

Chapter 16

Early Intervention for Children Birth to 3: Families, Communities, & Communication

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Introduction

Newborn hearing screening is just the beginning of a journey for infants who are deaf or hard of hearing (D/HH) and their families. The itinerary for this journey is packed with excursions that include visits to the pediatric audiologist for hearing evaluations, developmental assessments by an interdisciplinary team of professionals, exploring the array of assistive technologies, programs and services available, and gathering information about communication opportunities. The journey may be smooth or rocky depending upon the quality of the Early Hearing Detection and Intervention (EHDI) system and the effectiveness of the professionals and services provided. This chapter will explore early intervention programming and services, as well as communication opportunities for children who are D/HH.

The expansion of newborn hearing screening throughout the United States and many other countries means fewer children now miss the advantages of an early start in programming (Nelson, Bougatsos, & Nygren, 2008). Parents and caregivers who discover their child's hearing abilities in infancy have the potential to provide them with the same quality of early life experiences as their hearing peers. Families who access timely and comprehensive services from professionals knowledgeable about early development, communication, and language are more likely to witness greater progress in many areas of development than those without similar opportunities (Kennedy, McCann, Campbell, Kimm, & Thornton, 2006; Moeller, 2000, 2007; Yoshinaga-Itano, 2003).

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Context for Birth to 3 Programming

Educational, social, and political forces provide a context for understanding programming for young children who are D/HH and their families. Policies and practices have evolved from multiple sources and disciplines. These varied disciplines have had an impact on the quality of services for the birth-to-3 population, including the preparation of personnel (Winton, McCullom, & Catlett, 2008). Recommendations for early intervention programs and providers have been endorsed by professional organizations [e.g., American Speech-Language-Hearing Association (ASHA; 2008a); National Association for the Education of Young Children (NAEYC; 2009); and the Division for Exceptional Children of the Council for Exceptional Children (Division for Early Childhood, 2014)].

Professional organizations with special interests in programs for children who are D/HH from birth to 3 years of age have developed position statements, knowledge and skills documents, and reports addressing program quality (e.g., Alexander Graham Bell Association, American Society for Deaf Children, National Association of the Deaf, Council of American Instructors of the Deaf, and the Conference of Educational Administrators of Schools and Programs for the Deaf).

The [Joint Committee on Infant Hearing](#) (JCIH 2007; 2013), Joint Committee of ASHA and Council on Education of the Deaf (CED; ASHA, 2008b), National Consensus Conference Report (Marge & Marge, 2005), as well as an international panel of experts (Moeller, Carr, Seaver, Stredler-Brown, & Holzinger, 2013) have identified evidence-based recommendations specific to infants and toddlers who are D/HH and their families. Recommendations address the three phases of the EHDI process: newborn hearing screening, diagnostic evaluation, and early intervention. The

JCIH developed a supplement to the 2007 Position Statement that focuses exclusively on programs and services with recommendations and benchmarks for states and territories (JCIH, 2013).

The Individuals with Disabilities Education Act (IDEA, 2004) provides federal guidelines in the United States for provision of services for children with developmental delays or disabilities from birth to 3 years of age. IDEA (2004) requires states and territories providing early intervention services to refer eligible children to their Part C system. Each state has a lead agency that, with the collaboration of the state's Interagency Coordinating Council, is charged with the responsibility of implementing the requirements of Part C of IDEA. Each state also has an EHDI system and a coordinator who is responsible for facilitating the provision of appropriate services to all children who are D/HH and their families in a timely fashion through collaboration with other state agencies. A primary goal of the EHDI system is to ensure all newborns are screened by 1 month of age, have their hearing evaluated by 3 months, and are enrolled in early intervention by 6 months. States that meet these criteria typically have well coordinated Part C and EHDI systems that provide smooth transitions from screening to evaluation to early intervention.

