

# Chapter 18

## Deaf Community Support for Families: The Best of Partnerships

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### Why Deaf Community Involvement?

When a child is identified as deaf or hard of hearing, many professionals enter the scene. Families meet doctors, audiologists, speech-language pathologists, geneticists, and many others. Parents/caregivers bring their child to appointments for evaluations, services, and follow-up. For many families, life after determination of a child's hearing levels often is a flurry of calls and appointments with service providers.

Most parents/caregivers of deaf and hard-of-hearing children are themselves hearing and, in the majority of cases, are unfamiliar with the lives of deaf and hard-of-hearing children or adults. Parents/caregivers want to support their child as well as they can. Because they have so little prior knowledge about deaf and hard-of-hearing children, they depend heavily on the professionals to give them the information, support, and services they need.

Ideally, professionals serving family members work collaboratively to support them in adapting to the news that their child is deaf or hard of hearing and to the changes it brings. Unfortunately, more often than not, missing from the collaboration are professionals who are Deaf and Deaf community representation.

Deaf professionals and Deaf community organizations should be integral parts of Early Hearing Detection and Intervention (EHDI) systems. Individuals who have

My son was the first Deaf person I ever met . . .

As a family, we embraced Deaf culture, American Sign Language, Deaf role models, and Deaf families early in his life. He grew to become a confident, highly educated, tolerant, and patient adult. I am grateful and proud as I reflect on how enriched our lives have become.

—Parent

grown up Deaf or hard of hearing are in a unique position to provide information and support to families with young deaf or hard-of-hearing children. Research shows that contact with the Deaf community helps families transition to acceptance of their child as a Deaf person (Hintermair, 2006). Deaf community members are able to provide the deaf child with something hearing parents cannot: Experience as a Deaf person (Chute & Nevins, 2002). Deaf and hard-of-hearing adults can offer ideas and

strategies to assist families in communicating and functioning smoothly and reducing frustration and stress. This in turn provides the deaf or hard-of-hearing child a healthy sense of self-esteem and a feeling of respect and acceptance as a deaf or hard-of-hearing individual in the family (Benedict & Sass-Lehrer, 2007; Leigh, 2009; Meadow-Orlans, Mertens, & Sass-Lehrer, 2003). Contact with the Deaf community expands the family's pool of support. Interaction with the Deaf community paves the way for a whole new world of information and experiences that would not otherwise be available to the family.

When we found out our daughter was Deaf, we began early intervention services . . .

There was no mention of the Deaf community, ASL, or deaf schools and the resources they provided. The only Deaf person we knew was our child. It was through our own search that we stumbled upon these valuable resources. After we made these connections, our family's life became much easier, and our daughter's language began to flourish. Deaf professionals employed in every level of EHDI services and the resources that deaf schools provide are a critical missing link in today's early intervention programs. Parents deserve to have all the resources, information, and tools necessary to raise their deaf children.

Involving the Deaf community in EHDI systems can help move these systems from using a purely medical approach to employing a socio-cultural model. While the medical model sees deaf children as having a loss or deficit, the socio-cultural model focuses on the connections the child has in his or her environment, including the family. *Table 1* illustrates terminology reflecting those different perspectives (as adapted from Benedict, 2009).

*Table 1*  
**Medical Model vs. Socio-Cultural Model**

Medical Model	Socio-Cultural Model
Communication options (“either/or”)	Communication opportunities (“and”)
Hearing loss	Hearing level, status, abilities, or differences
Early Intervention	Early family support and collaboration
Failed hearing test	Refer with explanation
Diagnosis	Identification
Fix the ear	Enhance access to sound
Deafness	Deaf, deaf people, being deaf
Hearing impaired	Deaf or hard of hearing
Vocationally limited	Unlimited opportunities
Grief process	Journey
Disability (cannot)	Culturally diverse (adapt)
Auditory technology	Visual and auditory technology

When I first found out that my two youngest children have a condition that causes hearing loss, among other things, I could not get on the phone fast enough . . .

Doctors, our local county-sponsored early intervention program, therapists, support groups—I called them all. The only call that I did not make was to the nearby school for the deaf. Call it fear or denial or whatever you choose. I told myself I was too busy and that they weren't Deaf—they were hard of hearing. I finally made the call, because I was tired of saying “no” when people asked me if I had done it yet. I could not be happier to have made that call. From the beginning, the teachers, parents, professionals, and staff at [the school for the deaf] have made what could have been a truly distressing time instead a time that my children and I enjoy immensely. My children and I have found friends, confidantes, teachers, and all the support we could ask for within the school community. I could not be more grateful for the experience I have had there.

