

Deafblindness and the Role of the Intervener in Educational Settings

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Purpose:

- To define deafblindness and discuss its impact
- To describe the role of interveners
- To address systems issues



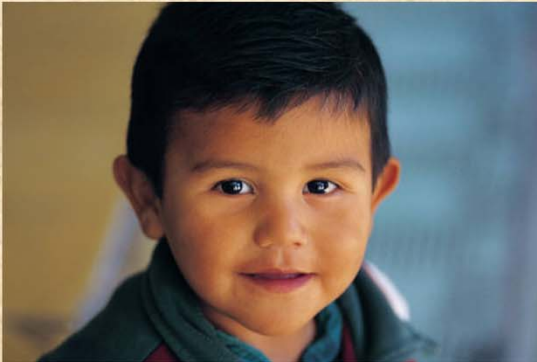
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The purpose of this presentation is:

- ◆ To define deafblindness and discuss the impact of combined vision and hearing loss on learning, communication, and overall development
- ◆ To describe the role of interveners in facilitating the process of intervention for children who are deafblind
- ◆ To address some system's issues related to the use of interveners with children who are deafblind in educational settings

What is Deafblindness?

We all must have information about the world



With typical vision and hearing, this information comes through our eyes and ears automatically without much effort

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First, what is deafblindness and how does it impact overall development? We know that we all must have sensory information about the world around us in order to learn, function, and interact with others. For those of us with typically developing vision and hearing, the majority of this vital information comes to us 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.

What happens when there is a loss of both vision and hearing?

- Natural flow of visual and auditory information doesn't occur
- Pieces of information may be:
 - Incomplete
 - Distorted
 - Unreliable
- Complete information cannot be accessed in a clear and consistent way



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But what happens when there is a loss of both vision and hearing? For children with both vision and hearing loss, the natural flow of visual and auditory information does not occur. Bits and pieces of information may be available, but those will be incomplete, distorted, and unreliable. Enough complete information cannot be accessed in a clear and consistent way.

Hearing loss or vision loss alone has great impact

- A child with a **vision** loss

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



- Hearing must compensate

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Either hearing loss or vision loss alone has a great impact. A child with a vision loss must rely more upon hearing to compensate for the lack of available visual information. Therefore, hearing becomes critically important and must compensate for the lack of vision.

- A child with a **hearing** loss
must rely more upon **vision** to
compensate for the lack of auditory
information



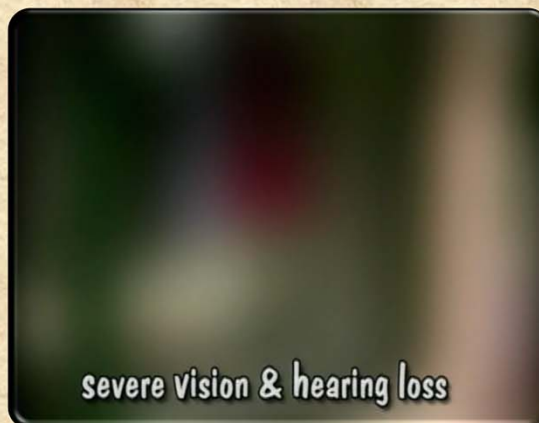
- Vision must compensate

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A child with a hearing loss must rely more upon vision to compensate for the lack of available auditory information. Therefore, vision becomes critically important and must compensate for the lack of hearing.

For children with a combined **vision** and **hearing** loss:

- Neither sense can adequately compensate for the lack of the other
- Access to the clear and consistent flow of visual and auditory information is not available



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For children with combined vision and hearing loss or deafblindness, neither sense can adequately compensate for the lack of the other. Access to the clear and consistent flow of visual and auditory information that is necessary for learning, interaction, and overall development is not available. Simulations can give some idea of what the world is like with combined vision and hearing loss.

For someone with a mild acuity loss, amounts of visual information become unclear or unavailable. For someone with a moderate hearing loss, amounts of auditory information become distorted or unavailable. For someone with a severe vision and hearing loss, the impact can be overwhelming.

