

A Family's Guide to Interveners

for Children with Combined
Vision and Hearing Loss



A Family's Guide to Interveners

**for Children with
Combined Vision and Hearing Loss**

Linda Alsop
Clara Berg
Vivecca Hartman
Melanie Knapp
Kimberly Lauger
Cheryl Levasseur
Mike Prouty
Sally Prouty



Acknowledgement

We wholeheartedly thank the Gibney Family Foundation for their generous contribution to this publication. We also thank Carolyn Anderson, Senior Advocate, and the PACER Center for reviewing the information related to the special education process. Finally, appreciation goes to Lori Rowan and Fran Payne for their help with the production of this booklet.

Copyright 2012
SKI-HI Institute
Utah State University
Logan, Utah



Table of Contents

Welcome.....	5
What Is Deafblindness and How Does It Impact Your Child?	7
Typical Learning vs. Deafblind Learning	13
Typical Learning	14
Deafblind Learning	15
Intervention.....	17
Intervener	18
Role of the Intervener	19
Access to Information	19
Access to Communication.....	20
Access to Social and Emotional Development	21
Interveners Play a Key Role in Educational Programming	22
Common Misconceptions About Interveners.....	23

Navigating the IEP Process to Determine the Need for an Intervener	25
IEP Fundamentals Regarding Interveners.....	29
Evaluation	31
Consideration of Special Factors	33
Present Level of Performance	35
Annual Goals and Short Term Objectives	41
Accommodations, Modifications, and Supplementary Aids and Services	43
Related Services	45
Prior Written Notice	47
Parent Thoughts and Perspectives.....	49
Tips From Parents	57
Terms to Know	59



Welcome

“Ever since she took my hand on the doorstep of my home, she has been not only my eyes and ears, but also a light in all dark places, a bond between me and the life of the world.”

Helen Keller

These were the words of Helen Keller in describing the impact of Annie Sullivan on her life. Although Annie was referred to as Helen’s teacher, her role was similar to that of an intervener.

This booklet has been developed by parents of children who have combined vision and hearing losses (or deafblindness) and professionals who are experienced in the use of interveners as individualized supports for these children. A critical component of effective intervention for children who are deafblind is having the support of a trained intervener who provides access to the information needed for learning, communication, and interaction in educational settings.

You’ve received these materials because you have a child with a combined vision and hearing loss who may benefit from the services of an intervener. This booklet and the enclosed DVD contain information about interveners and their role in supporting children with deafblindness and about the process of determining the need for an intervener in educational settings.

This booklet addresses the following:

- What is deafblindness?
- What is an intervener?
- What is effective intervention for children who are deafblind, and what role does the intervener play in providing that intervention?
- How can the need for an intervener be determined through the Individualized Education Program (IEP) process?

Contained in the cover flaps of this booklet are two resources:

- A DVD entitled **Deafblindness and the Role of the Intervener**
- A card entitled **Key Questions to Ask During the IEP Process**

These materials can help you as you advocate for your child's needs. The more you educate yourself on your child's needs, the better you can advocate knowledgeably and confidently, and the more successful your child will be. Please study these materials and share them in whatever way works best for you and your child.



What Is Deafblindness and How Does It Impact Your Child?

People must have sensory information about the world around them to learn, function, and interact with others.



The majority of this vital information comes through the major senses of vision and hearing.



This automatic flow of information through the eyes and ears begins at birth and continues throughout life without much effort on our part.

Either a hearing loss or a vision loss alone has a significant impact on learning and development.



A child with a vision loss ...

must rely more upon **hearing to compensate** for the lack of available visual information.

A child with a hearing loss ...

must rely more upon **vision to compensate** for the lack of available auditory information.



The important thing is that for these children, one of their distance senses will compensate for the lack of the other one.

For children with **both vision and hearing loss**, neither sense can adequately compensate for the lack of the other. The natural flow of visual and auditory information does not happen.

Bits and pieces of information may be available, but will be:

- incomplete,
- distorted, and
- unreliable.

Enough complete sensory information needed for learning and interaction cannot be accessed in a clear and consistent way without support.



The term deafblindness does not necessarily refer to total deafness and total blindness. Children who are deafblind are a diverse group, and the amount of vision and hearing loss they have varies greatly from child to child.

One child may have a moderate vision loss and a severe hearing loss, while another may have only light perception and a moderate hearing loss. Some children have some vision and/or hearing, but **the effects of both the vision and the hearing losses occurring together are significant.**



Many children who are deafblind also have other challenges such as:

- physical challenges,
- medical challenges, and
- cognitive challenges.



