Chapter 18
Family-Centered Early Intervention Programming for Infants & Toddlers Who Are Deaf or Hard of Hearing

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Background

The development of the young child can be best understood from a broad ecological perspective beginning with the family, the child’s immediate environments, and extending outward to include the broader environmental contexts that influence the child’s growth and development (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 1998). For a visual graphic of Bronfenbrenner’s ecological systems theory, see https://www.simplypsychology.org/Bronfenbrenner.html. Educational, social, and political environments provide a frame of reference for understanding programming for young children who are deaf or hard of hearing (D/HH) and their families. Policies and practice guidelines have evolved from multiple sources and disciplines, and recommendations for early intervention programs and services have been endorsed by professional organizations [e.g., American Speech-Language-Hearing Association (ASHA, 2008a); Division for Exceptional Children of the Council for Exceptional Children (Division for Early Childhood, 2014); and the National Association for the Education of Young Children (NAEYC, 2009)].
A primary goal of the EHDI system is to ensure all newborns are screened by 1 month of age, have their hearing levels evaluated by 3 months, and are enrolled in early intervention by 6 months.
When a family whose child has been identified as D/HH is referred to their state’s early intervention system, they likely have already received information and advice from a variety of sources. They may or may not have comprehensive information regarding child development milestones, communication opportunities, and/or early intervention services. At this point, some families may have already identified their preferences for assistive listening technology and communication. When an early intervention provider meets the family for the first time, the provider must first focus on building a trusting and collaborative relationship with the family. The provider will then be able to determine what information the family already has and how they can help the family process this information to make the best decisions for their child.

Family-Centered Early Intervention as the Foundation for Programming

This chapter presents a family-centered framework for early intervention professionals, programs, and services for young children who are D/HH and their families/caregivers. A family-centered philosophy provides the foundation for programs and services. Foundational components include:

1. Culturally and linguistically responsive services.
2. Collaboration and interdisciplinary teamwork.
3. Developmentally appropriate practice (DAP).
4. Evidence-based research and practices.

All four components are essential to comprehensive and coordinated services for children and their families. These components are aligned with federal legislation and guidelines and offer a framework for developing and implementing programs for children who are D/HH from birth to age 3 and their families/caregivers (Sass-Lehrer, 2011, 2016). Each of the four components includes underlying features that together provide the elements of effective programming. Importantly, these components are not discrete. Rather, they are interrelated and are transactional. This chapter describes how these components inform the development of early intervention programs and services (see Figure 1 illustrating these components).

Family-centered programming has replaced the professional-as-expert model in early intervention. A family-centered approach is sensitive to family complexity, responds to family priorities, cultural perspectives, and supports caregiver behaviors that promote the learning and social development of the child (Brotherson, Summers, Bruns, & Sharp, 2008; Shonkoff & Meisels, 2000). Family-professional partnerships encourage collaborations that recognize the expertise of families/caregivers and strive to minimize the potential imbalance of the power professionals may have. Partnerships with families strive to build power within the family rather than exert behaviors that impose power over the family (Sass-Lehrer, Porter, & Wu, 2016). Effective early intervention professionals have invaluable knowledge and share their expertise in ways that also acknowledge families’ unique experiences and perspectives. Central to a family-centered approach is understanding that the goal of early intervention is to provide services that support and strengthen families’ abilities to nurture and enhance their children’s development and overall well-being.

The importance of family involvement in their child’s early years cannot be overstated. Earlier enrollment in comprehensive birth-to-3 programs has been linked to better outcomes for children (Yoshinaga-Itano, 2003; Nelson et al., 2008). Moeller (2000) found that children who were enrolled in the Boy’s Town Parent Infant Program prior to 11...
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Moeller (2001) proposed that early intervention makes a positive difference in the lives of the majority of children, and early intervention should enhance family involvement and caregiver-child communicative interactions. The international consensus statement on best practices in family-centered early intervention (Moeller et al., 2013) endorses the importance of family involvement and partnerships between families and professionals.