Deafblindness is a disability of access - access to visual and auditory information about people and things in the environment

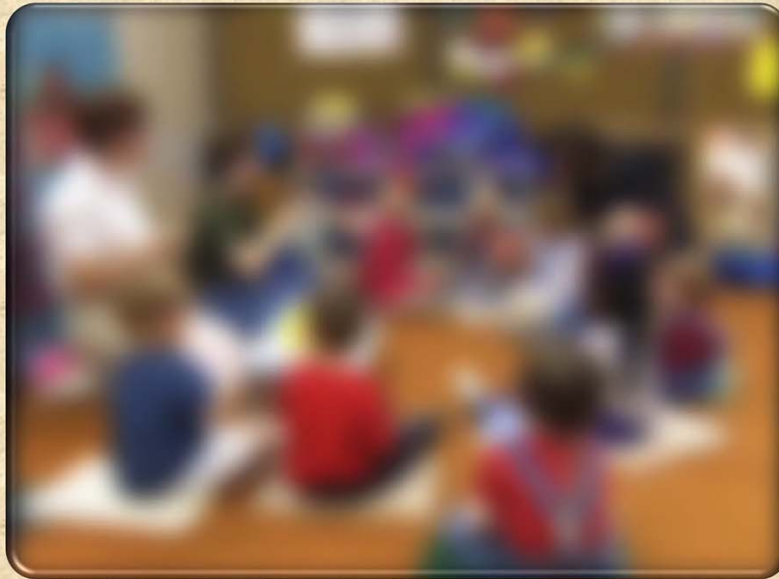
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In the simplest terms, deafblindness can be defined as a disability of access—access to visual and auditory information about people and things in the environment.

Deafblindness

- Does not usually refer to total deafness and total blindness
- Degrees of loss vary greatly

Example: A moderate visual acuity loss and a severe hearing loss



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The term deafblindness does not necessarily refer to total deafness and total blindness. Indeed, degrees of vision and hearing loss vary greatly. For example, one person may have a moderate visual acuity loss and a severe hearing loss.

Deafblindness

Example: Light perception only and a moderate hearing loss



The combined effects of both the vision and the hearing loss are significant

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Another person may have only light perception and a moderate hearing loss.

In each of these examples even though there is some visual and auditory information available, the combined effects of both the vision and the hearing loss are significant.

Many have other disabling conditions:

- Physical disabilities
- Health problems
- Cognitive challenges



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In addition, many children who are deafblind have other disabling conditions such as physical disabilities, health problems, and cognitive challenges.

Children who are deafblind are diverse with unique needs



All share:

- Similar learning and communication challenges
- Isolating effects of combined vision and hearing loss

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Overall, as a group, children who are deafblind are diverse and each has unique needs. Yet, they all share similar learning and communication challenges and the isolating effects of combined vision and hearing loss.