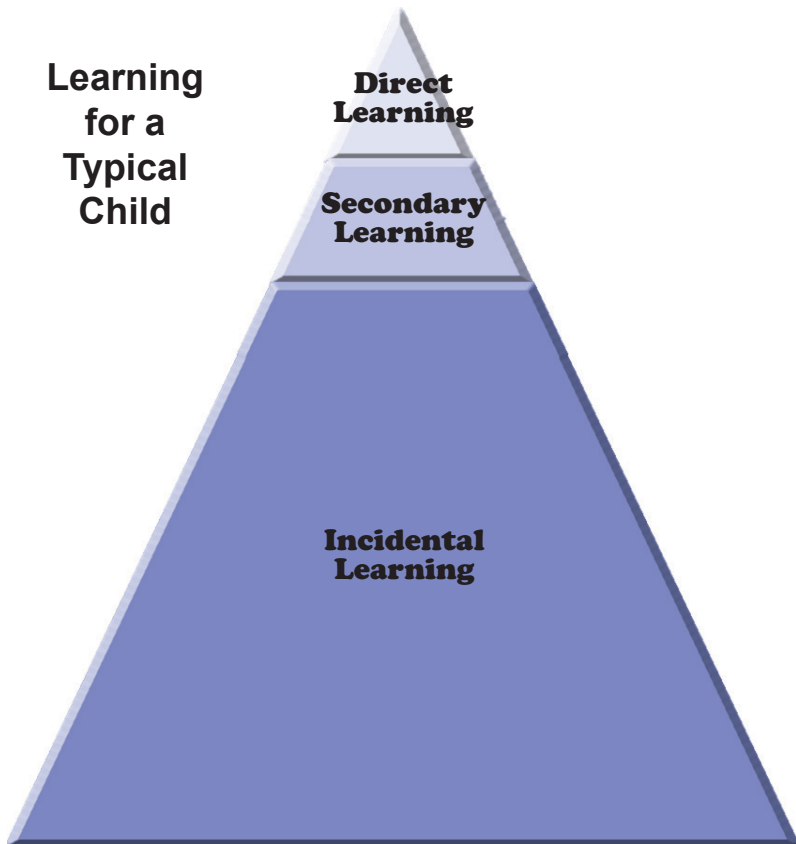
However, in spite of the diverse learning and communication challenges that children who are deafblind experience, with appropriate intervention, **they all can learn and interact with the world.**

Deafblindness can be defined as a disability of access - access to visual and auditory information about people and things in the environment.



Typical Learning vs. Deafblind Learning

Typical children with normal vision and hearing learn naturally in three ways: **direct learning**, **secondary learning**, and **incidental learning**.



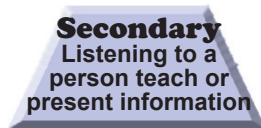
Typical Learning

Direct learning

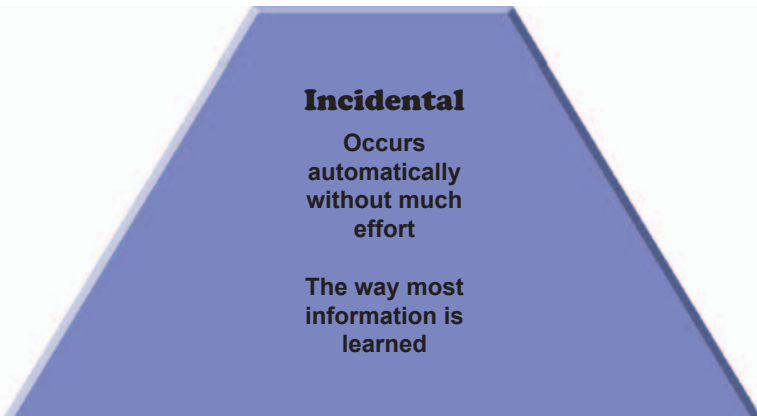
involves hands-on experiences and makes up a relatively small portion of overall lifetime learning.



Secondary learning happens by listening to another person teach or present information. It makes up a slightly greater portion of overall lifetime learning.



Incidental learning is that which occurs naturally and automatically from the flow of sensory information that is constantly available. It makes up the largest portion of lifetime learning and is the way most information is learned.



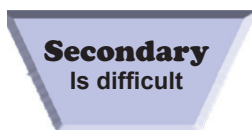
Deafblind Learning

For children who are deafblind, the typical way of learning does not occur naturally. **The triangle of learning is inverted for them.**

Direct learning is by far the most effective way for children with deafblindness to learn about the world. Hands-on experiences are essential.

