



NATIONAL CENTER
ON DEAF-BLINDNESS

**INTERVENERS IN THE HOME AND COMMUNITY:
AN UNDER-RECOGNIZED IMPERATIVE**

HOME AND COMMUNITY INTERVENER WORKGROUP

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At the request of the U.S. Department of Education's Office of Special Education Programs, in 2012 the National Consortium on Deaf-Blindness (NCDB) published Recommendations for Improving Intervener Services (NCDB, 2012a). Although the recommendations focus specifically on the use of intervener services in early intervention and educational settings, the nature of the disability of deaf-blindness makes these services important in home and community settings as well. Therefore, within the first recommendation, which promotes a coordinated and expanded national approach to the expansion of intervener services, an implementation strategy called for the establishment of a workgroup to explore issues related to interveners in home and community settings. This paper was developed by that workgroup. It summarizes current knowledge about the use of interveners in homes and communities and proposes actions to provide greater access to interveners for people of all ages who are deaf-blind.

Introduction

A person who is considered deaf-blind is someone who is deaf or hard-of-hearing in combination with a visual impairment or blindness. The range of capabilities and support needs of individuals with deaf-blindness varies substantially from person to person because of differences in the extent of partial vision or hearing, if any, or the presence of additional conditions such as intellectual or physical disabilities. In all cases, however, deaf-blindness results in difficulties detecting, gathering, and prioritizing reliable auditory and visual information from communication partners and the surrounding environment. Information received without support can be incomplete, fragmented, or distorted and especially difficult to obtain from a distance.

A lack of easy access to visual and auditory input typically results in severe information gaps—gaps in knowledge about what is happening here and now and gaps in conceptual knowledge. In addition, a person who is deaf-blind often has difficulty knowing where things are located, moving safely, and recognizing and interacting with people, places, and things.

In the United States there has recently been increased awareness of the value of employing trained interveners to provide access to sensory information and communication for the purpose of fostering independence for individuals with deaf-blindness. Although this awareness is a positive development, to date it has benefited almost exclusively children and youth in school settings and has overlooked the importance of intervener services as an option for both children and adults in their homes and communities. Our goal, in this paper, is to (a) raise awareness of the need for

intervener services in home and community settings, (b) describe how these services are different when provided in home and community settings, and (c) provide suggestions for increasing recognition and understanding of intervener services in home and community settings.

Defining Intervener Services

Interveners are paraprofessionals who have been trained to provide individualized support to people with deaf-blindness in order to improve access to information, environments, and communication partners. Existing definitions of intervener services share common themes, including individualized support, access to visual and auditory information, and specialized training (NCDB, 2013a). Recently, through the work of NCDB and others, the field has worked to clarify these common ideas and publish them in the document *Intervener Services and Interveners in Educational Settings – Definition* (NCDB, 2013b). The following is an excerpt from that definition:

Interveners, through the provision of intervener services, provide access to information and communication and facilitate the development of social and emotional well-being for children who are deaf-blind. In educational environments, intervener services are provided by an individual, typically a paraeducator, who has received specialized training in deaf-blindness and the process of intervention. An intervener provides consistent one-to-one support to a student who is deaf-blind (age 3 through 21) throughout the instructional day.

Working under the guidance and direction of a student's classroom teacher or another individual responsible for ensuring the implementation of the student's IEP, an intervener's primary roles are to (Alsop, Blaha, & Kloos, 2000):

- *provide consistent access to instruction and environmental information that is usually gained by typical students through vision and hearing, but that is unavailable or incomplete to the individual who is deaf-blind;*
- *provide access to and/or assist in the development and use of receptive and expressive communication skills;*
- *facilitate the development and maintenance of trusting, interactive relationships that promote social and emotional well-being; and,*
- *provide support to help a student form relationships with others and increase social connections and participation in activities.*

This definition accurately describes the intervener's role, but because it refers specifically to intervener services in school environments, terminology is limited to describing participants as "children," "students," and "classroom teachers." The need for interveners, however, is not limited to specific age groups or to certain times, circumstances, or locations. Adults who are no longer part of the educational system may benefit enormously from intervener services as may school-age students outside of school hours (e.g., after school and during holiday and summer breaks). The same type of support outlined in the definition can be accomplished in home and community settings within a different organizational structure.