Relationship-based partnerships with families involve an understanding and appreciation of the communities in which families live. The family’s community is an important resource offering a personal social network and access to a variety of community-based organizations and programs. Relatives and friends, co-workers, religious and civic groups, cultural/ethnic associations, childcare programs, schools, and libraries are all potential resources to the family. Professionals who are knowledgeable about the communities in which families live and work can help identify local resources that are within the family’s social and community network.
Culturally & Linguistically Responsive Services

Families and caregivers reflect the rich social, cultural, ethnic, and linguistic diversity of society. Cultural responsiveness is fundamental to establishing meaningful and trusting relationships with families. Families’ values and beliefs influence their perspectives regarding their child’s abilities, child-rearing practices, relationships with professionals, and involvement in their child’s overall development (Christensen, 2000; Meadow-Orlans, Mertens, & Sass-Lehrer, 2003; Steinberg, Davila, Collaza, Loew, & Fischgrund, 1997). Families’ backgrounds and experiences, such as their home language, hearing status, educational backgrounds, and personal and economic resources, require services that are relevant and accessible to meet diverse needs (Meadow-Orlans et al., 2003).

Professionals need to know how to connect with families whose home or preferred language is not English and how to work with interpreters and sometimes cultural mediators (Batemula, Kite Herbold, & Mitchiner, 2020). The cadre of professionals working with families and their young children, however, are overwhelmingly monolingual English speakers, white, well-educated, and female. Professionals often lack an understanding of the experiences and perspectives of the families with whom they work. With this in mind, there is an urgent need for more professionals whose backgrounds and experiences enable them to relate to these families through their personal life experiences, e.g., professionals who are Black, biracial, indigenous, and people of color (Sandy, 2016). In addition to increasing the number of professionals who are culturally and linguistically diverse, there is also a demand for professionals who are D/HH, including adults who are D/HH who are prepared to be role models and mentors. These adults who are D/HH are essential to young children’s development of identity and self-esteem, as well as to their families’ understanding of what it means to be D/HH in a majority hearing world.

Children who are D/HH benefit from an understanding that they are part of a larger community who share similarities in ways they acquire information, communicate, and socialize with others. Professionals must recognize that opportunities for families and their children to interact with adult role models and other children who are also D/HH are an essential part of enhancing the child’s self-awareness and self-esteem (Leigh, 2009). Hearing families indicate that meaningful interactions with other families who have children who are D/HH and adults who are D/HH are powerful influences in understanding the realities and possibilities for their children (Hintermair, 2000; Hintermair, 2006). Families who have had regular interactions with adults who are D/HH demonstrate better communication with their children and have a more realistic understanding of what it means to be D/HH than those who have not (Watkins, Pittman, & Walden, 1998). While the vast majority of professionals are hearing, professionals who are D/HH are essential members of the interdisciplinary birth-to-3 team (Benedict & Sass-Lehrer, 2007a). Adults who are D/HH not only provide young children and their families with knowledge and support (Hintermair, 2000) but also can be effective models for language learning (Watkins et al., 1998). For more information about adults who are D/HH, see Chapter 19 in the NCHAM EHDI eBook (Crace, Rems-Smario, & Nathanson, 2020).

Collaboration & Interdisciplinary Teams

In addition to professionals who are D/HH, teachers of the deaf are also essential members of the early intervention team. The team may also include developmental specialists, educators with expertise in working with young children who are visually impaired or have other developmental concerns, speech and language pathologists, educational audiologists, occupational and...
The IFSP is a process through which families and professionals identify a child’s strengths and needs, as well as the family’s priorities, resources, and concerns, to develop an integrated plan for services.