Characteristics of Effective Programs and Services

A family-centered philosophy provides the foundation for programs and practices in early intervention. Culturally sensitive, community-based, collaborative, and developmentally appropriate services are additional program features essential to comprehensive and cohesive services for children and their families. An interdisciplinary, team-based approach facilitates collaboration among professionals providing support to families and strategies of engagement that will

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enhance their children's development. These principles—derived from evidence-based research and practice and aligned with federal legislation and guidelines—offer a framework for developing and implementing programs for children who are D/HH from birth to age 3 and their families (Sass-Lehrer, 2011; Sass-Lehrer, 2016). These principles are summarized below.

Family-Centered

The development of the young child can only be fully understood within a broad ecological context, beginning with the family and extending outward to include the immediate environments with which the child interacts. Programs and practices that prioritize support for the well-being of the family are likely to witness a positive impact on the overall development of the child (Calderon & Greenberg, 2003). 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).

Collaborative, family-centered programming has amended the professional-as-expert model and utilizes family-professional partnerships to support and strengthen the families' abilities to nurture and enhance their child's development and overall well-being.

Families enroll in birth to 3 programs earlier than ever before—thanks to the expansion of newborn hearing screening and early hearing evaluation—and are spending more time in these programs. Families who enroll in comprehensive family-centered programs have the opportunity to learn from specialists who are hearing, D/HH, and other families what it means to be D/HH and how best to provide a supportive home environment (Marschark, 2007). Families benefit from comprehensive and accurate information, and yet, not all programs are equally effective in doing so. Program services are intended to reflect the needs of the child and the priority concerns of the family. However, services are often limited by the skills of the professionals and the resources available (Meadow-Orlans, Mertens, & Sass-Lehrer, 2003). Effective family programming assumes that professionals also incorporate best practices for working with adults (Moeller & Cole, 2016). Families benefit when professionals understand principles of adult learning and incorporate an adult-learner perspective in their work with families and with other professionals (Bodner-Johnson, 2001).

The importance of family involvement in their child's early years cannot be overstated. While 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 months of age and whose families were highly involved performed significantly better on vocabulary and verbal reasoning skills than those children who were enrolled early but whose parents were less involved. Moeller (2001) proposed that early intervention makes a positive difference in the lives of the majority of children and should emphasize enhancing family involvement and communicative interactions.



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Culturally Responsive and Community-Based

Families 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 development (Christensen, 2000; Meadow-Orlans et al., 2003; Steinberg, Davila, Collaza, Loew, & Fischgrund, 1997). Families' backgrounds and experiences, such as the hearing status of parents, their educational background, and personal and economic resources, require flexibility in type and delivery of services to ensure services are relevant and accessible (Meadow-Orlans et al., 2003).

An important resource to the family's support system is the community. A family's community offers a personal social network and a variety of community-based organizations and programs. Relatives and friends, co-workers, church and civic groups, cultural/ethnic associations, childcare programs, colleges, and libraries are all potential resources to the family. Professionals knowledgeable about the communities in which families live and work can help identify local resources, such as health and social services, that families indicate would be beneficial (Wolery, 2000).

Collaboration with Families and Professionals

Collaboration among families and professionals is necessary for a cohesive and integrative approach to programming. Professionals who establish effective reciprocal relationships with families—demonstrating trust and understanding—can significantly enhance the family's ability to boost their

child's development (Kelly & Barnard, 1999; Meadow-Orlans et al., 2003). The family–professional relationship is key to developing partnerships that facilitate shared decision-making and family participation at all levels of the program. Additionally, the family's control over resources promotes their self-efficacy and competence (Dunst, Trivette, Boyd, & Brookfield, 1994). Collaborative relationships should develop in ways that are culturally appropriate and consistent with the family's goals and expectations (Sass-Lehrer, Porter, & Wu, 2016).