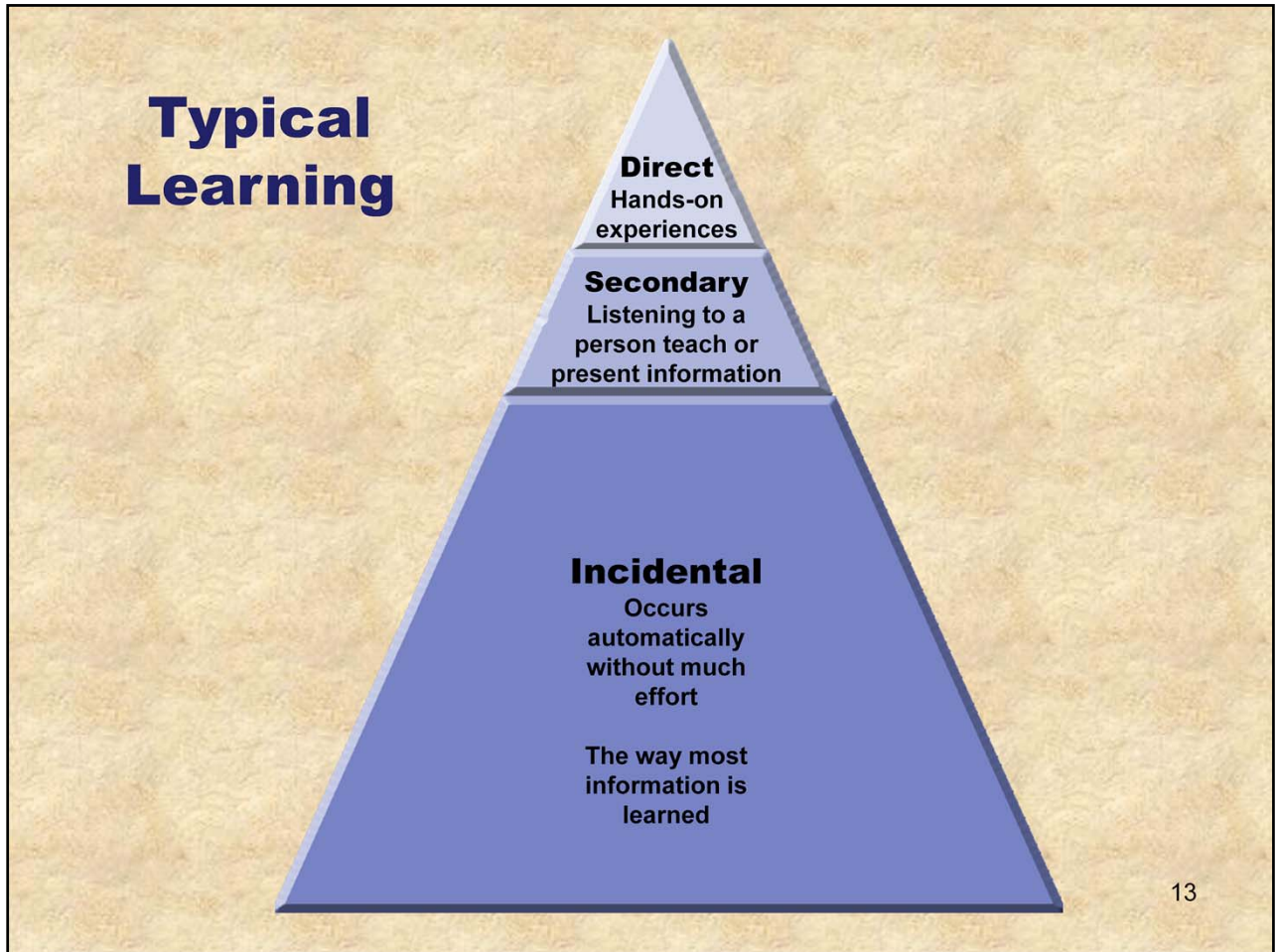
Learning

- Learning through independent observation and exploration is difficult
- Children:
 - Cannot learn what they do not detect
 - Are unaware of what information is missed
- Essential information is missed and incidental learning is greatly limited