The interdisciplinary team, including the family, collaborate from the very beginning of early intervention programming—beginning with the initial child assessments, the development and implementation of the Individualized Family Service Plan (IFSP), through transition to preschool. The IFSP is a process through which families and professionals identify a child’s strengths and needs, as well as the family’s priorities, resources, and concerns, to develop an integrated plan for services. One section of the IFSP requires a description of the child’s present level of functioning across developmental domains and establishes goals based on 6-month intervals. Another section of the IFSP is a language and communication plan that identifies supports essential to achieve the expected communication and language outcomes (DeConde Johnson, Beams, & Stredler-Brown, 2005; Gallegos, Halus, & Crace, 2016). The IFSP process requires a commitment from professionals to work collaboratively with families and community members toward common goals for the child and family. For more information about the IFSP process for children who are D/HH and their families, see https://deafchildren.org/2014/06/family-support-what-is-the-ifsp/.

Developmentally Appropriate Practice

According to the National Association for the Education of Young Children (NAEYC), DAP is a framework of principles and guidelines designed to help young children reach their full potential across all developmental domains. DAP guidelines are based on nine principles supported by extensive research that inform early childhood education and professional practice (NAEYC, 2020). For information on the various guidelines, see Developmentally Appropriate Practice.

Early intervention services are informed by what is known about child development and learning, the child’s individual characteristics, the child’s social and cultural contexts, professionals providing services, and the program as a whole (NAEYC, 2020). DAP relies on professionals’ knowledge of best practices as well as their understanding of each child and family, their culture, and community. DAP also acknowledges each professionals’ commitment to equity, including the recognition of the negative impact of systemic bias or discrimination on development and differences in families’ access to resources.

Adherence to a DAP framework requires professionals to focus on the development of the whole child. An integrated approach to programming strengthens development in all domains and facilitates meaningful connections among all areas of development. Effective professionals embrace a strength-based perspective and understand how to promote development by emphasizing children’s individual skills and abilities. Young children may be short-changed by programs that focus...
Young children who are D/HH have unique abilities and benefit when professionals recognize that differences in hearing levels do not in any way limit the potential for learning or the ability to achieve the same goals as their hearing peers.

At least one in three children in early intervention has a developmental concern in addition to a difference in hearing level (Chapman et al., 2011; Meadow-Orlans et al., 2003). The addition of a disability adds a level of complexity to the learning process that requires skilled practitioners and services to adopt a holistic approach rather than focus on discrete developmental challenges (Jones & Jones, 2003; Meadow-Orlans, Smith-Gray, & Dyssegaard, 1995). While some developmental differences are identified at birth or shortly thereafter, other developmental concerns may not emerge until later. Families and caregivers are often first to report behaviors that may warrant further assessment by a team of specialists. Professionals with expertise in related areas, along with family members, should assess the child’s interactions in different environments, daily routines, and with a variety of individuals to identify areas of development that require specialized support.

Evidence-Based Research & Practices

The Early Childhood Technical Assistance (ECTA) Center defines evidence-based practice in early childhood education as: “...the process that pulls together the best available research, knowledge from professional experts, and data and input from children and their caregivers to identify and provide services evaluated and proven to achieve positive outcomes for children and families” (https://ectacenter.org/topics/evbased/evbased.asp). Educators have long struggled with the challenge of closing the gap between research and practice (Buysse & Wesley, 2006; IDEA, 2006: Spencer & Marschark, 2010). Early intervention position statements and documents for young children who are D/HH outline guidelines for best practices by applying what we know from research and practice (e.g., JCIH, 2013, 2019; Moeller et al., 2013). Best practices emphasize the importance of focusing on outcomes for children and families (https://ectacenter.org/eco/pages/childoutcomes.asp). Professionals working with young children who are D/HH and their families have reason to expect that participation in early intervention programs will lead to enhanced developmental outcomes for children. Outcome-based goals should be established that are based on principles of DAPs, as well as research and recommendations developed by professionals with expertise in this area. Monitoring development through frequent assessment is essential to ensuring that the identified outcomes are achieved within the expected timeframe.