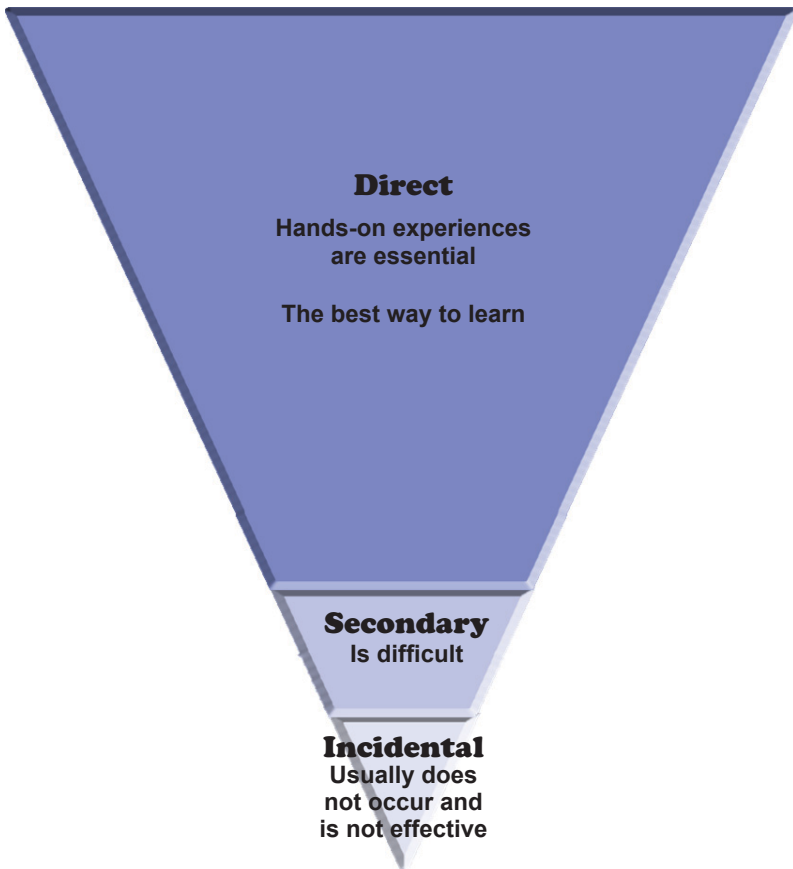


Secondary learning is difficult because of combined vision and hearing loss.



Incidental learning usually does not occur and is not effective because of the lack of consistent access to visual and auditory information.

The learning needs of children who are deafblind are different from those of typical sighted and hearing children. This poses unique challenges to most educational settings, because they are not generally designed to provide intensive amounts of direct, hands-on learning.





Intervention

Effective intervention for children who are deafblind must:

- Connect them to the world.
- Provide them with access to clear and consistent sensory information.
- Provide support for the development and use of communication.
- Provide support for social and emotional well-being.

Just as Helen Keller received this intervention from Annie Sullivan, so can children who are deafblind today receive this intervention from a person called an **intervener**.



Intervener

An intervener is defined as a person who:

- **Works consistently one-to-one with a child who is deafblind**
- **Has training and specialized skills in deafblindness**



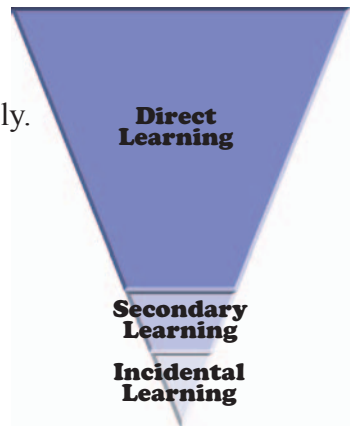
Role of the Intervener

The role of the intervener is to provide effective, deafblind-specific intervention for a child with deafblindness in the three following areas:

Access to Information

The intervener provides access to the environmental information that is usually gained through vision and hearing, but which is unavailable or incomplete to the child who is deafblind.

- The intervener presents information in ways that the child who is deafblind can understand it.
- The intervener helps the child be aware of people and things in the environment and encourages the child to reach out and connect with the broader world.
- The intervener helps the child learn concepts that sighted and hearing children learn incidentally.
- The intervener increases opportunities for direct learning to occur and provides access to the huge amount of incidental information that is unavailable with combined vision and hearing loss.



Access to Communication

The intervener facilitates the development and/or use of receptive and expressive communication skills for the child who is deafblind.

Receptive communication is the ability to receive communicative information.

Expressive communication is the ability to express communicative information.

- The intervener is a motivating and trusted partner who consistently responds to the child's communication.
- The intervener understands the child's unique mode of communication and facilitates his/her ongoing development of communication skills.
- The intervener provides opportunities for conversations and interactions with others.



Access to Social and Emotional Development

The intervener develops and maintains a trusting, interactive relationship that promotes social and emotional well-being for the child who is deafblind.

- An intervener connects the child with deafblindness to the world, reducing the sense of isolation and disconnection from the world.



- The intervener develops a bond of trust with the child who is deafblind. This decreases his/her anxiety about exploring the environment and trying new things.
- The intervener helps the child know where he/she is in the environment, and who is around him/her, and encourages interactions with others.
- The intervener supports self-determination by helping the child make choices, solve problems, and develop self-esteem.

Interveners Play a Key Role in Educational Programming

By assisting with **access to information, communication, and social and emotional well-being**, the intervener plays a critical role in the implementation of your child's Individualized Education Program (IEP). The intervener works under the direction of the classroom teacher and is a member of your child's IEP team. The intervener works closely with and supports other IEP team members in academic work, self-care routines, specialized therapies, and social activities.



Common Misconceptions About Interveners

Myth: An intervener hinders the child’s ability to interact with others and connect with the world.

Fact: Interveners are not a barrier between children who are deafblind and the world. They are a **bridge** to the world – a vital link to people and things in the environment.



Myth: An intervener creates dependency on the part of the child who is deafblind.

Fact: Interveners are trained to promote independence rather than dependence for children who are deafblind. They do **with** the child – not **for** the child.

Myth: Any classroom aide can be an intervener.

Fact: Interveners are different from general classroom aides because they must have training and specialized skills in deafblindness in order to be able to provide one-to-one effective intervention for children who are deafblind in educational settings.





Navigating the IEP Process to Determine the Need for an Intervener

The following section is intended to help you navigate the IEP process to determine whether or not an intervener is appropriate for your child and, if so, to ensure that intervener services are part of his/her educational programming.