A comprehensive birth-to-3 program includes an interdisciplinary team of professionals. All aspects of the program—from the initial child assessments through the development and implementation of the Individualized Family Service Plan (IFSP)—reflect the expertise of individuals from different disciplinary backgrounds and perspectives. 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 IFSP requires a description of the child's present level of functioning across developmental domains and establishes goals based on 6-month intervals. The IFSP requires a commitment from professionals to work collaboratively toward common goals for the child and family. Families can access services directly or benefit indirectly through professional consultation (Stredler-Brown & Arehart, 2000). The priorities of the family and abilities of the child dictate the composition of the interdisciplinary team.

Hearing, Deaf, and Hard-of-Hearing Partnerships

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 recognize that opportunities for families and their children to interact

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with adult role models and other children who are also D/HH is an essential part of enhancing the child's self-awareness and self-esteem (Leigh, 2009). Adults who are D/HH provide an important source of support that can strengthen the family's sense of well-being and the child's social-emotional development (Hintermair, 2000, 2006; Meadow-Orlans, Smith-Gray, & Dyssegaard, 1995; Pittman, Benedict, Olson, & Sass-Lehrer, 2016). Families whose infants are identified early and receive early support may experience less stress than those families whose infants are identified later (Pipp-Siegel, Sedey, & Yoshinaga-Itano, 2002). Reduced stress may result in increased sensitivity and emotional availability to their children (Lederberg & Goldbach, 2002) and gains in child language development (Pressman, Pipp-Siegel, Yoshinaga-Itano, Kubicek, & Emde, 2000).

Hearing families indicate that meaningful interactions with adults who are D/HH are powerful influences in understanding the realities and possibilities for their child (Hintermair, 2000). Families who have had regular interactions with adults who are D/HH demonstrate better communication with their children and 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; see also *Deaf Professionals & Community Involvement with Early Education* by Jodee Crace, Julie Rems-Smario, & Gloria Nathanson in the EHDI eBook).

Developmentally Appropriate

Developmentally appropriate practice “is a framework, a philosophy, or an

approach to working with young children” (Bredekamp & Rosegrant, 1992, p. 4) based on what we know from theory and literature about how learning unfolds (NAEYC, 2009). Program decisions are made on the basis of what we know about child development and learning; what we know about the child as an individual; and what we know about the child's social and cultural contexts, including the values of their family and community (NAEYC, 2009). The basic tenets of developmentally appropriate practice emerge from evidence-based research and practice. Developmentally appropriate practice recognizes the interrelationships among all areas of development and relies on the professionals' knowledge of best practices, as well as the individual child, family, culture, and community.

Young children may be short-changed by programs that focus solely on the development of communication. At least 1 in 3 children in early intervention programs has one or more developmental concerns in addition to hearing loss (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 programs to adopt a holistic approach rather than focusing on discrete developmental challenges (Jones & Jones, 2003; Meadow-Orlans et al., 1995). Interdisciplinary models of service provision, including families and professionals with expertise in related disciplines, can address the complex developmental needs of young children. Best practice guidelines emphasize the impact of learning in one domain on development in all areas and support an integrated approach that emphasizes multiple developmental domains (i.e., communication and language, cognitive, social-emotional, motor, and adaptive or functional skills; Division for Early Childhood, 2014; NAEYC, 2009). An integrated approach strengthens development in all domains and encourages children to make meaningful connections among all areas of development.

Assessment-Based Programming

Legislative and policy initiatives stress the need to monitor growth and measure child and family outcomes. The development of early learning standards and an emphasis on program accountability have focused attention on the importance of assessing program quality and ensuring that professionals working with young children and their families are well-prepared (Buysse & Wesley, 2006). 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. The goal of early childhood assessment is to acquire information that will facilitate the child's development and learning within the family and community (Meisels & Atkins-Burnett, 2000). The Division for Early Childhood (2014) recommends that assessment of young children involve families, be developmentally appropriate, and include a team 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 child's performance (Hafer, Charlifue-Smith, & Rooke, 2008a; Hafer, Charlifue-Smith, & Rooke, 2008b; Szarkowski & Hutchinson, 2016). Families and professionals should work together to identify individual outcomes for the child and family based on the results of the assessment process.