Evidence that children who are D/HH can perform at similar levels as their hearing peers when provided early, comprehensive, and effective programming (Calderon, 2000; Moeller, 2001; Yoshinaga-Itano, 2003) has put increased pressure on programs to document outcomes. Systematic assessment guides the child’s development and learning, including their participation in daily routines and community activities (Meisels & Atkins-Burnett, 2000). Ongoing assessments inform the effectiveness of services and provide evidence of the need for possible revisions in the IFSP or communication plan. Insufficient progress, for example, should lead to consideration of different approaches, services, or frequency of services. Families and professionals should regularly revisit outcomes for the child and family based on the results of the assessment process. The Division for Early Childhood (2014) recommends that
assessments of young children involve families, is developmentally appropriate, and is a team-based approach. In addition to the family, adults who are D/HH have a vital role in the assessment process and provide invaluable perspectives on the environment, assessment activities, and the child’s performance (Hafer, Charlifue-Smith, & Rooke, 2008a, 2008b; Szarkowski & Hutchinson, 2016).

Communication & Language Opportunities

For the majority of children who are D/HH, the acquisition of language and communication skills is the central focus of early learning and development. Establishing effective communication between families and their young children has long been recognized as the key to early language acquisition, family functioning, and the overall development of the child (Calderon, 2000; Calderon & Greenberg, 1997; Meadow-Orlans, Spencer, & Koester, 2004; Moeller, 2000; Rosenbaum, 2000).

Increased opportunities for children to acquire language during the early years and develop a range of communication skills means that families no longer need to choose one language or one approach over another. Advances in the quality and availability of auditory and visual technologies for infants and toddlers have significantly changed the possibilities for children who are D/HH. Early identification of hearing levels means that more children are using hearing aids or other assistive technologies, such as cochlear implants, during the early months of life when the brain is most receptive to auditory stimuli. Early identification and intervention also provide families with the opportunity to establish effective communication visually through signs and gestures—laying the foundation for language (monolingual or bilingual) and literacy development (Chamberlain, Morford, & Mayberry, 2000; Schick, Marschark, & Spencer, 2006; Spencer & Koester, 2016; Wilbur, 2000).

Professionals need to ensure that families maintain realistic expectations regarding the range and variability of outcomes associated with different technologies so that the focus remains on the child’s acquisition of age-appropriate language and other developmental milestones (Gárate & Lenihan, 2016).

Bilingualism—the acquisition of both a natural sign language (e.g., ASL) and a spoken and/or written form of the majority language (e.g., English)—has gained support from researchers who have found that children who acquire language early can more easily acquire a second or third language, whether that language is visually or auditory based (Cummins, 2000; Grosjean, 2008). Children who are D/HH live in a world that is predominately hearing where the use of spoken language and written expression of the majority language are expected. The goal of bilingualism is to develop and maintain proficiency in both sign language and a spoken or written form of the hearing majority language (Benedict & Sass-Lehrer, 2007b). The potential benefits of bilingualism to cognitive and literacy development have been well established (Cummins, 2000; Grosjean, 2008), and research evidence has shown that sign language can spur, rather than impede, the development of spoken language. Other researchers have found that sign language can have a positive effect on the development of spoken language skills, provided appropriate models, access, and opportunities to use the languages are available (Hassanzadeh, 2012; Preisler, Tvingstedt, & Ahlström, 2002; Yoshinago-Itano, 2003).

High expectations for acquiring language for those children who have benefited from early identification have changed the “wait and see” mentality to one of “assess, support, and monitor” to ensure age-appropriate language acquisition. The importance of early language acquisition (in any modality) and the consequences of a language delay (Spencer & Koester, 2016; Yoshinaga-Itano & Sedey, 2000) impact the advice and support services knowledgeable professionals provide families.
Many birth-to-3 programs recognize that it is often unrealistic to expect families (even with the help of professionals) to make decisions about a communication approach or language [spoken language or a natural sign language, such as American Sign Language (ASL)] in the first few months of their child’s life. Expecting families to choose one language or communication approach with limited information and understanding of their child’s abilities may be detrimental to the child’s overall development. Families often lament that professionals pressure them to choose one approach over another (Meadows-Orlans et al., 2003). Many families are pragmatic—focusing on what approaches appear to work best in specific situations (Meadow-Orlans et al., 2003; Wilkens & Hehir, 2008).