In their book, *The Parents' Guide to Cochlear Implants*, Chute and Nevins (2002) support collaboration between implant centers and the Deaf community and schools for the deaf. For example, they recommend that cochlear implant centers team with Deaf community members to create a website that will attract children with implants and their parents/caregivers and provide links to other established Deaf-related websites. They also recommend that centers collaborate with schools for deaf children and sponsor social gatherings for all deaf children in the area.

A recently published work by the [Joint Committee on Infant Hearing](#) (JCIH, 2007, p. 909) encourages opportunities for families to interact with the Deaf community and other individuals who are Deaf or hard of hearing:

Almost all families choose at some time during their early childhood programs to seek out both adults and child peers with hearing loss. Programs should ensure that these opportunities are available and can be delivered to families through a variety of communication means, such as websites, e-mail, newsletters, videos, retreats, picnics and other social events, and educational forums for parents.

The JCIH's recent supplement to the Year 2007 position statement builds on this. In the supplement, JCIH makes this formal recommendation for EHDI systems:

**Goal 11.** All Children Who Are D[eaf and] H[ard of] H[earing] and Their Families Have Access to Support, Mentorship, and Guidance From Individuals Who Are D[eaf] or H[ard of] H[earing].

It cites benefits to families who have experienced this contact, including developing a positive vision of their child's future. JCIH advises states on steps they should take to implement this recommendation, including establishing an advisory board with appropriate representation, developing guidelines and leadership training, and developing and implementing a monitoring system (JCIH 2013, p. e1338). In addition, JCIH sets as a goal:

**Goal 3a.** Intervention Services to Teach ASL Will Be Provided by Professionals Who Have Native or Fluent Skills and Are Trained to Teach Parents/Families and Young Children.

The JCIH recommends a number of actions that states should take to ensure ASL services, as well as spoken language services, are available and are of high quality (JCIH, 2013, p. e1330).

Families have the right to be informed of all resources and opportunities that can assist them in raising their child. The Deaf and hard-of-hearing community is key in this category of resources.

## Who is the Deaf Community?

The Deaf community is diverse, with individuals from all socioeconomic levels, educational backgrounds, and ethnic groups. Deaf people can be found in a range of occupations, including doctors, lawyers, accountants, teachers, scientists, architects, athletes, and more. Deaf persons live in the city and the country, along with being marathoners and couch potatoes, computer geeks and technophobes, introverts and extroverts. They come from all walks of life, nationalities, and religions. Deaf people reflect the same range of human experience as hearing people.

Deaf individuals may use auditory technology, such as hearing aids or cochlear implants, or they may not use any auditory technology at all. Many use computers and text messaging as well as visual alerting systems, such as a light that flashes when the doorbell is pressed. Deaf people may use sign language, spoken language, or both and may have learned sign language from birth, as an adult, or never at all. The Deaf community

shares a language—in the U.S. and Canada, American Sign Language (ASL)—and the experience of navigating a world in which most people hear. It also includes “allies;” that is, parents/caregivers, siblings, ASL interpreters, educators, children of Deaf adults, and other friends of the Deaf community who respect and celebrate ASL.

Involvement in the Deaf community varies from person to person according to each individual’s needs and interests. People connect in a range of ways, including through social gatherings, sporting events, cultural arts, religious expression, organizational membership, and political action. History and stories are handed down from generation to generation. The Deaf community is a living testament to the human ability to adapt and make a productive, wholesome, and happy life despite obstacles and resistance from the world around them.

Many members of the Deaf community did not learn sign language early in life, because parents or professionals were discouraged from using it with them. Once Deaf people see it is a viable language and desired way of communicating, they want to learn it and lament the fact that they didn’t have the opportunity earlier (Oliva, 2004). This fact has been reaffirmed by new research on Deaf and hard of hearing adults

### As parents, we do our best with what we have . . .

Parents of deaf and hard-of-hearing children have the Deaf community. As parents, we need to capitalize on the opportunities to socialize and interact with professionals in our Deaf community. Deaf children and families need Deaf professionals, and the Deaf community needs to embrace the young Deaf members of our community. Parents coupled with Deaf professionals make a perfect marriage of families and community working as a team to prepare our Deaf students for a successful future!



who are now between the ages of 18 and 34. Even with advances that have been made in public school accommodations, young adults still regret feeling isolated from “kids like me” in their K-12 years. They are very aware of what they missed in social interaction, identity development, and incidental learning (Oliva and Lytle, 2014).

Deaf professionals who use sign language may not be encouraged to be involved in early intervention. It is important to point out that research clearly shows that ASL does not inhibit either spoken English development or literacy but rather enhances it (Petitto, 2000). In addition, when hearing parents/caregivers are given signing adult language models and consistent support, such as ASL classes, they are able to become competent and to converse with their deaf child as early as 6 months of age (Easterbrooks, 2002).

