Introduction

When a baby is identified as Deaf, parents embark on a new discovery path. At the very beginning, Early Hearing Detection and Intervention (EHDI) programs refer parents/caregivers to resources that support their positive parenting with appropriate and comprehensive information. In the majority of cases, these parents are unfamiliar with the lives of Deaf children or adults. They depend heavily on professionals to give them the information, support, and services they need.

Families meet doctors, audiologists, speech-language pathologists, Part C early intervention providers, and geneticists for evaluations, services, and follow-ups. The professionals they encounter—most
of them hearing—work collaboratively to support new families in adapting to the news that their child is Deaf and to the changes it brings. For many families, life is a flurry of calls and appointments. One critical component of the service continuum may be overlooked—Deaf professionals and the Deaf community.

Deaf professionals and community organizations are integral parts of EHDI systems. Individuals who have grown up Deaf are in a unique position to provide information and support to families with young Deaf infants and young children. Contact with the Deaf community helps families transition to acceptance of their child as a Deaf person (Hintermair, 2006). Deaf people are able to provide the Deaf child with something hearing parents cannot: Experience as a Deaf person (Chute & Nevins, 2002).

Deaf adults provide an insider’s knowledge and experience of how to navigate the world. They can offer ideas and strategies to assist families in communicating with their Deaf child and reducing frustration and stress. This in turn provides the Deaf child a feeling of respect and acceptance as a Deaf 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 Deaf people paves the way for a whole new world of information and experiences that would not otherwise be available to the family. The benefits of supporting language, cognition, and social-emotional well-being with Deaf infants, young children, and their families during their early years are many.

Medical and Sociocultural Perspectives

Table 1 illustrates terminology reflecting the differences between medical and sociocultural perspectives (as adapted from Benedict, 2009).

Who Is the Deaf Community?

The Deaf community is diverse with members from all socioeconomic levels; cultural, educational, and social-emotional backgrounds; and ethnic groups. Deaf people can be found in a range of occupations, including doctors, lawyers, accountants, teachers, scientists, architects, and athletes. Deaf individuals come from all walks of life, nationalities, and religions. Some live in the city; others in the country. They may be marathoners or couch potatoes, computer geeks or technophobes, introverts or extroverts. Deaf people reflect the same range of human experience and diversity as hearing people. The Deaf community also consists of “allies;” that is, parents/caregivers, siblings, ASL interpreters, educators, children of Deaf adults, and other friends of the Deaf community. They all respect and celebrate ASL and support increased opportunities for Deaf people.

Deaf individuals may use auditory technology, such as hearing aids or cochlear implants, or no 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. They may have learned sign language from birth, as an adult, or never at all. Involvement in the Deaf community varies from person to person according to their needs and interests. People connect in a variety of ways, including social gatherings, sporting events, cultural arts, religious expression, organizational membership, and political action. History and stories are handed down from generation to generation.

I need more than anything to be able to understand you and to make you understand me . . .

I need to be able to sit with you and ask you why? To ask you to help me explore the universe around me. To understand the do’s and don’ts of everyday living. These are hard things to learn. Don’t make them any harder for me than they already are. Give me the freedom to ask and understand in the easiest way possible—if there is an easy way.”

(Bragg 2001, p. 191)
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.

A Deaf child’s identity and sense of self-worth are shaped by parental expectations, values and beliefs, decision-making strategies, and available resources. Appropriate and language-rich educational settings and accessibility within a healthy empowerment model help to shape the Deaf child’s life. Identity is fluid and can change throughout the child’s developmental stages. It varies based on anticipated outcomes and availability of the support system of the Deaf community in partnership with professional service providers and educators.

The Parents’ Guide to Cochlear Implants (Chute & Nevins, 2002) supports collaboration between the Deaf community, implant centers, and schools for the Deaf. For example, they recommend that cochlear implant centers team with Deaf community members to create websites for children with implants and their families that will 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. While awareness and recognition of the value of including Deaf specialists has been recognized for a very long time, including them as an integral part of the EHDI system is still emerging. The Joint Committee on Infant Hearing (JCIH, 2007, 2013) has encouraged availability of opportunities for families to interact with the Deaf community and other Deaf individuals.