IDEA

The **Individuals with Disabilities Education Act** or **IDEA** is a complex and lengthy law which ensures specific rights for children in special education. It is critical that you understand and use this law to make sure your child receives appropriate services. IDEA offers six key principles to guide the special education process which are as follows:

Children with disabilities have the right to:

- **A Free Appropriate Public Education (FAPE)**, which requires that an eligible child receive special education and related services provided at public expense. These services include appropriate education in the general education curriculum and activities, as well as specialized educational services and appropriate instruction based on a child's needs. A child has the right to make meaningful educational progress on his/her IEP goals and in the general education curriculum as much as is appropriate for him/her.



Note that a child cannot make progress without access to the information and instruction needed for learning and interaction in educational environments. An intervener provides the access which facilitates the provision of FAPE to that child.

- **Appropriate evaluation**, which is used as the basis for developing the IEP.
- **An Individualized Education Program (IEP) for children ages 3-21**, which is a written statement for a child with disabilities that is developed, reviewed, and revised, and which states the special education and related services that the educational program provides to the child.



- **Receive services in the least restrictive environment (LRE) possible.** According to this principle, each public agency must ensure that:
 - ◆ To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are nondisabled.

- ◆ Special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.
- **Participate in and have their parents participate in decision-making.** Under IDEA, parents remain the most important advocates for children with disabilities.
- **Procedural safeguards**, which refers to the specific rights and responsibilities of parents in the special education process.



IDEA ensures a Free Appropriate Public Education or FAPE to all children with disabilities; and FAPE requires that a child have **access** to general education, the general education curriculum and activities, and specialized educational services. **Access** is a key term in the requirements of IDEA; and for children who are deafblind, **access** is an especially relevant term. Their combined vision and hearing losses prevent them from having clear and consistent **access** to the auditory and

visual information they need for learning and interactions. Without this **access**, educational environments become restrictive and FAPE cannot be ensured.

Interveners can play a critical role in the provision of a Free Appropriate Public Education (FAPE) for your child because their role is to provide **access** to information, learning, and communication. Under the IEP process, interveners can be designated as “related services” or as “supplementary aids and services.” In whichever way intervener services are designated in your child’s IEP, these services must help your child:

- advance appropriately to accomplish special education goals,
- be involved in and make progress in the general education curriculum as appropriate for your child, and
- be educated and participate with other children with and without disabilities.



IEP Fundamentals Regarding Interveners

Special education has to be designed to meet the unique needs of your child and to provide meaningful educational benefits to him/her. The purpose of special education is to prepare children to lead productive and independent adult lives to the maximum extent possible. As each year's IEP is developed, you should consider what special education services will be necessary for your child to become independent and/or productive.

The Individualized Education Program (IEP) document is the cornerstone of the special education process and the key to the services your child receives. By understanding your child's IEP and taking an active role in developing it, you can help ensure that your child receives the education and services to which he or she is entitled.

You, as a parent, are an important member of the IEP team that develops your child's IEP. You are the one who knows your child best. It's critical that you learn the educational system in order to be able to navigate it for your child's success. When you attend your child's IEP meetings, you can invite a professional who is knowledgeable about your child's needs to provide input during the evaluation and planning process. You can also invite a support person (spouse, friend, family member) or advocate to attend the IEP meeting with you to provide emotional support. It's important that you are prepared to discuss your child's needs for an intervener in the development and implementation of your child's educational plan.



Whether or not your child needs an intervener is determined through the IEP process. Instead of asking for an intervener for your child first thing, you should use the IEP process to make this determination based on the needs of your child to have access to information, learning, and interaction in educational settings.

There are critical components of the IEP process which are especially important in determining your child's need for an intervener. These include:

- **Evaluation**
- **Consideration of Special Factors**
- **Present Levels of Performance**
- **Annual Goals and Short Term Objectives**
- **Accommodations, Modifications, and Aids and Services**
- **Related Services**



Evaluation

Your child's evaluation is very important. It's used as the basis for developing the IEP.

The 3-year evaluation and IEP are critical for you to understand because they are the BEST tools to help get what your child needs in school. Avoid using the word "want" when talking to the IEP team. Instead, use the terminology, "my child needs," and base these needs on what has already been identified by the IEP team.

Get out your child's most recent Evaluation Report (done every 3 years) in which the school district has identified your child's strengths and needs. Use a highlighter to highlight in the document every place you see a statement about what your child needs. If you don't already have it, you may need to ask for a copy of your child's evaluation information before the IEP meeting so that you'll be better prepared.

These "needs" will/should be the basis upon which the IEP team develops the IEP and defines what's "appropriate" for your child in order to ensure him/her a Free Appropriate Public Education (FAPE). It's important for you to emphasize that deafblindness is a disability of **ACCESS TO VISUAL AND AUDITORY INFORMATION ABOUT PEOPLE AND THINGS IN THE ENVIRONMENT, AS WELL AS ACCESS TO COMMUNICATION**. Focus on your child's NEED TO HAVE ACCESS.

Keep in mind:

- IDEA requires that parental input must be considered in the evaluation of every child with a disability.



- IDEA requires that the evaluation be conducted in the language most likely to collect the needed information about your child's strengths and needs. How your child communicates is the heart of the evaluation. If your child uses sign language, the evaluation must be done by a person at or above your child's level of communication.
- IDEA requires that the evaluation is administered by trained and knowledgeable personnel. Make sure evaluators understand the impact of combined vision and hearing losses and are able to communicate using your child's forms of communication.