Intervener Services in the Home and Community Versus Educational Settings

The basic role of intervener services is the same in both home/community settings and in educational settings: providing access to visual and auditory information and access to communication, facilitating relationships with others, and promoting independence.

There are, however, a number of differences in the two circumstances in the way that intervener services are funded, how interveners are supervised, the nature of the relationship between an intervener and an individual with deaf-blindness, and the types of activities for which interveners provide support.

Funding Sources

In educational settings, the funding for intervener services as defined in a student's individualized educational program (IEP) is the responsibility of the student's school district. Though there may be differences in the frequency, intensity, and quality of educational services from place to place across the nation, all special education services must follow the requirements of the Individuals with Disabilities Education Act (IDEA). The provision of intervener services is not as straightforward in home and community settings, which have no single guiding authority. They may potentially be provided by a combination of community service programs, agencies, and organizations that vary from state to state and from community to community.

As a result, funding might come from diverse sources including Medicaid waiver programs, vocational programs, respite services, independent living centers, and other support programs for individuals with developmental disabilities. In some cases, when no

support programs are available, families have privately hired interveners for family members with deaf-blindness.

Supervision/Autonomy

In school settings, interveners work as part of an educational team within the framework of an individualized educational program (IEP), and there is, or should be, a distinct line of supervision. An intervener works under the direction of professional educators (teachers and related service staff) who develop educational goals, instructional content, and learning activities for students who are deaf-blind. The role of the intervener is to provide the student with sensory access to these learning activities and implement the accommodations and adaptations identified in the IEP. In contrast, there may not be an organized team framework or line of supervision in home and community settings, and as a result, the intervener may have greater decision-making responsibility as they collaborate closely with the individuals with deaf-blindness whom they serve and often with family members.

Relationship to Individuals with Deaf-Blindness

In schools, interveners work with children and youth 21 years of age or younger. They assist students with accessing instruction and interacting with peers and educators according to school schedules and procedures. In home and community settings, the individual with deaf-blindness and his or her family members have more control over their own schedules and their own ways of doing things.

Supported Activities

In educational settings interveners work with educators and other IEP team members to implement a student's IEP goals. Most of the support that interveners provide is related to learning activities, but it may also be related to extracurricular activities or social opportunities during the school day. In home and community settings interveners support activities needed or suggested by the individuals who are deaf-blind and their families, such as self-care, home management, errands, employment, community involvement, volunteering, recreation, social events, neighborhood groups, clubs or organizations, and transportation. Intervenors may need to provide guidance or sometimes help an individual with deaf-blindness to learn new skills, but they must take the person's own plans and preferences into account.

Current Status of Intervenors in Home and Community Settings

Most states offer some types of community support for individuals with disabilities. These include personal attendants, habilitation aides, job coaches, and respite providers who may or may not have knowledge and skills related to deaf-blindness. The use and availability of home and community intervenors is uncommon, but our workgroup did identify two states—Minnesota and Texas—in which intervenors are paid to work in home and community settings.

Minnesota

Minnesota's Department of Human Services (DHS) funds Deafblind Services Minnesota (DBSM) to provide trained intervener and support service providers to individuals who

are deaf-blind in homes and communities (see Appendix B for a description of support service providers). A child or adult may receive 18 to 24 hours per month of one-to-one services through this program. Many are also served through Minnesota's Medicaid waiver programs with the objective of promoting and maintaining independence.

Minnesota has strong family and intervener communities through the cooperation of DBSM and the federally funded Minnesota DeafBlind Project. For example, families are provided with opportunities to network through a variety of workshops and activities such as parent retreats and picnics honoring interveners. Additionally, both school and community interveners statewide are provided with a comprehensive six-weekend training course.