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

### Table 1
Medical Model vs. Sociocultural Perspectives

<table>
<thead>
<tr>
<th>Medical Perspective</th>
<th>Sociocultural Perspective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication options (“either/or”)</td>
<td>Language acquisition opportunities</td>
</tr>
<tr>
<td></td>
<td><strong>NOTE:</strong> Originally it was framed as</td>
</tr>
<tr>
<td></td>
<td>“communication opportunities”</td>
</tr>
<tr>
<td>Hearing loss</td>
<td>Hearing level, status, abilities, or</td>
</tr>
<tr>
<td>Early Intervention</td>
<td>differences</td>
</tr>
<tr>
<td>Failed hearing test</td>
<td>Refer with explanation</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Identification</td>
</tr>
<tr>
<td>Fix the ear</td>
<td>Enhance access to sound</td>
</tr>
<tr>
<td>Deafness</td>
<td>Deaf, Deaf people, being Deaf</td>
</tr>
<tr>
<td>Hearing impaired</td>
<td>Deaf or hard of hearing</td>
</tr>
<tr>
<td>Vocationally limited</td>
<td>Unlimited opportunities</td>
</tr>
<tr>
<td>Grief process</td>
<td>Journey</td>
</tr>
<tr>
<td>Disability (cannot)</td>
<td>Culturally diverse (adapt)</td>
</tr>
<tr>
<td>Auditory technology</td>
<td>Visual and auditory technology</td>
</tr>
</tbody>
</table>

My son was the first Deaf person I ever met . . .
Deaf Community and Sign Language

In the U.S. and Canada, the Deaf community shares a language—American Sign Language (ASL)—and the experience of navigating in a hearing-privileged society. Deaf people share unique language, experiences, values, and a common way of interacting with each other. Their linguistic, social, cultural, political, and audiological experiences bind them together.

For various reasons, many members of the Deaf community did not learn sign language early in life. Once Deaf people see ASL as a viable language and desirable 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 Deaf adults 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 & Lytle, 2014).

Several studies have shown that the most accessible pathway for full access to linguistic information for many Deaf children is through vision. Children have been found to be capable of absorbing multiple languages via multiple modalities with no negative side effects on their language acquisition and development. When a language is used exclusively—or at least extensively—in the home and community, it will be acquired by the young child (Baker, 2011). Children learn best through positive and nurturing interactions of parents in the home environment. When hearing parents/caregivers interact with signing adult language models who provide consistent support, they are able to develop the necessary skills to converse with their Deaf child as early as 6 months of age (Easterbrooks, 2002).

Skill development is enhanced by working with Deaf specialists by "teaching" (modeling, mentoring, introducing, exposing) and use of strategies. The Deaf specialist is a linguistic and social expert—for having grown from experiences navigating in society—where the primary modality is hearing and speaking.

Many families choose at some time during their early childhood programs to seek out both Deaf adults and children (peers). Programs should ensure that these opportunities are available to families through a variety of communication means, such as websites, emails, newsletters, videos, retreats, social events, educational forums, and social media.

JCIH Goals and Recommendations

The JCIH position statement (2007) supports the goals of universal access to hearing screening, evaluation, and early intervention for newborn and young infants. More specifically related to this chapter, the emphasis is on the inclusion of the Deaf adults and the Deaf community as partners of family learning. Families have the right to be informed of all resources and opportunities that can assist them in raising their Deaf infant and young child. A supplement to the

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I thought my daughter did not need ASL, because she had moderate hearing level . . .

Through a Deaf specialist, I was at ease knowing that ASL boosts her spoken English. I believe that any babies with any hearing levels can learn ASL.

—Parent

Devika is 2 years old now . . .

In these 2 years, we have learned to respect every Deaf person's ability to survive in this strongly opinionated and prejudiced hearing world. Destiny has chosen us to be her parents, and we have chosen not to disappoint.

—Harshada & Sachin Kadu (CSD Thrive Magazine, 2014)
JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention After Confirmation That a Child Is Deaf or Hard of Hearing (2013) focuses on the practices of early education providers outside of the primary medical care and specialty medical care realms. The most relevant JCIH (2013) goals to encourage families to have contact with Deaf professionals and the Deaf community are:

**Involving the Deaf Community**

**The Role of the Deaf Specialist**

Deaf specialists are professionals with expertise to work with families to enhance their communication interactions with their Deaf infants and young children through teaching, modeling, demonstrating, and/or mentoring. Specifically, they provide linguistic and social-emotional engagement activities and/or lessons in the home and community.