Notes:

Consideration of Special Factors

The Individuals with Disabilities Education Act (IDEA) lists five special factors that the IEP team must consider in the development, review, and revision of each child's IEP. The discussion below will highlight the importance of these special factors in the education of children with disabilities and the need for individualized consideration of these factors in IEP development and revision. The discussion of these special factors needs to be documented.

The IEP Team must consider the following special factors. Do any of these special factors apply to your child?

- In the case of a child whose behavior impedes the child's learning or that of others, consider the use of positive behavioral interventions and supports, and other strategies, to address that behavior.
- In the case of a child with limited English proficiency, consider the language needs of the child as those needs relate to the child's IEP.
- In the case of a child who is blind or visually impaired, provide for instruction in Braille and the use of Braille unless the IEP Team determines, after an evaluation of the child's reading and writing skills, needs, and appropriate reading and writing media (including an evaluation of the child's future needs for instruction in Braille or the use of Braille), that instruction in Braille or the use of Braille is not appropriate for the child.



- Consider the communication needs of the child, and in the case of a child who is deaf or hard of hearing, consider the child's language and communication needs, opportunities for direct communications with peers and professional personnel in the child's language and communication mode, academic level, and full range of needs, including opportunities for direct instruction in the child's language and communication mode.
- Consider whether the child needs assistive technology devices and services.

The fourth factor above is particularly important for your team to consider. If the communication needs of your child are not being adequately addressed, this part of the IEP process can reinforce your child's needs to be able to communicate in his/her mode of communication and to have opportunities for direct instruction from professionals and direct communication with peers and others.

Notes:

Present Level of Performance

One of the first critical discussions at the IEP meeting focuses on establishing your child's Present Level of Academic Achievement and Functional Performance. This lays the groundwork for the rest of your child's Individualized Education Program (IEP). The following must be considered during this discussion:

- The strengths of your child
- Your concerns as parents
- The results of your child's most recent evaluation
- Your child's functional and classroom performance including the academic, developmental, and functional needs of your child



The “Present Level of Academic Achievement and Functional Performance” must include an impact statement. **In other words, how does your child’s disability-related needs impact his/her performance and participation?** The IEP goals and objectives (which will be developed next) must address each of the needs established during this initial discussion, so it’s important to clearly articulate your child’s needs right from the beginning.

Since your child has both vision and hearing losses, **the access to information in educational environments** is a major need. It’s important that your child’s team understand that deafblindness is a disability of access to the visual and auditory information that is necessary for learning, communication, and overall development. So, the discussion can begin with the needs related to **access** for your child.

Access to Information Needed for Learning. Issues that should be addressed related to Access to Information include:

- How does your child’s vision loss affect his/her ability to access visual information?
- How does your child’s hearing loss affect his/her ability to access auditory information?
- How is your child going to have consistent access to the visual and auditory information and instruction needed for learning and interaction in the educational environment?
- How is your child going to have access throughout the day to incidental information vital to learning and interaction?

- How is conceptual learning going to be provided consistently to your child?
- How is your child going to be connected to the educational environment and engaged in learning on a consistent basis?

Keep in mind that IDEA ensures a Free Appropriate Public Education (FAPE) for your child. FAPE requires, to the extent appropriate for your individual child, access to general education, the general curriculum and activities, and access to specialized educational services. So how will clear, continuous, and consistent access to information be provided to your child?



Access to Communication Needed for Learning and Interaction. Since communication is impacted greatly by combined vision and hearing loss, your child's needs for communication and interaction must be addressed. Your child's communication system should be individually designed and used with a high degree of consistency throughout the day.

Issues that should be addressed related to Access to Communication include:

- How does your child communicate?
- Who will be able to communicate with your child in his/her mode of communication?
- How will information be communicated to your child?
- How will others understand what your child is communicating?
- How will your child be able to get someone's attention, request something, and make his/her needs known?
- How will your child's communication attempts be responded to?
- How will your child be able to communicate with peers?
- What instructional strategies will facilitate your child's development and use of both receptive and expressive communication?
- How is your child going to be exposed to a language level that is beyond where he/she is functioning so as to facilitate his/her language development?
- What support will be provided to your child for communication and interaction?



Access to Social and Emotional Well-Being. Since deafblindness creates isolation, anxiety, frustration, etc., it's important to address your child's needs for social and emotional well-being in the educational environment. Issues that should be addressed include:

- How will your child know what is happening around him/her and who is present?
- How will your child know when he/she is safe and can feel safe?
- How will your child be motivated to try new things and to learn?
- How will your child's behavior be seen as communication?
- How is your child going to have trusting relationships with others?
- How is your child going to be able to make choices, solve problems, and develop self-determination?
- What needs to be done to make the educational environment emotionally manageable for your child?
- How will social and emotional well-being be ensured for your child?



Overall

- How will the Least Restrictive Environment be provided?
- How will a Free Appropriate Public Education (FAPE) be ensured?

