

# Chapter 19

## Deaf Adults Connecting with Birth to 3 Families

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### Common Word Usages in this Chapter

**Deaf.** Deaf is inclusive of all hearing levels and linguistic-social usages, including those who are seen as, or identify as, Deaf, deaf, or hard of hearing.

**Birth to 3.** This chapter concentrates on birth to 3 families, and it is inclusive of all families with Deaf infants and young children who are (or may not be) receiving EHDI and Early Intervention (Part C) Services. Infant and young child. This term is inclusive of Deaf birth to 3 children.

**Deaf specialist.** For this chapter, this term applies to any Deaf adults who provide services with the birth to 3 children and the families, such as Deaf Mentor, Deaf Role Model, Sign Language Specialist (or Instructor), Deaf and Hard-of-Hearing Guide, and/or Developmental Educator.

### Introduction

Birth to 3 families and professionals will learn and understand how Deaf specialists can become involved, support, and teach family-centered linguistic and social strategies in the families' homes and communities. The goal for these families is to appreciate the value and benefits of partnering with Deaf specialists, to understand the variety of roles, and to be able to receive a continuum of services that best meet the family's needs and goals. In a timely manner, the families will be knowledgeable and confident in supporting their infant and young child's overall development.

This chapter is based on recommendations contained in the following supporting documents:

- NCHAM eBook (2014) Chapter 21, Deaf Community Support for Families: The Best of Partnerships.
- Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention after Confirmation That a Child Is Deaf or Hard of Hearing.
- National Association of the Deaf (NAD) Position Statement on Early Cognitive and Language Development and Education of Deaf and Hard-of-Hearing Children.

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These documents state that, due to the critical importance of linguistic and social competencies, all Deaf infants, young children, and their families should receive services from qualified Deaf specialist(s) who are native or fluent in American Sign Language (and spoken language, if families request this) and have the ability and resources to connect the families with other families who want to share or learn about their goal(s). This chapter will concentrate on helping families learn “what and how” to receive services from the Deaf specialist.

### Why Include/Involve Deaf Adults as Specialists?

For parent(s), their newborn baby is a new and exciting experience that is not provided with a “personal instruction manual.” When the baby is Deaf, a host of new learning experiences into the unfamiliar and unknown is necessary. Upon entry in Early Hearing Detection and Intervention (EHDI) programs, families are led to resources that can support their positive parenting journey with comprehensive information. What can the families add to their existing lifestyle and beliefs that will allow their journey to become a healthy (and exciting) new normal?

While awareness and recognition of the value of including Deaf specialists have been shared for a very long time, including them as an integral part of the EHDI system is still emerging.

Deaf specialists provide insider’s knowledge and experience of how to navigate the world as a Deaf individual. The benefits for supporting language, cognition, and social-emotional well-being with the Deaf infants, young children, and their families during their growing developmental years are plentiful. The Deaf specialist is a tremendous and valuable resource that can greatly benefit the child’s outcomes.

#### A trained Deaf specialist provides . . .

- Real-life experiences.
- Structured home visits. Insights into what it is like to be Deaf. For example, learning a visual language—American Sign Language (ASL)—in tandem with the existing spoken home language.
- Insight into the culture of being Deaf.
- Current trends and the history involving Deaf people.
- Involvement in the Deaf community.
- Meeting other Deaf people in order to develop linguistic and social competencies.
- Acclimating to being a “person of the eyes.” Acquiring navigating skills that a Deaf person will need in a limiting (or negated) environment.
- Identifying the tools a Deaf person needs in order to be independent in all areas of life.
- Additional opportunities based on the Deaf specialist’s need to be resourceful.

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#### Many places are struggling with . . .

- What do the services of Deaf specialists look like?
- What roles or activities do they perform?
- Who coordinates these services?
- What are the basic necessities of ensuring that the family’s Deaf infant and young child thrives in all aspects of development, such as language, cognition, and social-emotional?
- Who can the new parents “call” and reach out to?

### Deaf People, The Deaf Community, and Their Identity

Deaf people come from all walks of life. Their experiences vary widely, based on their audiological, linguistic, cultural, education, and social-emotional experiences.

Deaf identity and diversity are shaped by parental expectations, such as values

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and beliefs, and available resources, such as existing educational settings and accessibility within a healthy empowerment model. Identity is fluid and changes throughout the child's development stages and family structures based on living outcomes and availability within reach of the support system of the Deaf community.