Discovering which modalities offer a young child the best opportunities for acquiring language is a collaborative undertaking (Sass-Lehrer, Porter, & Wu, 2016; Stredler-Brown, 2010). Comprehensive assessment of language milestones in listening and spoken and/or sign language, as well as cognitive and social development, provides families and professionals with benchmarks to monitor the effectiveness of the approach(es) utilized. For a description of different communication and language approaches, see Marschark, 2007; Pittman, Sass-Lehrer, & Abrams, 2016; Schwartz, 2007; Stredler-Brown, 2010; and the following websites: www.raisingdeafkids.org, www.ncbegin.org, www.handsandvoices.org.

The concept of collaborative, informed decision making reflects the fundamental belief that families need comprehensive, meaningful, relevant, and evidence-based information to make decisions that are most appropriate for their child (Porter, Creed, Hood & Ching, 2018; Young et al., 2006). Families indicate that the choice of communication approaches is one of the most stressful decisions they make, and they value information from professionals that is accurate, impartial, and respects their views (Meadow-Orlans et al., 2003). Families play an active role in determining not only the communication and language pathways but also appropriate technologies and programming opportunities. Together, families and professionals can explore the best paths forward and monitor how well the decisions they have made are working to achieve their children’s goals.

Service Delivery Models

A variety of service delivery models exist among programs for the birth-to-3 population with little evidence that one model is superior to another (Calderon & Greenberg, 1997; Spencer & Marschark, 2010). The key to effective programming is a cohesive and integrated approach that includes a wide range of services to children and families in a variety of settings (Astuto & Allen, 2009). The delivery of services should reflect the needs of the child and family and be provided in settings that are most appropriate, e.g., home, school/agency, community. Services may be provided by a team of specialists or by one specialist in consultation with others. The frequency and intensity of the services must be directly related to the needs of
the child and priorities of the family. Families can access services directly or benefit indirectly through professional consultation (Stredler-Brown & Arehart, 2000; Gallegos, Halus, & Crace, 2016).

A traditional approach to services involves a professional visiting with a family in their home— or in another setting that works for the family— once a week for approximately one hour. In addition to this weekly home visit, the family may meet with other specialists (e.g., auditory-verbal, occupational, or physical therapists; sign language specialists; and speech-language pathologists). Meeting separately with different specialists creates challenges for families if professionals provide conflicting information. Collaboration among professionals streamlines services and minimizes the possibility of overlapping services or different messaging. Professionals may provide more effective and collaborative interdisciplinary services by asking families what works best for them and how to enhance services and communication among the team. Flexibility in scheduling and effective team collaboration are creative ways to reach families and achieve higher family involvement.

Telepractice has become increasingly available to families with young children who are D/HH. Telepractice has several advantages for families (and professionals) who may have difficulty meeting in person. For families who live far from specialized services or whose availability is limited by work or other responsibilities, remote visits via the Internet can enhance the frequency and regularity of services (Cole, Pickard, & Stredler-Brown, 2019; Houston & Stredler-Brown, 2012). During the COVID-19 pandemic, services have been provided exclusively through Internet platforms. Telepractice has prevented a disruption of services for many families and opportunities for more family members to participate in early intervention services. Sign language instruction and listening and spoken language skills training are available via distance learning and provide families with increased opportunities to connect with specialists, including deaf adults, regardless of where they live. Although high-speed Internet service and specialized training on the part of the professional is needed, researchers agree that telepractice provides enhanced opportunities for family involvement. For more detail about telepractice in early intervention for infants and toddlers who are D/HH and their families, see Chapter 20 in the NCHAM EHDI book (Houston, 2020).