Notes:

Annual Goals and Short Term Objectives

The next step in the IEP process is the determination of Annual Goals and Short Term Objectives for your child. These goals and objectives must be matched to the needs identified in the previous discussion of your child's Present Level of Performance. Sometimes team members bring goals for your child to the IEP meeting. If this occurs, take the time to review these goals and determine if they reflect your child's needs as established in the discussion of your child's Present Level of Performance. Don't hesitate to ask questions if you think the goals and objectives don't correlate with your child's needs. Be sure that your child has access to the information, instruction, and learning needed to achieve his/her goals and objectives. Your child has the right to make meaningful educational progress on goals and the general curriculum.



Notes:



Accommodations, Modifications, and Supplementary Aids and Services

Next is the discussion of the Accommodations, Modifications, and Supplementary Aids and Services that are needed for your child to achieve the goals and objectives.

Supplementary aids and services refers to aids, services, and other supports provided in regular education classes or other education-related settings to enable children with disabilities to be educated with nondisabled children to the maximum extent appropriate. It also refers to accommodations and modifications to the curriculum and to participation in nonacademic services and extracurricular activities.

Supplementary aids and services can also include direct services and supports to the child. So the need for an intervener can be determined at this time as an accommodation or as a supplementary service.

It's important to note here that any staff providing a service to a child must be able to meet the needs of that child. If the IEP states that a child who is deafblind will have an intervener, then the duties of that intervener must be included in the adaptations section of the IEP (adaptations can be included with the supplementary aids and services that will be provided to the child).

The needs of your child drive the services. Your child needs access to learning, and that access can be provided by the services of an intervener. If a one-to-one paraprofessional/aide is assigned to your child but doesn't have the skills to be



an intervener, then the services cannot be provided to meet your child's needs. Therefore, **training** will be needed for that paraprofessional/aide so that intervener services can be provided to your child. This need for intervener training can be included with the intervener duties listed under "adaptations" in this section of the IEP.

Notes:



Related Services

The need for related services must also be addressed during the IEP process. Related services are specifically connected to special education instruction and are those needed for the child to benefit from special education programs. Related services provide extra help and support in needed areas.

As listed in IDEA, related services can include but are not limited to:

- Speech language therapy and audiology services
- Physical and occupational therapy
- Orientation and mobility services
- Psychological services
- Medical services for diagnostic or evaluation purposes
- Interpreters

As previously stated, under the IEP process, interveners can be designated as “related services” or as “supplementary aids and services.” In whichever way intervener services are designated in your child’s IEP, these services must help your child:

- advance appropriately to obtain goals,
- be involved in and make progress in the general education curriculum, and
- be educated and participate with other children with and without disabilities.



Notes:

Prior Written Notice

Prior written notice is an important procedural safeguard that can help you in the discussion of your child’s needs for an intervener and will give you more information about what is in or not in the IEP. The IEP team must document team decisions on the prior written notice, including an explanation of why the proposal or refusal was made, a description of the data used to make the decision, a description of other options considered, and a description of other factors affecting the proposal or refusal.

Parents shouldn’t have to request a copy of the prior written notice, but if they find that they must, they can do so at any time they find it appropriate. For example, if during the IEP discussion it appears that the district will be saying “no” to the request for an intervener, the parent could say, “It looks like the district is denying my request. I will look forward to seeing in writing all your reasons including the data used for making your decision, on the prior written notice form that you will be giving me with the IEP proposal.” After an IEP meeting parents should always receive the proposed IEP, the prior written notice, and a form for them to give or deny consent to the IEP.

WHEN YOU DON’T AGREE: The vast majority of people working in special education are passionate about their work and want to do the best for each child. Unfortunately, many professionals do not understand the unique communication and learning needs of children who are deafblind. If there continues to be disagreement with the IEP team, you have rights as a parent under IDEA. Most disagreements can be



settled early. The following options are available and are listed here from informal to more formal.

- Call an IEP team meeting and try to work it out with team members to come to a compromise.
- Ask your school district if they support a “facilitated IEP” run by an impartial facilitator.
- Ask for mediation which is a more formal approach to resolving disputes between parents and schools. These voluntary meetings are facilitated by a skilled and impartial mediator to resolve a dispute. The state selects impartial mediators and bears the cost of the mediation process.
- File a state complaint which is the next step to resolving disputes and is an important procedural safeguard in IDEA. Contact your state director of Special Education and request information about how to file a complaint.
- Request a Due Process Hearing which is used as a way to resolve a dispute between a school and parent by a hearing officer.

Each state has their own specific way for parents and schools to resolve their differences. For more information, contact your state Parent Training and Information Center (www.parentcenternetwork.org/parentcenters.html).

Another parent resource is the Council of Parent Attorneys and Advocates (COPAA) (www.copaa.org).





Parent Thoughts and Perspectives

The following are thoughts and perspectives from parents about the importance of interveners for children with deafblindness.



*Melanie Knapp,
Mother to Christian*

When I first learned about interveners, my son, Christian, was 18 years old. It took us three years to get our intervener, Ann. I knew how smart Christian was, and I knew that he needed that person that could bridge the gap between his deafblindness and the seeing and hearing world. It was a difficult time for us because, not only did we have to educate our school and district about the intervener model, but we needed to find someone who had training and experience with the deafblind. We were lucky. We found Ann.

Christian started out using calendar symbols and gestures. Then he began to learn tactile sign. He made friends in school and friends in our community. He owned and operated his own

vending machine business. Most importantly, he was happy. He had a full life that would not have been possible if he didn't have an intervener. Christian's success came when he was 21 years old.