Recently, DBSM has been providing intervener services to surrounding states such as Wisconsin. Families in these states with children who are deaf-blind may purchase intervener services using waivers provided at the county level. DBSM will seek out qualified applicants in a child's community to hire and train to become an intervener. Depending on a waiver's budget, a child typically receives between 4 and 8 hours of intervener services per week.

Texas

Texas has a Medicaid waiver program for individuals who are deaf-blind with additional disabilities. The program uses the term "intervener" as a job title and service category. State law also defines a career ladder for interveners. The Medicaid reimbursement rate increases as the intervener gains additional education and skills. Recipients of the Medicaid waiver program can request intervener services from a menu of services.

Although the program is a step forward for individuals with deaf-blindness in Texas, there are insufficient numbers of trained and qualified interveners to meet the demand. College-credit classes in deaf-blindness are required to advance on the career ladder; thus, the development and availability of intervener-training courses that address the work of interveners in home and community settings is greatly needed.

Steps to Increase the Use of Intervenors in Home and Community Settings

Programs like those in Minnesota and Texas are rare. Real barriers to the provision of these services, such as limited funding and a lack of trained interveners, exist in almost every state. As families, professionals, and policymakers work to increase the availability of intervener services within educational settings, there is a need to simultaneously build an infrastructure that supports intervener services in home and community settings as well. As noted at the beginning of this paper, the need for help to access information and communication by those with combined hearing and vision loss is not limited to certain settings or age groups. Without proper support, deaf-blindness impairs the ability to communicate throughout a person's life.

We suggest the following steps to begin addressing the need to provide greater access to interveners in home and community settings for individuals of all ages who are deaf-blind:

- Raise awareness about the need for intervener services in the home and community for individuals of all ages who are deaf-blind and require this level of support.

- Identify potential sources of funding for home and community interveners within states and local communities.
- Work with existing and emerging intervener-training programs to add content about working in home and community settings, including examples of interveners supporting individuals of all ages.
- For students who already receive intervener services in educational settings, include consideration of intervener services needs during non-school hours and following graduation in IEP team discussions (see Appendix A).

In carrying out these actions, stakeholders in both educational and community sectors should cooperate to make the most of limited resources and to establish cohesive connections between the two systems. The low-incidence nature of deaf-blindness makes efficient leveraging of resources a crucial imperative.

These actions to promote the use of interveners and prepare them to work in a variety of settings would likely make intervener services a more attractive career choice and result in a more stable workforce. Retaining individuals trained in intervener services as a career has been a challenge for the field because the low-incidence nature of deaf-blindness has led to limited employment opportunities in many areas.

For family members and service providers who are currently involved in efforts to expand the availability of intervener services in schools, the following additional actions will promote awareness and acceptance of intervener services by acknowledging that interveners also work in areas outside of educational settings.

- When discussing the role of interveners, describe the person being supported with more universal words, such as “person” or “individual,” rather than “student” or “child.”
- In publications that address the use of interveners only in school settings, label the material as relevant to “interveners in schools” rather than to “interveners” in general.
- When discussing intervener services issues that are unique to schools, such as the intervener’s role on the IEP team, clarify these issues with phrases like “When working in a school setting...”

Conclusion

For many individuals with deaf-blindness, interveners serve an essential role in providing access to information missed as a result of limited or absent visual and auditory input, as well as in facilitating communication, social interactions, and independence. The current expansion of efforts to increase the availability of intervener services in educational settings is an extremely important development in the U.S., but as we have identified in this paper, many individuals with deaf-blindness of all ages can benefit from these services in other settings. As the field of deaf-blindness moves forward with efforts to improve the infrastructure of intervener services for school-age individuals, it is also important to focus attention on resources and strategies that lead toward expanding intervener services in home and community settings for individuals with deaf-blindness of all ages.

APPENDIX A

Questions for Discussion by IEP Teams of Students Who Receive Intervener Services

- Are there circumstances in which support provided by an intervener in an educational setting is also needed after school, during holidays, and in the summer?
- How should the IEP team collaborate with interveners who serve students in the home and community outside school hours?
- In what cases will support provided by an intervener in school continue to be needed after the student graduates?
- What issues related to intervener services should be discussed during transition planning? (Consideration of the need for intervener services following graduation or exit from the school system should *always* be included in transition planning for students with deaf-blindness. A student who requires intervener services while in school is likely to continue to need them following graduation.)
- What funding sources are available to support intervener services that are necessary outside of the educational setting?