A trained Deaf specialist provides . . .

- Learning a visual language—American Sign Language (ASL).
- Insights into what it is like to be Deaf.
- Structured home visits utilizing the family’s daily routines.
- Insight and/or immersion experiences of Deaf culture.
- Current trends and the history involving Deaf people.
- Involvement in the Deaf community.
- Meeting other Deaf people.
- Acquiring helpful navigation skills.
- Identifying the tools a Deaf person needs in order to be independent.
- . . . and anything else the families want to know.

Listed in Table 2 are descriptions of currently available Deaf specialists. Examples of program variations are listed in Table 3.

**What Are the Roles of Deaf Community Members in EHDI?**

Deaf professionals and individuals who use sign language are to be encouraged to become involved in early intervention programs. JCIH (2013) 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.
### Table 2

**Descriptions of Currently Available Deaf Specialists**

<table>
<thead>
<tr>
<th>Deaf Mentor</th>
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<td>The Deaf Mentor Program (DMP) was created by the SKI•HI Institute to complement family-centered and home-based early education services. DMP provides trained Deaf adults as American Sign Language models and teachers. The DMP utilizes a curriculum that has three main components:</td>
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<td>• ASL for Families</td>
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<td>• Deaf Culture Program</td>
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<td>SKI•HI conducted a 3-year study (1991-1993) of family language and confidence levels, comparing a set of families who had a Deaf mentor with families who did not. Families who had a Deaf mentor made greater language gains (with considerably larger vocabularies) and scored higher on measures of communication, language, and English syntax (Watkins, Pittman, &amp; Walden, 1998).</td>
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<td>Several states have received training to utilize the DMP, including Georgia, Illinois, Indiana, Maine, Minnesota, New Mexico, Utah, Vermont, and Wisconsin, as well as British Columbia, Canada, and South Africa. These states have similar programs; yet they differ in how they receive funding and administrative oversight. For example, New Mexico has two Deaf mentor programs—one partnering with AmeriCorps to provide services specifically to Native American families with Deaf infants and young children. The other program 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 (<a href="http://www.nmsd.k12.nm.us/outreach/mentor.php">http://www.nmsd.k12.nm.us/outreach/mentor.php</a>).</td>
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<td>Illinois's Hearing and Vision Connections describes its Deaf mentor’s role as one that:</td>
</tr>
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<td>• Provides a language model in the communication modes chosen by the family.</td>
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<tr>
<td>• Provides information on the local Deaf community.</td>
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<tr>
<td>• Is a resource for assistive technology.</td>
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<tr>
<td>• Shares personal experiences as they relate to the family's situation.</td>
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<td>• Offers support as the family develops its understanding of the child’s hearing levels.</td>
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<td>All of the Deaf mentors receive additional training through the state’s early intervention system and work closely with other providers to become an interdisciplinary team member (<a href="http://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</a>).</td>
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<td>Deaf role models are adults who provide the family with someone to whom they can relate. Deaf role models can show that being Deaf does not need to be a barrier to success, and they share useful adaption techniques and accommodations. Ideally, the family and the child will meet a wide variety of role models—some who share similar experiences and others that have varied backgrounds. That way, children can see that they are not limited to one way of “being.”</td>
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<td>Deaf role models can be considered as “cultural mediators,” where the Deaf role models may be considered as “cultural mediators,” because the Deaf adult provides ongoing strategies to help parents interpret their Deaf child’s communication. They can show/model the differences between Deaf culture and hearing culture. The Deaf role model is a bridge to bringing hearing families into the world of being Deaf.</td>
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Guide By Your Side (GBYS) is a Hands & Voices program (http://www.handsandvoices.org/gbys/index.htm) that embodies strong values of direct peer connections and networking. It promotes self-efficacy and reduces isolation by exploring common bond, shared experiences, challenges, wisdom, and insight for families. Within GBYS, there is a Deaf/Hard-of-Hearing (D/HH) Guide. Colorado, Maine, and Minnesota are among the states that provide trained D/HH Guides.

Early Intervention programs provide opportunities for in-home or center-based services. Part C strongly encourages a natural learning environment, which most often means “in the home.” Some families are not comfortable with in-home services, so having alternative options is important. A classroom environment can foster development of a support group for the family’s language learning process, alleviating the sense that they are going about this process alone.