I am so proud of Christian. He taught so many others what a deafblind individual can do with the right support.....an intervener.



**Sally Prouty,
Mother to Andrew**

Thirty years ago, we never imagined Andy would be living, working, and traveling independently and being a contributing member of society as he is now. When he was born, we were overwhelmed with the uncertainty of how he would be educated — he couldn't access information and communication as effortlessly as his siblings. Fortunately, we learned about the concept of intervention when Andy was just a couple months old, so we educated ourselves and those around us. He eventually had interveners at home and in school to provide access to information and communication. We believe interveners have been a key to his success.

Your child can have an exceptional educational team; but if your child doesn't have access to them, their expertise is minimized. Interveners provided that access for our son and

supported and reinforced the teaching done by teachers and his related services providers.

It's been quite a journey, and in the process we learned to be "respectfully demanding" to get the services Andy needed. We learned that when you give respect, you are more likely to get respect in return. Most likely, you will be working for many years with the same educational team members so it's very important to develop and maintain good relationships. Remember, YOU are part of the education team – you have expertise on your child that no one else has so don't be afraid to speak up. Because deafblindness is so unique, this booklet will help guide you.



**Kimberly Lauger,
Mom to Dylan**

We were lucky in that our deafblind project started an intervener training program when Dylan was 2½ years old. He's always had an intervener.

But it has been important to understand the IEP process in making sure that he has access to his intervener for his full school day, that she be available to facilitate interactions with other members of the team, and to make sure the intervener is included as part of his IEP team. All of this is important for Dylan having continued access.

By understanding the IEP process, we can stay focused on what Dylan needs rather than what I want.

The people that I work with have not been so lucky. They are in districts who believe that the intervener leads to dependence, or they don't believe interveners are necessary, because all team members understand deafblindness.

What I encourage you to pay attention to is does your child have access? No matter what school it is, when your child is in that setting, continue to ask does my child have continual access to the educational curriculum and to what his/her peers are doing? If not, then continue to follow the IEP process outlined in this book to make sure that access is provided.



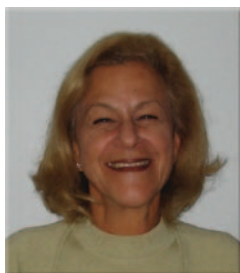
**Cheryl Levasseur,
Mother to Glenn**

A skilled intervener has the potential to be such a powerful and positive model of support for children with combined vision and hearing loss. I have seen firsthand the impact that gracefully refined intervention can have on a deafblind child who, as a result of having an intervener, is able to access so much of the world via the intervener.

The intervener is often a misunderstood option. The intervener is not always someone “out there” that the team has to go and locate outside of the district. This mindset can result in the

“unattainable” because so frequently no one knows where to find a trained intervener. Finding a good match for your child is sometimes about training the right person, such as someone who is already working with your child or someone with whom your child has already formed a relationship. This person can be trained as your child’s intervener and can provide rich, meaningful, and interactive learning opportunities for your child. Resources, online information, and training opportunities are becoming ever so abundant.

Keep in mind, deafblind intervention is a process. The intervener facilitates that process, and the process is never static. An open mind and a willingness to keep learning are crucial to providing effective and productive intervention. And remember, it is NEVER too late to get, pursue, or train an intervener for your child, no matter what the age!



**Clara Berg,
Mother to Kenny**

I wish I knew then what I know now! How many times do we hear ourselves saying that phrase?

When Kenny was 4 years old, I heard for the first time the word “intervener.” After doing a little research talking to parents who knew about the benefits of having one person specially trained to work with a deafblind child, I embraced the concept

of interveners and started requesting that type of specific support for Kenny. He was denied the services of an intervener. Some of the reasons we got for the denial were: "We don't have interveners in our state." "There is not a budget category for them." "Your son does not need an intervener." Unfortunately, I did not have then the advocacy tools that I have today to fight the system, and I had to accept situations that made Kenny and us very unhappy.

Kenny went through his full educational cycle with sporadic one-on-one classroom support. The majority of his classes were taught by instructors who were not specifically trained on dealing with a child who is deafblind and would either choose to follow (or not follow) instructions from us. We had to overcome and learn how to deal with challenging behaviors that continued to escalate because of their lack of expertise with children like Kenny.

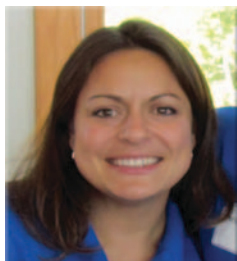
As soon as Kenny turned 21, he started working on a farm with the support of a job coach named Arnie. Arnie worked with Kenny 40 hours a week, and he was motivated and eager to continuously learn more details about deafblindness. He wanted to set higher standards for their daily routine, and we offered him the financial support to take an intervener course.

Arnie, with his new acquired intervener skills, made a world of difference in Kenny's life. He ultimately became the link or connection Kenny needed to access information about his new environments and the people and the community at large. This holistic approach has transformed Kenny's life, and today we are proud to say that Kenny lives a productive and happy life thanks to the interveners he has had over the last many years.