## What Are Roles of Deaf Community Members in EHDI?

Today, Deaf community members contribute to EHDI systems in many ways: they serve as members of state EHDI advisory boards, service providers, language specialists and role models, mentors, ASL teachers, educators, presenters at conferences and workshops, and contributors to EHDI publications and taskforces. In addition, there are currently two known deaf audiologists.

Despite this, there is a scarcity of Deaf professionals in EHDI fields. They are underrepresented in all aspects of EHDI programs. Despite the JCIH

recommendations in 2008, only a small number of EHDI systems actually solicit the participation of Deaf and hard-of-hearing people.

In the future, Deaf and hard-of-hearing individuals should serve in all EHDI roles. They should be included as directors of EHDI programs, pediatricians, researchers, geneticists, etc. EHDI programs at the national, state, and local levels should take steps to increase the number of trained and qualified Deaf professionals who are prepared to step into these roles. This includes allocating funds for preservice and inservice education and training.

## How Can EHDI System Coordinators Recruit and Involve More Deaf and Hard-of-Hearing Individuals to Participate in Your State’s EHDI Activities?

State EHDI system coordinators who have not already done so should reach out to members of the Deaf community in their state to initiate relationships. Each state has a state association of the Deaf. Contact information for state associations of the Deaf can be found at [www.nad.org/community/state-association-affiliates](http://www.nad.org/community/state-association-affiliates). State EHDI system coordinators should also ensure that representatives of schools for the deaf are included in all EHDI activities. Many schools for the deaf serve families statewide and offer training and technical assistance through outreach programs. They are staffed by professionals with specialized training and expertise serving deaf and hard-of-hearing children and their families. They are part of a national network of educators of deaf children that exists for the purpose of helping deaf children maximize their potential. EHDI systems can benefit greatly by using the resources offered by schools for the deaf.

My wife and I found the services offered through the [state school for the deaf] to be instrumental . . .

. . . in helping our entire family comprehend the Deaf culture and the components that would be necessary for our son to transition from a Deaf and hard-of-hearing program to a mainstream kindergarten program in our county.

State EHDI system coordinators should ensure that the perspectives of the Deaf community are reflected in all actions taken under EHDI. For example, EHDI system coordinators should include Deaf community members in the development of materials and planning of conferences for families. State EHDI systems can organize activities and events, such as conferences, “family fun” days, and others that promote awareness of the Deaf and hard-of-hearing community to hearing families. Deaf and hard-of-hearing community members should be part of the planning committee for these events.

State EHDI systems should fairly compensate Deaf and hard-of-hearing community members who contribute to these systems. They should actively seek out qualified Deaf and hard-of-hearing individuals when hiring for EHDI positions. They should work to ensure that federal, state, and local funding is

available for professional training for Deaf and hard-of-hearing individuals to take on EHDI roles (i.e., funding for masters degrees, certification, etc.). EHDI programs should establish goals and monitor the number of Deaf and hard-of-hearing individuals in the EHDI system through a system of self-identification (e.g., individuals have an opportunity to identify themselves as Deaf or hard of hearing).

The ultimate impact of intervention is dependent not only on the expertise of practitioners but also on “. . . the quality and continuity of the personal relationship established between the service provider and the family that is being served” (National Research Council, 2000, p. 365). It is in the best interest of children and families to ensure that the personal relationships available to families include those with members of the Deaf and hard-of-hearing community.

I recently asked [a mother of a Deaf adult] what she wished had been different during [her daughter’s] K–12 years . . .

She said, “I wish that the fighting between the two factions had been nonexistent. I always felt like I was being pulled and that I had to take a side. And really, I didn’t have to. [My daughter] can be and is part of both worlds, and that message should have been there from the start” (Oliva, 2004, p. 169).

# Some Examples of Partnerships

Examples of successful partnerships between EHDI systems and the Deaf community include the following:

## 1

Some states require the state EHDI advisory panel to include a representative of the Deaf community. For example, the Maryland Universal Hearing Screening Law requires the state Universal Newborn Hearing Screening (UNHS) Advisory Council to include one representative from the Maryland Association of the Deaf and one from the Maryland School for the Deaf.

## 2

The California Department of Education recently established a Deaf Education Resource Center in partnership with the two schools for the deaf in the state (<http://www.rcselpa.org/common/pages/DisplayFile.aspx?itemId=1964971>). This statewide agency provides resources for families of all deaf and hard of hearing children in California public schools (including assessment centers) and the community at large. The professional staff that is mainly Deaf provides inservice trainings, workshops, distance learning opportunities, along with creating resources and media to educate the community about deaf and hard of hearing children's educational needs in regards to age-appropriate language development.