The Deaf community consists of individuals who share a common language, experiences, values, and a common way of interacting with each other. Their linguistic, social, political, and audiological experiences are what bind them together.

Participation level within the Deaf community varies. To be involved with a Deaf infant or young child's (and their families) life, some people:

- Provide services within a speciality area (education or social service).
- Participate to increase awareness and skills through socialization and linguistic skill development.
- Promote advocacy.
- Enjoy connecting with one another via a shared cultural and linguistic experience.

Some people are quite participatory and active in the Deaf community. Others may just be there when providing services, depending on their interest, need, understanding, and acceptance.

## Language Development and Engagement

Family involvement and linguistic skills for both the parents and the infant and young child are important to ensure a high language outcome. Initially, it is naturally important to consistently respond to an infant or young child's cues (crying, fussing, happiness, facial expressions, and body movements) to help build a connection. The responses may be during feeding, diaper changing, swaddling, smiling, picking up the baby, or using

word/phrases. The Deaf infant or young child will benefit from visual input to learn and express needs/wants. Building linguistic competencies via the visual modality requires learning from a native signed language person vocabularies and grammar, as well as how to do shared reading. Receiving this support from a Deaf specialist who is native to sign language acquisition and delivery can help the family become comfortable in using it.

There need not be any concern about families that provide both signed language and spoken language for the first years of the infant's life, as children have been found to be capable of absorbing multiple languages via multiple modalities with no negative side effects on their language acquisition/development. The evidence suggests that when a language is used exclusively—or at least extensively—in the home and community, it will be acquired by the infant and young child. Children learn best through the bonding and responsivity of the parents, and the home environment is conducive to bonding. Thus, skill development is accrued by working with Deaf specialists who specialize in these language(s) by “teaching” (modeling, mentoring, introducing, exposing) and use of strategies. The Deaf specialist is a linguistic and social expert.

## Deaf Adult Early Involvement Services with Families

Every state or region can actively invest energy and thoughtful planning in setting 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. An example of collaborating with another human services organization, AmeriCorps (<http://www.>

It is preferable to have multiple Deaf people involved to provide a more comprehensive range of experience and perspectives. However, it is also recognized that it can be challenging, especially in regions where there is a scarcity of Deaf individuals available. Fortunately, technology is making it increasingly easier to connect people across a significant distance.

[nmsd.k12.nm.us/outreach/mentor.php](http://nmsd.k12.nm.us/outreach/mentor.php)) supported outreach efforts in New Mexico, which allowed them to send six Deaf specialists to live in rural locations of the state to provide direct signed language instructions to families.

An example of legislative funding, money to fund Deaf mentors and Deaf role models came from a bill that allocated a portion of money earned from newborn blood-spot screening to go towards Deaf specialist programs, which stabilized the programs' ability to provide services to all who needed it. Some places use volunteers to perform certain duties, which is acceptable at times, but effort should be devoted to developing some consistent opportunities with quality providers for services throughout the state and creating some form of reimbursement system for the providers.

There are different types of roles that a Deaf specialist can perform. They are listed in Family Friendly, Chapter 4 (National Deaf Children Society, United Kingdom, [www.ndcs.org.uk/document.rm?id=3039](http://www.ndcs.org.uk/document.rm?id=3039)), as role models, sign language trainers, and advocates.

For the duration of a Deaf infant and young child's life, a Deaf educator (teacher of the Deaf) as well as a Deaf paraprofessional, should be added to that list. Both should be present, directly and indirectly, with the Deaf infant and young child.

Incorporating cultural mediators is a valuable asset. For example, Chicagoland Deaf Parent-to-Parent Project (Hulsebosh & Myers, 2002) studied cultural mediation through a series of workshops designed for families to learn strategies of how to optimize visual aspect of parent-child interactions. Finally, The Deaf Mentor Program ([www.skihi.org](http://www.skihi.org)) focuses primarily on language instruction and at the same time introducing and including cultural experiences.

Sometimes the same person can provide the full range of services, or sometimes

they are provided by multiple people. Ideally, there is a unified collaboration process in place. It is preferable to have multiple Deaf people involved to provide a more comprehensive range of experience and perspectives. However, it is also recognized that it can be challenging, especially in regions where there is a scarcity of Deaf individuals available. Fortunately, technology is making it increasingly easier to connect people across a significant distance, such as distance video ASL learning.

Listed in *Table 1* are descriptions of currently available programs. These can be found on their respective websites by using the tag words deaf mentors or deaf role models or can be located by checking the state agencies involved with providing services to Deaf children.

### Shared Reading Project (SRP)

Studies have found that Deaf children of Deaf parents often have higher reading scores, so further studies were conducted on Deaf parents to find out what early literacy techniques they used. Fifteen principles were formulated based on results of that study. As part of SRP, trained Deaf community signing models are sent to the home and bring prepackaged materials (books and DVD with Deaf models signing the selected children books) and practice the storytelling process with the families. These materials are then left with the family to help them review it independently and to actually use with their child. This project is sponsored by Gallaudet University's Clerc Center ([http://www.gallaudet.edu/clerc\\_center/information\\_and\\_resources/info\\_to\\_go/language\\_and\\_literacy/15\\_principles\\_for\\_reading\\_to\\_deaf\\_children.html](http://www.gallaudet.edu/clerc_center/information_and_resources/info_to_go/language_and_literacy/15_principles_for_reading_to_deaf_children.html)).

### Advocates and Resources

Along with parent support organizations, such as American Society of Deaf Children ([www.deafchildren.org](http://www.deafchildren.org)) and Hands & Voices ([www.handsandvoices.org](http://www.handsandvoices.org)), some

## Table 1

### Descriptions of Currently Available Programs

#### Deaf Mentor

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:

- ASL for Families
- Early Visual Communication Program
- Deaf Culture Program.

The mentors provide a model for ASL—demonstrating how to incorporate ASL into literacy development, provide information on local Deaf community and resources, as well as assistive technology. They offer

support to the family as they develop their understanding of the child's hearing status and show them how to connect ASL with the child's spoken language. The expectations, roles, and best practices of a Deaf mentor are in tandem with the expectations of other providers, such as a parent advisor (SKI-HI), a speech-language therapist, and/or a developmental therapist. 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 have a Deaf mentor. The outcome from this study was that the 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, & Walden, 1998).

Several states have received training to utilize the DMP, such as Georgia, Illinois, Indiana, Maine, Minnesota, New Mexico, Utah, Vermont, and Wisconsin, as well as in British Columbia, Canada, and South Africa. These states have similar programming components; yet they may differ in how they receive funding and administrative oversight. They may need to receive additional and ongoing training through the state's early intervention system. Finally, they may need to work closely with other providers to become an interdisciplinary team member. Those interested can learn more about an individual state's DMP at their websites.

#### Deaf Role Model

Deaf role models are adults that provide the child with someone older that they can relate to. Deaf role models can show that being Deaf does not need to be a barrier to success, and they can share useful adaptation techniques and accommodations. Ideally, the family and the child will meet a wide range of role models—some who share similar experience as themselves along with others that have varied backgrounds. That way, children can see that they are not limited to one way of “being.”

Deaf role models can be considered as “cultural mediators,” where the

Deaf adult provides ongoing strategies to help parents interpret their Deaf child's communication attempts and usage. 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 and allowing this to be an addition to their life as a hearing family.

A unique arrangement for other families to meet Deaf role models was created in Chicago called Adult Role Models in Education of the Deaf (ARMED; [\[program-a-counseling-services/youth-program/adult-role-models-in-education-of-the-deaf-armed\]\(http://www.chicagohearingociety.org/youth-program-a-counseling-services/youth-program/adult-role-models-in-education-of-the-deaf-armed\)\). This program arranges for various Deaf adults to visit schools to discuss career opportunities. Even though this is not geared towards birth to 3 families, this unique arrangement could be considered to provide families with reassurances that their child has many opportunities for future employment and finding out early how to successfully support the steps towards achieving that for their child.](http://www.chicagohearingociety.org/youth-</a></p>
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### Deaf and Hard-of-Hearing Guide

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 hinders isolation by exploring common bond, shared experiences, challenges, wisdom, and insight for families. Within GBYS, there is a

Deaf/Hard-of-Hearing (DHH) Guide. Colorado, Maine, and Minnesota are among the states that provide trained DHH Guides.

### Sign Language Specialist (or Instructor)

Early Intervention programs often provide opportunities for in-home or center-based services. Part C strongly encourages natural learning environment, which most often means “in the home.” Some families are not comfortable with in-home services, so having options for classroom-type of environment is important to have available in your area. The 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.