We, as parents, know our children best. We need to educate ourselves and stay informed to become strong advocates to provide them with all of the opportunities available.

If I knew then what I know now, I would not have taken “NO” for an answer! Had I been aware of Kenny’s potential as he was growing up, I would have followed my instincts and advocated harder to get an intervener to be with him in school at all times.



Vivecca Hartman
Mother to Christopher

If only we had known in the beginning how to educate and raise a deafblind child when Christopher was born to us, it would have been so wonderful. We know how to raise a child based on our own childhood experiences, and there are systems in place that meet the needs of the majority of children when they hit school age.

If only we could have started out knowing what the emotional, communication, and educational needs were when Christopher was a healthy baby. Instead, we had to learn from trial and error and all the while my son was at a loss because of our (both the parents’ and the school system’s) lack of knowledge. By the time we all got on board and figured it out, we had all the past experiences to overcome. Christopher was so

frustrated and had developed defense mechanisms that we then had to work around and try to “unteach,” if possible.

The goal of this project is for families to learn from our experiences. Using interveners is real, is valid, and works. With interveners, deafblind children can prosper and do wonderful things and grow and be happy. You should strongly advocate for a trained intervener for your child. When you see an intervener interact with a child, it is just heartwarming to see that child come alive, where they were not before.





Tips from Parents

- Ask the IEP team to start each team meeting with “celebrations” of your child. This will set the tone of the meeting to be positive to help your child succeed.
- Put time into learning the IEP process and be familiar with your child’s assessment and the terminology of your child’s identified needs.
- If your child functions differently at home, feel confident in sharing that with your team.
- Make sure you provide the school with your child’s current ophthalmology and audiology reports and get confirmation that team members have the ability to interpret the results.
- Work together with other team members to set meaningful educational priorities and determine the best strategies for learning based on evaluation results.
- Remember every child can learn.
- Honor the efforts of your child.
- Work with the school district as a partner in your child’s educational experience.
- Know your school district’s hierarchy (chain of command).



- Share information about deafblindness and interveners with district representatives, school administrators, and team members well in advance of the IEP meeting.
- Honor the efforts of your educational team, and try to work with the team rather than against the team to be more productive.
- Remember the educational team is in the business of helping children. Ask for their support in helping your child. Being knowledgeable, humble, and respectful will help build a productive team.
- Choose your battles (keep these to a minimum), know your negotiables (have a lot of these) – what is a must, and what is not.
- Keep the long term goal and bigger picture in sight.
- It's important for you to know what you are advocating for and be clear about it.
- Don't give up even if you experience some resistance!
- You can do it!





Terms to Know

Accommodation

A change that helps a student overcome or work around his/her disability. It doesn't lower the standard. Allowing a student who has trouble writing to give his answers orally is an example of an accommodation.

Due Process Hearing

A process available to parents and school districts to resolve special education disputes.

FAPE

An acronym for Free Appropriate Public Education; the guaranteed right of children with disabilities to receive an education that meets their unique needs at no cost to parents.

IDEA

An acronym for Individuals with Disabilities Education Act; a federal law that was established to ensure that children with disabilities receive educational instruction that meets their needs; reauthorized in 2004 and referred to Individuals with Disabilities Improvement Act.

IEP

An acronym for Individualized Education Program; a written statement for a child with a disability that is developed, reviewed, and revised in accordance with federal and state laws, regulations, and rules and outlines the special education and related services that the educational program provides to the child.

LEA

An acronym for Local Education Agency; term used for a school district.

LRE

An acronym for Least Restrictive Environment; the placement and services a child with disabilities receives are appropriate to the child's individual needs. By law, children with disabilities have the opportunity to be educated with peers without disabilities to the greatest extent appropriate, have access to programs that peers without disabilities access, and receive supplementary aids and services necessary for appropriate educational placement.

Mediation

Refers to a formal process of resolving disagreements between parents and schools regarding a special education program of a student. This process is facilitated by a trained and neutral mediator.

Modification

A change in what is being taught to or expected from a student with a disability. Making an assignment easier so the student is not doing the same level of work as other students is an example of a modification.



Procedural Safeguards

Refers to the specific rights and responsibilities of parents in the special education process; IDEA 2004 requires school districts to give parents a copy of the procedural safeguards.

Prior Written Notice (one of the procedural safeguards):

The IEP team must document team decisions on the Prior Written Notice, including an explanation of why the proposal or refusal was made, a description of the data used to make the decision, a description of other options considered, and a description of other factors affecting the proposal or refusal. The Prior Written Notice will give you more information about what is in or not in the IEP.

Related Services

Refers to additional help that a child with disabilities may need in order to benefit from special education. Related services can include: audiology, routine checking of cochlear implants, counseling services, hearing aids, interpreting services, medical services, occupational therapy, orientation and mobility, parent counseling and training, physical therapy, psychological services, recreation, rehabilitation counseling, related services, school health services, school nurse services, social work services in schools, speech-language pathology, and transportation.

Special Education

Specially designed instruction, at no cost to the parents, to meet the unique needs of a child with a disability.



Supplementary Aids and Services

Aids, services, and other supports that are provided in regular education classes, other education-related settings, and in extracurricular and nonacademic settings, to enable children with disabilities to be educated with nondisabled children to the maximum extent appropriate.



Notes:

Notes:

