/page/2062>

Communication at Home and in the Community:
Helpful Strategies and Suggestions from Parents and Families
with a Child Who is Deaf-Blind.

<http://documents.nationaldb.org/products/parent99.pdf>

SECTION III *How can families support their child's learning at home?*

Improving your child's education experience at home typically includes addressing three important needs:

Need to encourage and support communication. Establishing a communication system that meets their child's needs is one of the most important things families can do. Different systems will be appropriate at different age levels as your child's communication needs change. Assistive technology—such as amplification systems, low vision aids, and braille software—can be vital to the development of communication skills in children with deafblindness.

Need to support orientation and mobility. Many children with deafblindness need orientation and mobility instruction to navigate their environments safely and confidently. Having the skills to get around independently increases children's self-esteem and social opportunities. Finding and following through on effective orientation and mobility instruction, advice, and assistance can be crucial to your child's development.

Need to bridge home and school. It is important to bridge home and school by using the same strategies at both places. Children who cannot hear or see what is happening can become anxious and even defensive because they don't know what to anticipate. Following the same communication and educational methods at home and at school creates a familiar, reassuring routine for the child.

At times, being a parent of a child with deafblindness can feel more like a marathon than a journey. Early intervention and other educational efforts take time and energy to yield positive results. Fortunately, there are family support services that can help.

Red Treehouse can help you make connections and gain important information about resources such as parent training and child-care providers. Access this site at www.redtreehouse.org to discover answers to questions about such subjects as

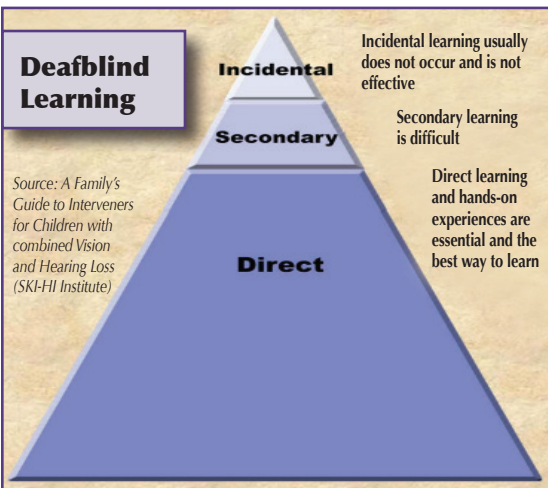
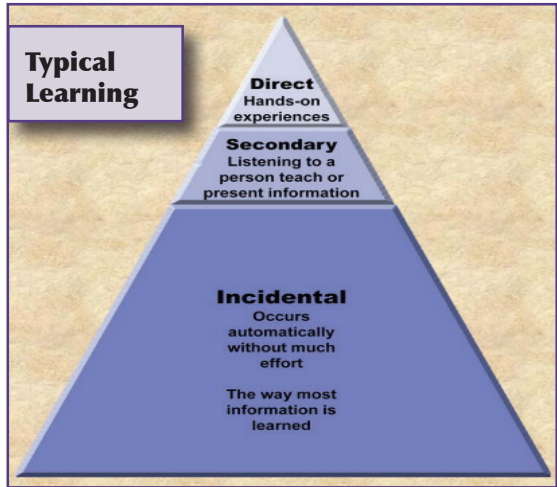
child growth and development, recreation and education, and community-based health and social services.

The National Family Association for Deaf-Blind also offers information and support to families of children who are deafblind through its activities and website, <http://nfaadb.org>. Many families in Ohio are associated with this organization and/or with the National Federation of the Blind <https://nfb.org/>.

Many organizations focus on specific disorders and syndromes. A few such organizations that have been helpful to parents of children with deafblindness are the National Institute on Deafness and Other Communication Disorders at <https://www.nidcd.nih.gov/>, CHARGE Syndrome Foundation, <http://www.chargesyndrome.org>, and Alport Syndrome Foundation at <http://alportsyndrome.org/> among others.

SECTION IV *How can families maximize their child's learning in school?*

Many parents and educators have come to understand that a child who is deafblind experiences the world differently than other children. This difference can create challenges in the classroom, but up-to-date skills and knowledge about how children who are deafblind learn can help ensure that your child has the kind of access to the learning environment that works best for her or him.



Learning, for a typically developing child, is represented in this graphic. It shows that most children require relatively little direct one-on-one instruction. They learn most of what they know through incidental learning that takes place as they experience the events going on around them. They also learn much from just listening to what parents, teachers, and others tell them.

Incidental learning is not as beneficial for children with

vision and hearing losses because of their lack of access to sensory information. Secondary learning is difficult for the same reason. Learning, for a child who is

deafblind, typically takes place in the opposite way—through direct one-on-one interaction, as shown in the second pyramid.

Deafblindness presents educational challenges that are best addressed through individualized instruction. These challenges often include problems that affect learning in school and out:

- difficulty with communication
- distorted perceptions of sights, sounds, space, and time
- lack of anticipation of events and consequences
- lack of motivation

Just as your involvement in the individualized family service plan (IFSP) is essential to early intervention, involvement in your child's individualized education program (IEP) in kindergarten through twelfth grade is of paramount importance as well. The IEP guides your child's education in elementary, middle school, and high school.

To be an effective partner in identifying adaptations and services your child needs in school, you must understand your and your child's rights under the Individuals with Disabilities Education Act (IDEA). This is not an easy undertaking; but the Ohio Department of Education Office for Exceptional Children (ODE/OEC), is willing—indeed, required—to help you understand these services and safeguards.

The Ohio Department of Education's Office for Exceptional Children has prepared a parent guidebook, *Whose IDEA is This? A Parent's Guide to the Individuals with Disabilities Education Improvement Act (IDEA) of 2004*. The guide explains your child's right to a "free appropriate public education" and tells how special education services are provided through the school system. The guidebook can be accessed at <http://education.ohio.gov/Topics/Special-Education/Whose-IDEA-Is-This-A-Parent-s-Guide-to-the-Individ>.

As your child approaches high school, your planning focus should begin shifting toward the development of a post-secondary transition plan as part of the IEP. This transition plan focuses on post-secondary education (including college or other post-secondary programs), employment, and community living.

Transitions can be challenging for any student; however, students with combined hearing and vision loss have additional needs to be considered by their educational team, needs related to communication, self-advocacy and self-determination, for example. The transition plan identifies goals, assessments, and services needed to prepare your child for success after high school. OCDBE has developed the Post-Secondary Transition Manual, which you may access within the Deafblind Information tab on the OCDBE website listed in section V.

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SECTION V

What are some additional resources?

As you continue learning about deafblindness and what it means for your family, you are likely to have many questions. The following organizations, along with others mentioned in previous sections of this guide are ready to help you find answers.



Ohio Center for Deafblind Education, www.ohiodeafblind.org

Ohio Department of Education/Office for Exceptional Children, www.education.ohio.gov

Ohio Coalition for the Education of Children with Disabilities, www.ocecd.org

Ohio Center for Autism and Low Incidence, www.ocali.org

Opportunities for Ohioans with Disabilities, www.ood.ohio.gov

National Center on Deaf-Blindness, www.nationaldb.org

National Association of the Deaf, <https://nad.org/>

National Organization on Disability, <https://www.nod.org/>

www.ohiodeafblind.org