In British Columbia, sign language classes are provided to the family and extended family at home or at the child’s daycare or preschool (http://www.deafchildren.bc.ca/programs/sign-language). These fun and enjoyable lessons are offered on a weekly or biweekly basis depending on the family’s needs. Qualified Deaf instructors provide sign lessons that meet the day-to-day communicative needs of the family—starting with basic sign language vocabulary working up to sentences and literacy skills. Sign language instruction is also available on an outreach basis in some places. Ideally, families will have both types of services available, depending on their preferences and availability.

School districts may offer family-centered sign language classes. Local colleges or universities may have ASL classes as well. However, the class content may not necessarily be targeted to the families’ specific experiences or needs. To maintain consistency and quality in school-based classes, they should be taught by a native ASL Deaf instructor.
Table 3  
Examples of Program Variations

<table>
<thead>
<tr>
<th>Shared Reading and Literacy</th>
<th>Parent Education and Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>• The Clerc Center at Gallaudet University sponsors a Shared Reading Project that brings together Deaf community members and families, so that the families can learn how to read to their Deaf child in ASL (<a href="https://www.gallaudet.edu/clerc-center/our-resources/shared-reading-project.html">https://www.gallaudet.edu/clerc-center/our-resources/shared-reading-project.html</a>)</td>
<td>• The National Association of the Deaf (NAD) provides an education advocate to some of their state association boards. These advocates are responsible for working with families of Deaf children, schools, and the legislature regarding education issues or advocacy. NAD has also partnered with the American Society for Deaf Children to establish a similar program for parents, so they can be called upon by other parents for support and to work with the Deaf community within their state.</td>
</tr>
<tr>
<td>• 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. One of its products is the storybook apps in ASL and English for children (<a href="http://vl2storybookapps.com">http://vl2storybookapps.com</a>)</td>
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• American Society for Deaf Children—an organization for parents—partners with many schools and programs for the Deaf and also provides national resources, including an annual family conference in June, a website (http://www.deafchildren.org), a quarterly publication with articles from a variety of contributors, and a national 800 number (800-942-2732). First-year membership is offered free to families of Deaf children.  

• California Deaf Education Resource Center in Riverside, California. This agency provides resources for families of all Deaf children in California public schools (including assessment centers) and the community at large. The center provides inservice trainings, workshops, distance learning opportunities, along with creating resources and media to educate the community about Deaf children's educational needs. It is interesting to note that the majority of the staff at the center are Deaf (http://www.rcselpa.org/common/pages/DisplayFile.aspx?itemId=1964971)

• Language Equality and Acquisition for Deaf Kids (LEAD-K). The LEAD-K Campaign is a visual civil rights movement to end the nationwide epidemic of language deprivation by promoting language equality. They promote ASL and English as a basic human right for all Deaf babies, leading to a new generation of Deaf children who are kindergarten-ready. In California, LEAD-K championed SB 210, which enforced language acquisition accountability during the first 5 years of the Deaf child's life. Other states are working on passing a similar bill (http://www.ASL4DeafKids.org)  

• National Association of the Deaf Education Advocate Program can be found at http://www.nad.org. Many local and state associations of the Deaf hold gatherings for families, such as showings of Deaf-produced movies that star Deaf actors, ASL dinners, comedy/variety shows, Deaf festivals, and sporting events.

• Thrive Magazine, Babies and Toddlers Issue (2014) California School for the Deaf–Fremont, offers a yearly online magazine with resources for families of Deaf Children (http://issuu.com/csdthrive/docs/baby_thrive_2014_print_2)

• 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 also offers a parents' information package and toolkit (http://vl2parentspackage.org/)
### Table 3 (continued)

**Distance ASL Learning**

- California School for the Deaf–Fremont has weekly online ASL instruction for families. The online Deaf instructors offer three ASL levels for the entire family: Introduction to ASL, Conversational ASL, and Sibling Class (http://www.csdeagles.com/)

- Maine Educational Center for Deaf and Hard of Hearing provides ASL instruction for families utilizing distance learning centers around the state. It offers ASL classes exclusively for families, caregivers, and others in close contact with children. The 8-week course content is driven by the families’ needs and teaches signs that apply to regular, daily communication (http://www.mecdhh.org/parents/asl-for-families/)

- The Educational Outreach Center on Deafness at the Texas School for the Deaf, Family Signs Program provides online personalized family sign language classes. The goal of Family Signs is to engage parents of Deaf children (ages birth to 21) to begin or improve their sign language skills, so they can communicate more effectively with their children.

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

Parents of Deaf 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!

—Parent
Involving the Deaf community in EHDI programs can help families understand that being Deaf is not purely a medical issue, but also a sociocultural phenomenon. While many professionals embrace a medical perspective of being “Deaf” that emphasizes “loss” or “deficit” of hearing, the sociocultural model focuses on the connections the child has in his or her environment, including the family.

Deaf individuals are able to serve in all EHDI roles. Qualified Deaf professionals can be included as directors of EHDI programs, pediatricians, researchers, geneticists, audiologists, early intervention directors, and in other positions. 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.

However, there is a scarcity of Deaf professionals in EHDI fields. They are underrepresented in all aspects of EHDI programs. Despite the JCIH recommendations in 2007 and the specific goals in the 2013 supplement recommending having more Deaf adults provide direct services to families, only a small number of EHDI systems actually solicit the participation of Deaf people.

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

State EHDI coordinators need to reach out to members of the Deaf community 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.

State EHDI coordinators can also ensure that representatives of schools for the Deaf and programs 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 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.

State EHDI coordinators can ensure that the perspectives of the Deaf community are reflected throughout the program. For example, Deaf community members can be invaluable contributors to the development of materials and planning of conferences for families, “family fun” days, and other activities that promote awareness of the Deaf community. One of the National Association for the Education of Young Children’s (NAEYC) 10 standards for high-quality early childhood programs recommends that a program establish relationships with and uses the resources of communities to support the achievement of program goals (http://families.naeyc.org/accredited-article/10-naeyc-program-standards#8). Some states require the state EHDI advisory panel include at least one representative of the Deaf community. For example, the

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.

—Parent
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.

Every state or region can actively work to set up a long-term, sustainable infrastructure to properly and equitably compensate Deaf specialists for their expertise and time spent with families. Funding strategies range from private pay, grants or sponsorships, support from human services organizations, special education or early education funds, or inclusion in a legislative budget. They can actively seek out qualified Deaf individuals when hiring for EHDI positions.

Today, Deaf community members contribute to EHDI programs in many ways. They serve as members of state EHDI advisory boards, service providers, language specialists, lawyers, advocates, audiologists, role models, mentors, ASL teachers, educators, researchers, and contributors to EHDI publications and taskforces. Increasing amounts of research information about the importance of including Deaf professionals have increased our understanding of the value of Deaf professionals and best practices in supporting families.

Conclusion

There are many ways that families and professionals can incorporate the expertise and wholesome experiences of Deaf specialists and the richness of the Deaf community into EHDI programs. There are unlimited and long-lasting possibilities and productive benefits. Trained Deaf specialists have a great deal to offer the families and can make a significant difference in the dynamics of the families’ experiences.

Resources and research information are increasing throughout the nation. To ensure that families and professionals receive appropriate resources, the infrastructure needs to be streamlined to create strength in numbers to offer expertise by the Deaf professionals. Because Deaf infants and young children will live out their life as Deaf individuals, it is necessary to provide services that have stable infrastructure, consistent funding, and support of all the agencies involved. This eBook is a reflection of long-overdue and new beginnings to remedy the missing link in early education that is led by the Deaf people and Deaf community themselves.

We believe that communication is the key to unlocking the potentialities of the Deaf . . .

And when we speak of communication, we mean free and easy communication that will have the opportunity to grow as we grow, change as we change, and continue to evolve until something develops that will be the best possible means we can devise.

—Frederick C. Schreiber (1981). The Deaf Adult’s Point of View

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National Resources for Families

- American Society for Deaf Children, www.deafchildren.org (includes Deaf Autism America)
- Conference of Educational Administrators of Schools and Programs for the Deaf, www.ceasd.org
- Deafhood Foundation, www.deafhoodfoundation.org
- Deaf Life, www.deaflife.org
- Laurent Clerc National Deaf Education Center, http://clerccenter.gallaudet.edu
- National Black Deaf Advocates, www.nbda.org
- Sacred Circle, www.deafnative.com
- Visual Language Visual Learning (VL2), www.vl2.gallaudet.edu

References and Additional Readings