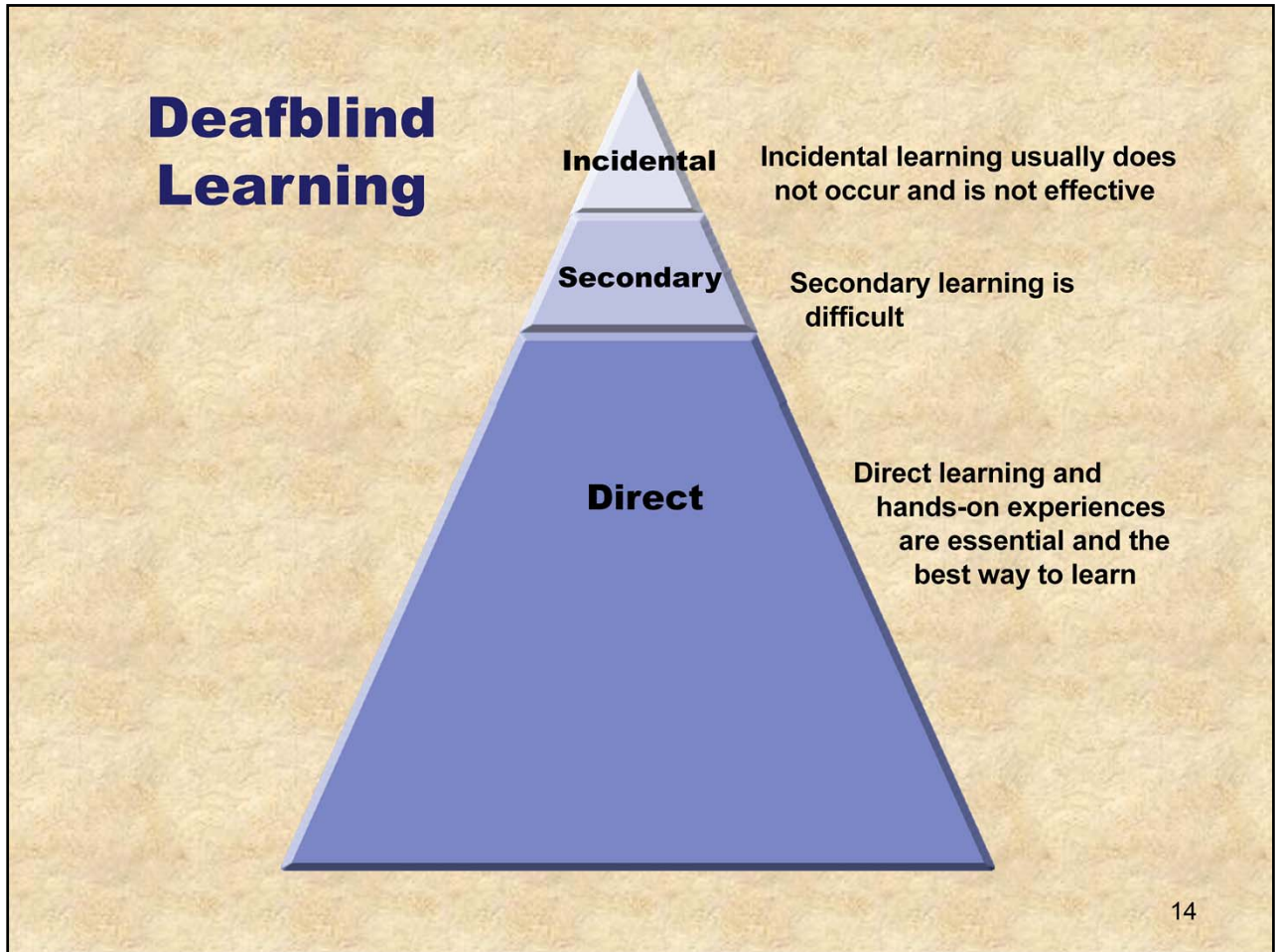


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Although deafblindness affects all areas of development, learning is especially impacted. For children with deafblindness, learning through independent observation and exploration is difficult. Because the flow of visual and auditory information is limited, they cannot learn what they do not detect, and they are unaware of what information they're missing. For these children, much essential information is missed, and incidental learning is greatly limited.



If we look at typical learning for children with normal vision and hearing, direct learning or that which involves hands-on experiences makes up a relatively small portion of their overall lifetime learning. Secondary learning or that which is obtained by listening to another person teach or present information, such as a teacher in a classroom, makes up a slightly greater portion of their overall lifetime learning. The largest portion of lifetime learning comes through incidental learning or that which occurs automatically without much effort simply from the flow of sensory information that is constantly available. This is the way most information is learned.



For children who are deafblind, this typical way of learning does not occur naturally. Incidental learning usually does not occur and is not effective because of the lack of access to information, and secondary learning is difficult for the same reason. Direct learning is by far the most effective way for these children to learn about the world, so hands-on experiences are essential. However, many educational settings are not generally designed for this type of learning.

Communication



- Development of formal language is difficult
- Ability to connect to others and be a part of the world is difficult

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Communication is especially impacted. Because of the lack of access to visual and auditory information, not only does the development of formal language become very difficult, but the basic ability to connect to other people and be a part of the world is also difficult.

Communication

Children who are deafblind miss opportunities to:

- Observe the communication of others
- Participate in communication themselves



Communication attempts may be missed or misunderstood

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Children who are deafblind miss opportunities to observe the communication of others and to participate in communication themselves. Often, their own communication attempts are missed or misunderstood by others.

Communication

Children who are deafblind:

- May try to express their wants through behaviors that *seem* inappropriate
- May be unaware of what their actions are communicating to others
- May have behavioral problems
- Cannot develop formal communication and interaction skills on their own



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They may try to express their wants through behaviors that seem inappropriate to others. They may be unaware of what their actions are communicating to others, or that their actions are even being observed and interpreted by others as a form of communication. Without the ability to communicate, they may have behavioral problems. They cannot develop formal communication and interaction skills on their own.

Social and Emotional Development

Lack of access to complete visual and auditory information results in varying degrees of isolation and disconnection from the world that are incomprehensible



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For children with deafblindness, social and emotional development is also affected. The lack of access to complete visual and auditory information results in varying degrees of isolation and disconnection from the world that are incomprehensible to those with vision and hearing.

Social and Emotional Development

Children who are deafblind may:

- Live lives of chaos
- Find social interactions to be confusing, purposeless, and even fearful
- Detach from others and avoid interactions



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Children who are deafblind may live lives of chaos with people and things coming and going randomly. They may find social interactions to be confusing, purposeless, or even fearful, so they may detach from others and avoid interactions.