For example, in British Columbia (<http://www.deafchildren.bc.ca/programs/sign-language>), sign language classes are provided to the family and extended family at home or at the child’s daycare or preschool. These fun and enjoyable lessons are offered on a weekly or bi-weekly 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 stories. 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.

Sometimes if a school district has a sufficient number of Deaf students, they may offer family-centric sign language classes to families. Local colleges or universities may have ASL classes as well, usually for a small charge. This places an additional financial burden on the parents, and 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.

Another option is distance ASL learning. Some states have distance learning centers that provide opportunities for families to learn and interact with someone distant from where they reside. Below are two examples of that:

- Maine Educational Center for Deaf and Hard of Hearing (MECDHH) (<http://www.mecdhh.org/parents/asl-for-families/>) provides ASL instruction for families, utilizing distance learning centers around the state. It offers American Sign Language classes exclusively for families, caregivers, and others in close contact with children. They primarily teach signs that apply

to regular, daily communication. The 8-week course content is driven by the families’ needs.

- The Educational Outreach Center on Deafness at the Texas School for the Deaf, Family Signs Program (<http://www.familysigns.org>) provides personalized family sign language classes over the Internet at mutually agreed times and any location. The goal of Family Signs is to help parents of deaf or hard-of-hearing children (ages birth to 21 years old) begin or improve their sign language skills, so that they can communicate more effectively with their children. These classes are ideal for parents who would like to participate in sign language classes but can’t attend traditional classes for a variety of reasons, such as distance or work schedule conflicts.



*Photo courtesy of Centers for Disease Control and Prevention*

## Table 1 (continued)

### Developmental Educator (Part C)

As an example, Indiana's Part C agency (known as First Steps) has designated serving families with Deaf infants and young children as the role of the developmental therapist (DT). Their responsibilities consist of family education, training, counseling, and home visits to assist the family in understanding the special needs of the child and enhancing the child's development. The DT is credentialed as an early intervention provider. Also, one other specialization could be included, specialized instruction: early childhood specialist (DT-EC). This individual focuses on infant/toddler development and ways to promote development. This includes designing learning environments and activities to promote development across all domains: cognitive, physical, communication,

social/emotional, and adaptive (<http://www.in.gov/fssa/ddrs/4653.htm>). Other specialties that may be included are focus area communication (DT-C) and focus area hearing impaired (DT-HI) ([http://www.cibaby.org/prior\\_to\\_2010\\_site%20folders/whats%20new%20page%20parts/First%20Steps%20Personnel%20GuideRevised%2012.pdf](http://www.cibaby.org/prior_to_2010_site%20folders/whats%20new%20page%20parts/First%20Steps%20Personnel%20GuideRevised%2012.pdf)).

Indiana's SKI-HI parent advisor (PA) is categorized within developmental therapist (or DT-HI or speech-language therapist). The PA provides family-centered, home-based early education services. These providers adhere to IDEA-Part C regulations and need to be credentialed by Indiana's First Steps. Deaf mentors can be recognized under this category and can work as a team with the parent advisor.

Deaf adults connecting with birth to 3 families can make a significant difference in the dynamics of the family and future success of the child.

states have commissions or resource centers specializing in deaf, hard-of-hearing, and deaf-blind. These are good places to get some information. There are also organizations of Deaf adults that devote their work to advocating for Deaf infants and young children and their families, including National Association for the Deaf ([www.nad.org](http://www.nad.org)).

### Conclusion

There are many ways that birth to 3 families and professionals can incorporate

the expertise and holistic experiences of Deaf specialists. There are unlimited possibilities to tap into, and there are long-lasting and productive benefits. Ultimately, it is necessary to provide services that have stable infrastructure, consistent funding, and support of all the agencies involved. Trained Deaf specialists have a great deal to offer families of Deaf infants and young children. Deaf adults connecting with birth to 3 families can make a significant difference in the dynamics of the family and future success of the child.

## Key Supporting Statements from the 2013 Supplement to the JCIH 2007 Position Statement

### Goal 3

All children who are D/HH from birth to 3 years of age and their families have EI providers who have the professional qualifications and core knowledge and skills to optimize the child's development and child/family well-being.