Ensuring access to community-based services and programs is one of several goals of IDEA. The legislation encourages families and professionals to consider the child’s “natural environments” when identifying settings in which services are provided. According to IDEA, “to the maximum extent appropriate, [early intervention services] are provided in natural environments, including the home, and community settings in which children without disabilities participate [IDEA, 2004, Section 632(4)(G)(H)]. This provision of the law has sometimes been interpreted as a prohibition against center-based services for young children and their families. However, services may be provided in a variety of different settings, provided that a justification is included in the IFSP [IDEA, 2004, Section 636(d)(5)]. Consideration of special language and communication needs and opportunities for direct communication with peers and adults in the child’s language and communication modality(ies) are appropriate rationale for providing center-based services (ASHA, 2008b). The Joint Committee of ASHA and CED have developed a fact sheet on natural environments that describes the need to consider a range of settings, including center-based programs, to meet the individual needs of children who are D/HH and their families (see http://www.asha.org/aud/Natural-Environments-for-Infants-and-Toddlers/).

Families often prefer to go to the school or center for services rather than, or in addition to, receiving services in their
The quality of early education and developmental services hinges on the skills of the providers. Researchers suggest that outcomes for young children and their families are better when providers have specialized training in early intervention for children who are D/HH. Providers may have a wide range of disciplinary backgrounds (Stredler-Brown & Arehart, 2000) and rarely have sufficient preservice coursework and practicum experiences to address the needs of this unique population (Jones & Ewing, 2002; Proctor, Niemeyer, & Compton, 2005; Rice & Lenihan, 2005; Roush et al., 2004). This lack of adequate training has put an increased burden on states and related agencies to identify training needs and provide professional development experiences. Opportunities for professional learning and development are available through webinars, individual courses, and a few online programs (Sass-Lehrer, M., Crace, J., & Neild, R. 2020). Sass-Lehrer, Moeller and Stredler-Brown (2016) reviewed the literature and recommendations of professional organizations and initiatives regarding the knowledge and skills needed by early intervention providers. For a list of these documents and a complete listing of the knowledge and skills statements for each of the competency areas, see Appendix 1 of the Supplement to the 2007 JCIH Position Statement (JCIH, 2013). The nine major knowledge and skills areas are listed in Table 1.

The success of early identification and early provision of services has created a challenge for professionals and families to ensure that developmental gains are maintained as children transition to preschool and beyond. Children transitioning to preschool may no longer qualify for specialized services if they do not demonstrate a significant developmental delay and may be at risk for academic and/or social difficulties ahead without appropriate support (Seaver, 2000). Individualized language and communication plans, as well as preschool program guidelines, can help families advocate for appropriate preschool placements and services as they transition from early intervention to preschool (DeConde Johnson, Beams, & Stredler-Brown, 2005; Gallegos, Halus, & Crace, 2016).
Table 1
Areas of Knowledge and Skill

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Summary

Principles and policies for birth-to-3 programs have emerged from research, legislative guidelines, and professional recommendations. Comprehensive birth-to-3 programs should embrace a family-centered and developmental perspective, providing support to children and families through interdisciplinary and community-based collaboration that is evidence-based. Professionals, including those who are D/HH, should develop partnerships with families and implement culturally and linguistically responsive practices that reflect the family’s strengths and values. It is vital that everyone involved recognize the family as the most significant resource for the child.

Earlier enrollment and longer stays in early intervention programs than ever before provide increased opportunities for families to gain greater understanding of their child’s needs and potential. The challenge to the EHDI system is to ensure the full realization of every child’s potential and ability to sustain the benefits of early intervention into and beyond the school-age years. To do this requires the availability of skilled and knowledgeable professionals from the time families are first informed that their child may be D/HH through early intervention and transition to school-age educational programs and services.
References