Social and Emotional Development

- Emotional bonding and trusting relationships may be difficult
- Self-identity and self-determination are difficult to achieve
- Educational environments may not be emotionally manageable



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Emotional bonding and trusting relationships may be difficult to achieve. Self identity and self determination may also be difficult to achieve. Typical educational environments may not be emotionally manageable for them.

What is effective intervention for children who are deafblind?

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So what is effective intervention for children who are deafblind?

Deafblind Intervention

Intervention for children who are deafblind must:

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



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Intervention for children who are deafblind must connect them to the world. It must provide access to clear and consistent visual and auditory information, support for the development and use of receptive and expressive communication, and support for social and emotional well being.

Intervener

A person who:

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



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This connection to the world can be made through a person called an intervener. An intervener is defined as a person who works consistently one-to-one with a child who is deafblind and who has training and specialized skills in deafblindness.

Role of the Intervener

- To facilitate access to environmental information usually gained through vision and hearing
- To facilitate the development and/or use of receptive and expressive communication skills
- To develop and maintain a trusting, interactive relationship that can promote social and emotional well-being

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The role of the intervener is to provide effective deafblind-specific intervention. The intervener facilitates 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 facilitates the development and/or use of receptive and expressive communication skills, and the intervener develops and maintains a trusting, interactive relationship that can promote social and emotional well-being for the child who is deafblind.

Access to Environmental Information

The intervener:

- Increases and clarifies information
- Facilitates access to incidental information
- Facilitates the learning of concepts
- Provides consistency and constancy



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Let's look at each of these areas specifically. In the area of access to information, the intervener increases and clarifies information by presenting it in ways that the child who is deafblind can detect and interpret it. The intervener facilitates access to incidental information about people and things in the environment and facilitates the learning of concepts that sighted and hearing children learn incidentally. At all times, the intervener provides consistency and constancy.

Development and Use of Communication Skills

The intervener:

- Facilitates both receptive and expressive communication development
- Is a motivating and trusted partner who consistently responds to a child's communication
- Provides opportunities for conversations and interactions with others



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In the area of communication, the intervener facilitates the development and use of both receptive and expressive communication. The intervener is a motivating and trusted partner who consistently responds to the child's communication. And the intervener provides opportunities for conversations and interactions with others.

Social and Emotional Well-Being

The intervener:

- Develops a bond of trust with the child that decreases anxiety
- Helps the child know where he is and who is around him
- Encourages interactions with others
- Supports self determination by helping the child make choices, solve problems, and develop self esteem



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In the area of social and emotional well-being, the intervener develops a bond of trust with the child who is deafblind that decreases anxiety about exploring the environment and trying new things. The intervener helps the child to know where he is in his environment, and who is around him, and encourages interactions with others. The intervener supports self-determination by helping the child make choices, solve problems, and develop self-esteem.

Process of Intervention

- Access to information
- Communication
- Social and emotional well-being



- Academic work
- Self-care routines
- Specialized therapies
- Social activities

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In each of these areas, access to information, communication, and social and emotional well-being, the intervener facilitates the process of intervention in all educational programming, including academic work, self-care routines, specialized therapies, and social activities.

Interveners are trained to promote independence rather than dependence



Interveners are not a barrier between the child and the world ... but a vital link to people and things

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It's important to note that interveners are trained to promote independence for the child who is deafblind rather than dependence. Interveners are not a barrier between the child and the world, but a bridge to the world – a vital link to people and things in the environment.

Brenda Willets Parent



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Brenda Willets is the mother of a young boy with deafblindness who has the support of an intervener in his classroom. She shares her thoughts as follows.

I have a 6-year-old son with cerebral palsy. He is also deafblind due to cortical and neurological issues that he has. I've seen the importance of having a well-trained skilled intervener with Brady in the classroom. He has had a one-on-one aide, and he just hasn't made the progress with that. As he's had his intervener, he's making progress in communicating, in making choices, in social interactions with his peers, and in access to all the environment that's going on around him. And he's happy. His intervener is bringing information to him; helping him learn about his environment, concept development, and the things that he just doesn't learn incidentally like other children do. At school, it's fun too, because his peers can communicate with him, and they love it. They love to come up, and his intervener will help them communicate with him, and then he can communicate back to them. And it's opened up a whole new world for him.

Andrew Prouty Young Man with Deafblindness



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Andrew Prouty is a young man with deafblindness who had an Intervener throughout his school years. He shares his experiences and perspectives about interveners as follows:

I had an intervener in school to help me access communication and know what was going on around me. If I didn't have an intervener, I wouldn't have all that. I think an intervener helped me when I was growing up become more independent because now I live in my own apartment, I pay my own bills, I do my own shopping, and I travel independently to work. I think it is important for deafblind children to have interveners for a variety of reasons. So they have access to the world and communication, fewer behavior problems, and independence.

Debbie Nozawa Teacher



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Debbie Nozawa is a teacher who has worked with interveners in her classroom. She shares her perspective as follows:

I think having interveners in my classroom makes it more possible for me to reach more children. Before interveners, to reach our children who were deaf and blind, I needed to be with them and right close or I couldn't reach them. Unless there was a staff with that child then there was no way to reach that child.

National Perspectives

Using one-to-one supports with children who are deafblind in educational settings is not new

Relatively new:

- Use of the term “intervener”
- Recognition that interveners need specialized training and skills in deafblindness



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Nationally, the practice of using one-to-one support with children who are deafblind in educational settings is not a new one. What is relatively new is the use of the term “intervener” to designate a deafblind specific one-to-one support person, and the recognition that interveners need specialized training and skills in deafblindness in order to work effectively with children who are deafblind.

Systemic Issues and National Efforts

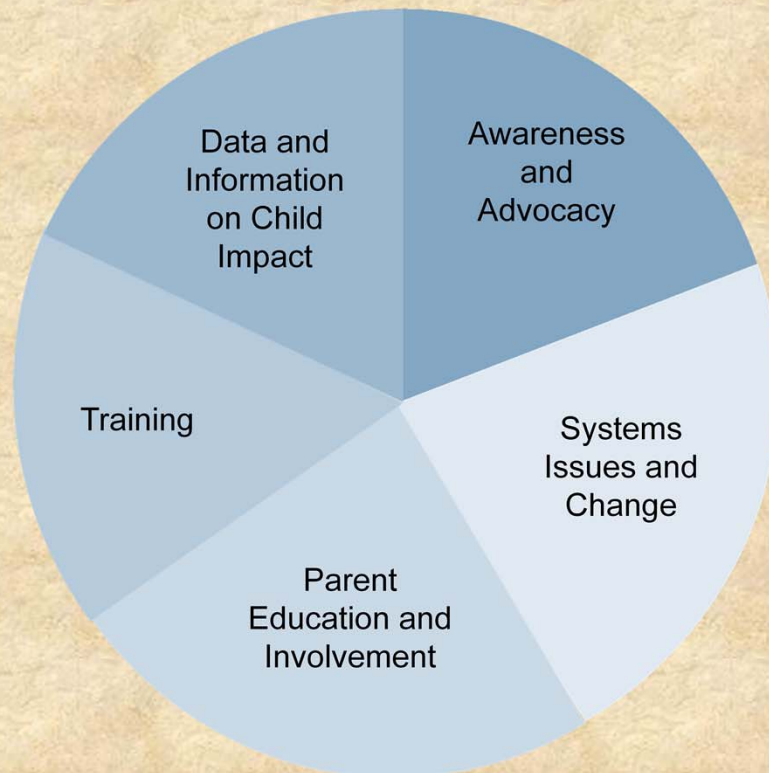
National Intervener Task Force formed to:

- Provide an open forum for discussion about the use of interveners
- Increase awareness of the role of the intervener with children who are deafblind
- Establish the intervener practice as a credible option of support

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There are some systemic issues to consider related to the use of interveners, and there are a number of national efforts to address these issues. In 2002, a National Intervener Task Force was formed to provide an open forum for discussion about the use of interveners, to increase awareness of the role of the intervener with children who are deafblind, and to establish the intervener practice as a credible option of support for these children.

Focus of National Intervener Task Force



Establish interveners as a credible service delivery option for children who are deafblind

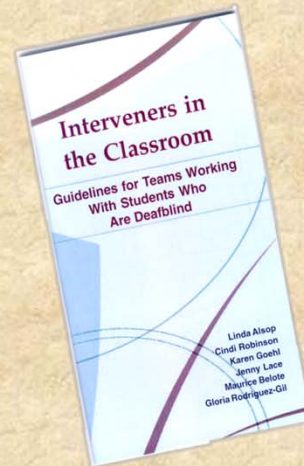
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This task force identified five areas on which to focus their efforts: ♦Awareness and Advocacy, ♦Systems Issues and Change, ♦Parent Education and Involvement, ♦Training, and ♦Data and Information on Child Impact .

Since then, this task force has worked collaboratively with educators, parents, professionals, lawmakers, and others to address issues in each of these five areas, with the overall goal of establishing the practice of using interveners as a recognized and credible service delivery option for children who are deafblind.

Resources

“Interveners in the Classroom Guidelines for Teams Working With Students Who Are Deafblind”



Interveners and Paraprofessionals

Similar:

- Abide by district or agency policies
- Work under direction of classroom teacher

Different:

- Training
- Providing deafblind-specific intervention

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Various resources and materials have been developed that guide the practice of using interveners. *Interveners in the Classroom – Guidelines for Teams Working with Students Who Are Deafblind* is a resource booklet that defines the role of interveners, teachers, and administrators, as they work together on behalf of students who are deafblind. These guidelines also described the difference between interveners and regular classroom paraprofessionals. The intervener and the paraprofessional are similar in that they both abide by the policies of the district or agency and they both work under the direction of the classroom teacher. Beyond that, they are different in their training and in their role providing one-to-one deafblind-specific intervention.

Incidence of Deafblindness

- Children who are deafblind:
 - Are a low incidence population with high and intense needs
 - Many are counted in the multiple disabilities category
- Discrepancies exist between SEA count and national deafblind child count
- SEA deafblind child count doesn't represent actual numbers



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When considering the incidence of deafblindness, it is important to note that children who are deafblind make up a low incidence population with high and intense needs. Many of these children have additional disabilities and are identified and counted in the multiple disabilities category rather than the deafblind category. Consequently, there are discrepancies in numbers between the state education agency (SEA) deafblind child count and the numbers reported by the state deafblind projects. Therefore, the SEA deafblind child count does not adequately represent the actual numbers of deafblind children ages birth to 22.

Annual Performance Report (APR)

State Improvement Activities (reported under SPP Indicators)

- Show efforts to ensure Free and Appropriate Public Education (FAPE) for every child with disabilities
- Should reflect efforts to ensure FAPE for children who are deafblind



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Every year states have an Annual Performance Report, or APR, in which they must report their state improvement activities under each of the OSEP required SPP Indicators. These activities show a state's efforts to ensure that every child with disabilities receives a Free and Appropriate Public Education (FAPE). Even though children who are deafblind represent a low number of the disability subgroup reported under No Child Left Behind and have minimal impact statistically on the district or state, these improvement activities should reflect efforts to ensure FAPE for these children.

State Improvement Activities

Including interveners can:

- Be a part of activities that target performance, behaviors, and outcomes for children with deafblindness
- Demonstrate the district's inclusion of children with deafblindness
- Demonstrate a state's efforts to ensure FAPE



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Including interveners in state improvement activities can be an important part of any activities that target the performance, behaviors, and outcomes for children with deafblindness and can demonstrate the district's inclusion of children with deafblindness and the state's efforts to ensure FAPE for these children.

(The State Performance Plan or SPP and Annual Performance Report or APR is required by OSEP. They are the vehicles for the federal government to provide quality assurance, accountability, and general supervision for state implementation of IDEA 2004. The indicators included in the State Performance Plan are directly connected to the provision of a Free and Appropriate Public Education or FAPE for children with disabilities.)

Improvement Activities Related to Interveners

- The training of interveners
- The recognition of interveners in state educational policies
- Awareness training or administrators and staff at state, district, and local levels



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Although each state determines its improvement activities for their Annual Performance Report (APR), some examples of possible improvement activities that relate to the use of interveners include: ◆the training of interveners, ◆the recognition of interveners in state educational policies, and ◆awareness training for administrators at state, district, and local levels on the benefits, needs, and rights of children who are deafblind to have interveners.

Interveners and Part B SPP Indicator Alignment

Indicator 3: Participation and Performance in Statewide Assessments

Interveners can provide:

- Access to the general education environment
- Access to all activities and programs to improve the performance of children who are deafblind



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There are natural places to embed the use of interveners into state improvement activities which align with some of the Part B SPP indicators.

Under Indicator 3: Participation and performance on statewide assessments: Interveners can provide access to the general education environment and access to all activities and programs geared to the performance of children who are deafblind.

Interveners and Part B SPP Indicator Alignment

Indicator 7: Preschool Outcomes

Interveners can facilitate improvement for preschool children who are deafblind in:

- Acquisition of knowledge
- Early language, communication, and literacy skills
- Social-emotional skills
- Appropriate behavior



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Under Indicator 7: Preschool outcomes: Interveners can facilitate improvement for preschool children who are deafblind in the acquisition of knowledge; early language, communication, and literacy skills; social-emotional skills; and appropriate behavior.