### 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.

### Goal 9

All families will have access to other families who have children who are D/HH and who are appropriately trained to provide culturally and linguistically sensitive support, mentorship, and guidance. four recommendations.

### Goal 10

Individuals who are D/HH will be active participants in the development and implementation of EHDI systems at the national, state/territory, and local levels; their participation will be an expected and integral component of the EHDI systems.

### Goal 11

All children who are D/HH and their families have access to support, mentorship, and guidance from individuals who are D/HH.

### Appendix 3

Example of fidelity of intervention monitoring for ASL for use by parents and providers/facilitators with children ages birth to  $\geq 4$  year—visual skill development.

## References and Works Cited

- Baker, S. (2011, January). *The advantages of early visual language (Research Brief No. 2)*. Washington, DC: Visual Language and Visual Learning Science of Learning Center, <http://issuu.com/vl2newsletter/docs/rb2eng/1>
- Baker-Shenk, C., & Cokely, D. (1980). American Sign Language. The original green books. A teacher's resource text on grammar and culture. What is the Deaf community? Chapter II, p. 54. Silver Spring, MD: T. J. Publishers, Inc. Deaf and Hard of Hearing Guide. Hands and Voices, <http://www.handsandvoices.org/comcon/articles/mentorsRolemodels.htm>
- Enns, C., & Price, L. (2013, June). *Family involvement in ASL acquisition (Research Brief No. 9)*. Washington, DC: Visual Language and Visual Learning Science of Learning Center, <http://vl2.gallaudet.edu/research/research-briefs/english/family-involvement-asl-acquisition/>
- Hulsebosch, P., & Myers, L. R. (2002). Minority parents as cultural mediators for education: Deaf parents mentoring hearing parents of deaf children. *The School Community Journal*, <http://www.adi.org/journal/ss02/Hulsebosch%20%20Myers.pdf>
- Indiana First Steps Early Intervention Personnel Guide. (2010, December 1). [http://www.cibaby.org/prior\\_to\\_2010\\_site%20folders/whats%20new%20page%20parts/First%20Steps%20Personnel%20GuideRevised%2012.pdf](http://www.cibaby.org/prior_to_2010_site%20folders/whats%20new%20page%20parts/First%20Steps%20Personnel%20GuideRevised%2012.pdf)
- Joint Committee on Infant Hearing. (2007). Year 2007 position statement: Principles and guidelines for Early Hearing Detection and Intervention programs. *Pediatrics*, 120(4), 898-921, [www.pediatrics.org/cgi/doi/10.1542/peds.2007-2333](http://www.pediatrics.org/cgi/doi/10.1542/peds.2007-2333)
- Joint Committee on Infant Hearing. (2013). Supplement to the JCIH 2007 position statement: Principles and guidelines for early intervention after confirmation that a child is deaf or hard of hearing. *Pediatrics*, 131(4), e1324-e1349, <http://pediatrics.aappublications.org/content/131/4/e1324>
- Minimum Components Under IDEA for a Statewide, Comprehensive System of Early Intervention Services to Infants and Toddlers With Special Needs (Including American Indian and Homeless Infants and Toddlers), <http://ectacenter.org/partc/componen.asp>
- National Association of the Deaf (NAD) Position Statement on Early Cognitive and Language Development and Education of Deaf and Hard of Hearing Children, <http://nad.org/print/position-statement-early-cognitive-and-language-development-and-education-dhh-children>
- National Deaf Children Society. Family friendly! Working with deaf children and their communities worldwide. Working Together with Deaf Adults, Chapter 4, [www.ndcs.org.uk/document.rm?id=3039](http://www.ndcs.org.uk/document.rm?id=3039) pp. 63-80
- National Center for Hearing Assessment and Management. (2014). *eBook 2014: Chapter 21*, [http://www.infanthearing.org/ehdi-ebook/2014\\_ebook/21-Chapter21DeafCommunity2014.pdf](http://www.infanthearing.org/ehdi-ebook/2014_ebook/21-Chapter21DeafCommunity2014.pdf)
- Rogers, K. D., & Young, A. M. (2011, March). Being a deaf role model: Deaf people's experiences of working with families and deaf young people. *Deafness & Education International*, 13(1), 2-16. UK: University of Manchester.
- The Deaf Mentor Experimental Project for Young Children who are Deaf and Their Families, (1998). *American Annals of the Deaf*, 143(1).