APPENDIX B

Interveners Compared to Other Support Roles

The key role of an intervener is to provide an individual who is deaf-blind with access to communication, the environment, and social interactions. In home and community settings, there are two other types of service providers who assist with some elements of this support—interpreters and support service providers (SSPs). Like interveners, interpreters work in both educational and community settings, but SSPs are an emerging type of service provider unique to home and community settings. Because aspects of these three roles may often be confused, the information in this appendix briefly describes the differences between (a) interveners and interpreters and (b) interveners and support service providers.

How does an intervener differ from an interpreter?

Interpreters are trained and certified to translate communicated information from one language or mode to another, such as from spoken language to sign language and vice versa. They act as a neutral channel through which information flows. When working with individuals who are deaf-blind, they use the style of communication that is best adapted for the individual (e.g., close vision, reduced field, or tactile sign language).

In contrast, although interveners must be skilled in the communication modes that best suit the individual with whom they are working, they are typically not required to be trained and certified as interpreters (some certified interpreters do, however, undergo additional training to become interveners). The forms of communication used by

individuals with deaf-blindness vary depending on particular abilities and preferences but include nonlinguistic forms of communication (e.g., gestures and tangible symbols such as objects, pictures, or tactile symbols), speech, and sign language.

In addition, interpreters operate within a code of professional conduct to faithfully convey “the content and spirit of what is being communicated, using language most readily understood by consumers,” and to “refrain from providing counsel, advice, or personal opinions” (RID, 2005). Although, interpreters take environmental information and necessary accommodations into consideration when working with deaf-blind individuals, they primarily convey only what is being communicated as it is being communicated. Interveners, on the other hand, provide additional communication and other supports, including the following:

- providing explanations to help an individual understand a situation or message;
- filling in background information related to unfamiliar concepts;
- providing information about what is happening in the environment around the individual;
- prioritizing information if it is coming too quickly for the individual to understand;
- providing emotional support to help the individual feel safe, secure, and successful;
- helping to direct the individual’s attention to materials through physical guidance; and
- helping the individual to move from place to place.

How does an intervener differ from an SSP?

Like interveners, support service providers (SSPs) are an emerging support service for individuals with deaf-blindness in the United States (Bourquin, et al., 2006). SSPs provide support in accessing communication, information, and environments at the direction of the person with deaf-blindness, who is the decision-maker in the relationship. The SSP model is designed for people who are deaf-blind and have the skills, abilities, maturity, and experience to independently provide direction to the SSP. The primary roles of an SSP are to provide transportation (e.g., by car or bus and as a human guide while walking) and to relay “visual and environmental information that may not be heard or seen by the person who is deaf-blind” (Bourquin, et al., 2006). A typical SSP assignment might include providing the support a person needs to fully enjoy a social event—for example, providing transportation, describing the scene and the people, and facilitating activities like mingling, getting refreshments, finding a place to sit, and participation in games. In addition to social occasions, SSPs provide support for activities like meetings, doctor’s appointments, banking, shopping, travel, and reading mail.

While SSPs and interveners both provide sensory access to guide and facilitate communication, interveners provide support in many additional ways that SSPs traditionally do not. Intervenors assist in the home and community by performing activities *with*, rather than *for*, the individuals they are supporting. Some people who are deaf-blind may not be comfortable with or capable of self-direction because of additional disabilities, youth, or lack of experience. These individuals may not be able to plan and initiate activities, or they may not have the knowledge and experience to take the lead and

make decisions. In these cases, the intervener's role is to provide the initiation and direction needed so that the person can have more opportunities for meaningful and satisfying experiences with preferred activities. This may include assistance with making decisions if the person is unable to do so successfully on his or her own and teaching new skills to increase independence.

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