Interveners and Part B SPP Indicator Alignment

Indicator 14: Secondary Transition

Interveners can be the bridge to postsecondary services and positive outcomes by providing access to services and programs that meet postsecondary goals



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Under Indicator 14: Secondary transition: Interveners can be the bridge to postsecondary services and positive outcomes by providing access to services and programs that meet postsecondary goals.

Interveners and the Provision of FAPE and LRE

- Interveners can play a critical role
- FAPE mandates
 - Access to general education, the general curriculum, and activities
 - Access to specialized educational services
- LRE is based upon “Access”
 - Not a place
 - Supports and services that provide access, participation, and progress in the general education curriculum



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Related to the provision of a Free and Appropriate Public Education, or FAPE, and the provision of the Least Restrictive Environment, or LRE, for children who are deafblind, interveners can play a critical role. FAPE mandates access to general education, the general curriculum, and activities and access to specialized educational services. The Least Restrictive Environment is also based upon “Access.” LRE is not a place, but refers to the supports and services that provide access, participation, and progress in the general education curriculum.

Interveners and the Provision of FAPE and LRE

- Access:
 - A key term in IDEA
 - A critical issue for children who are deafblind
 - Without it educational environments are restrictive

- The intervener can:
 - Be the individualized support that facilitates access to information, participation, and progress
 - Facilitate LRE
 - Support the provision of FAPE



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“Access” is a key term in the requirements of IDEA, and it is an especially critical issue for children who are deafblind, because of their lack of access to visual and auditory information. Without access to the information needed for learning and interaction, educational environments are restrictive. The intervener can be the individualized support that facilitates “access” to information, participation, and progress; facilitate LRE; and support the provision of FAPE.

Interveners and the IEP

Interveners can:

- Be designated as **related services** or as **supplementary aids and services**
- Help children who are deafblind:
 - Advance appropriately to obtain goals
 - Be involved in and make progress in the general education curriculum
 - Be educated and participate with other children with and without disabilities



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Under the IEP process, interveners can be designated as “related services” or as “supplementary aids and services” (depending upon the individual state). As such, they can help children who are deafblind 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.

Determining the Need for an Intervener

- How will the access of visual and auditory information be provided?
- What support will be provided for communication and interaction?
- How will the Least Restrictive Environment be provided?
- How will FAPE be ensured?



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When determining the need for an intervener during the IEP process, some important questions should be considered: How will the access of visual and auditory information be provided to this child? What support will be provided to the child for communication and interaction? How will the Least Restrictive Environment be provided? And how will FAPE be ensured?

Intervener Training

- Office of Special Education Programs (OSEP) requires State Deafblind Projects to address training for interveners
- National Intervener Competencies specify the knowledge and skills needed by interveners
- The Council for Exceptional Children established an Intervener SPA in 2009 setting standards for university and college intervener training programs



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The training of interveners is another systemic issue. Intervenors have been recognized by the Office of Special Education Programs (OSEP). Each state has a federally funded State Deafblind Project, which is now required to address the training needs of intervenors. There are National Intervener Competencies that specify the knowledge and skills needed by intervenors to work effectively with children who are deafblind. In the spring of 2009, these competencies were approved by the Council for Exceptional Children, or CEC, and a new Intervener Specialized Professional Association, or SPA, was established, which set standards for university and college intervener training programs. As of 2009, Utah State University and East Carolina Central University currently have preservice intervener training programs. And currently, efforts are being made to establish a national credential for intervenors.

Administrative Support

Steve Kukic

Former Utah Special Education Director



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It's important that administrators understand the role of interveners in educational settings and provide the support needed for them to work successfully as IEP team members. Steve Kukic, a former State Director of Special Education in the state of Utah, directed a statewide initiative there to obtain state funding for intervener services. He shares his perspectives about the use of interveners:

Let me just talk for a minute about the value of interveners and the essential nature of interveners for these students. When I even say that, it is sort of incredible to me even today to say it. My view up from front was that it was better not to have an external person with any individual. The reason is that I want that individual to be as independent as possible.

What I learned through my exposure to this amazing and wonderful and awful disability, is that these young people have to have someone with them who will not only translate what is going on in the world to them, with their budding intelligence, but will also get a relationship with them that that child can trust.

Grateful acknowledgement goes to The Gibney Family Foundation whose generous funding contributed to the development and dissemination of these materials.

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