## 3

Some entities offer a Deaf mentor program. One such state is New Mexico, which has two Deaf mentor programs—one partnering with AmeriCorps to provide services specifically to Native American families. The other program in the state is a result of collaboration between the state school for the deaf and the state's early intervention service agency to serve families with deaf children from birth to age 6 all over New Mexico (<http://www.nmsd.k12.nm.us/outreach/mentor.php>). Illinois's Hearing and Vision Connections describes a Deaf mentor's role ([www.morgan.k12.il.us/isd/hvc/providers/providers.aspx#Deaf%20Mentor](http://www.morgan.k12.il.us/isd/hvc/providers/providers.aspx#Deaf%20Mentor)) as one that:

- Provides a language model in the communication modes chosen by the family.
- Provides information on the local Deaf community.
- Can be a resource for assistive technology.
- Shares personal experiences as they relate to the family's situation.
- Offer support as the family develops its understanding of the child's hearing loss.

## 4

The Clerc Center at Gallaudet University sponsors a Shared Reading Project (<http://>

[clerccenter.gallaudet.edu/Clerc\\_Center/Information\\_and\\_Resources/Info\\_to\\_Go/Language\\_and\\_Literacy/Literacy\\_at\\_the\\_Clerc\\_Center/Welcome\\_to\\_Shared\\_Reading\\_Project.html](http://clerccenter.gallaudet.edu/Clerc_Center/Information_and_Resources/Info_to_Go/Language_and_Literacy/Literacy_at_the_Clerc_Center/Welcome_to_Shared_Reading_Project.html)), which brings together Deaf community members and families to help families learn how to read to their child in ASL.

## 5

The Educational Outreach Center on Deafness at the Texas School for the Deaf offers a Family Signs Program ([www.familysigns.org/](http://www.familysigns.org/)), which provides personalized family sign language classes over the Internet.

## 6

Under the leadership of the National Association of the Deaf, state associations of the Deaf have started to add an education advocate to their boards who is responsible for working with families of deaf or hard of hearing children, schools, and the legislature related to education issues or advocacy. NAD has also partnered with the American Society for Deaf Children to establish a similar program for parents, so that they can be called upon by other parents for support and to work with the Deaf community within their state. More information on the NAD Education Advocate program can be found at <http://www.nad.org>.

## Some Examples of Partnerships Cont.

Many local and state associations of the Deaf hold gatherings at which families are welcome, such as showings of Deaf-produced movies that star Deaf actors, ASL dinners, comedy/variety shows, Deaf festivals, and sporting events.

### 7

The American Society for Deaf Children—an organization for parents—partners with many schools for the deaf and also provides national

resources, including a biannual family conference, a website (<http://www.deafchildren.org>), a quarterly publication with articles from a variety of contributors, and a national 800 number (800-942-2732), along with a videophone number at 202-644-9204. First-year membership is offered free to families of deaf or hard of hearing children.

### 8

Visual Language and Visual Learning (VL2) is 1 of 6

Science of Learning Centers (SLC) funded by the National Science Foundation (NSF) and is hosted by Gallaudet University. It partners with 12 national and international universities, and works closely with affiliated researchers and universities to develop parent-friendly research briefs on various topics related to visual learning and visual language ([vl2.gallaudet.edu](http://vl2.gallaudet.edu)). They also offer a parents information package and toolkit which can be found at <http://vl2parentspackage.org/>.

### By sharing information about local Deaf community events . . .

. . . the Maryland School for the Deaf alerted me to one hosted by the National Black Deaf Advocates, where I was beyond thrilled to meet the first Deaf African American to earn a PhD. This gave me both inspiration and hope for my 3-year-old son.

—Shermanda Williams



## National Resources

- American Society for Deaf Children, [www.deafchildren.org](http://www.deafchildren.org)
- Conference of Educational Administrators of Schools and Programs for the Deaf, [www.ceasd.org](http://www.ceasd.org)
- Deaf Autism America, <http://www.deafchildren.org/deaf-autism-america>
- Laurent Clerc National Deaf Education Center, <http://clerccenter.gallaudet.edu>
- National Asian Deaf Congress, <http://www.icdri.org/dhhi/nadc.htm>
- National Association of the Deaf, [www.nad.org](http://www.nad.org)
- National Black Deaf Advocates, [www.nbda.org](http://www.nbda.org)
- National Council of Hispano Deaf and Hard of Hearing, [www.nchdh.org](http://www.nchdh.org)
- Sacred Circle, [www.deafnative.com](http://www.deafnative.com)

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