Communication and 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 who is D/HH (Calderon, 2000; Calderon & Greenberg, 1997; Meadow-Orlans, Spencer, & Koester, 2004, 2014; Moeller, 2000; Rosenbaum, 2000).

The number of infants identified to have hearing that is unilateral or in the mild-to-severe range has increased due to the sensitivity of newborn hearing screening technologies and sophistication of diagnostic procedures. The sensory modalities and technologies that provide the best access to language vary from one child to another. Families—with guidance from professionals—must consider the modality(ies) (i.e., vision, hearing, touch) that provide the best access to early linguistic development and effective communication (Rushmer, 2003). 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 spoken and/or sign language, as well as cognitive and social development, provides families and professionals with benchmarks to monitor the

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effectiveness of the approach(es) utilized. The concept of “informed choice” reflects the fundamental belief that families need comprehensive, meaningful, relevant, and evidence-based information to make decisions that are most appropriate for their child (Young et al., 2006). Families indicate that the choice of communication approach 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). (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)

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 only one language or one approach over another. Early identification of hearing abilities 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 environmental stimuli. Early identification and intervention also provides 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; Wilbur, 2000). 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. 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).

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. Forcing 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 development. Families often lament that professionals pressure them to choose one approach over another (Meadow-Orlans et al., 2003) despite research evidence that young children are capable of acquiring more than one language simultaneously or sequentially, whether the languages are auditory or visual (Grosjean, 2008; Petitto, 2000). Many families are pragmatic, focusing on what approaches appear to work best in specific situations (Meadow-Orlans et al., 2003; Wilkens & Hehir, 2008).

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 are minorities in a world that is predominately hearing, and 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 (Hassanzadaeh, 2012; Preisler, Tvingstedt, & Ahlström, 2002; Yoshinaga-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.

Families who are hearing—and an increasing number of those who are deaf (Mitchiner & Sass-Lehrer, 2011)—express a desire for their children to “have it all” (Spencer, 2000; Eleweke & Rodda, 2000; Meadow-Orlans et al., 2003). Not only do they want their children to be able to communicate through a natural sign language (e.g., ASL), but they also want their children to read and write the majority language (e.g., English) and communicate in the family’s

home language, if other than English. In short, families want their children to have the ability and flexibility to choose what works best for them in a range of situations (Wainscott, Sass-Lehrer, & Croyle, 2008). Professionals with expertise in different disciplinary areas must work together to assess the efficacy of communication modalities and language approaches for each child. They must also provide families with the guidance they need to make informed decisions that will promote the development of effective and age-appropriate cognition, communication, and language for their child.

Skills of Providers

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 (Calderon, 2000; Kennedy, McCann, Campbell, Kimm, & Thornton, 2005; Moeller et al., 2007; Nittrouer & Burton, 2001; Yoshinaga-Itano, 2003). However, many birth-to-3 providers lack the specialized knowledge and skills they need. Providers 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 population (Proctor, Niemeyer, & Compton, 2005; Roush et al., 2004; Jones & Ewing, 2002; Rice & Lenihan, 2005). This lack of adequate training has put an increased burden on states and related agencies to identify training needs and provide professional development experiences. Stredler-Brown, Moeller, and Sass-Lehrer (2009) reviewed the literature and recommendations of professional organizations and initiatives regarding the knowledge and skills needed by early intervention providers (AGBell, ASHA, 2008a; JCIH, 2007; Marge & Marge, 2005; NAD; CEASD; Proctor et al., 2005). These knowledge and skill areas are listed in Table 1.



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Table 1

Areas of Knowledge and Skill

1	Family-centered practices
2	Socially, culturally, and linguistically responsive practices
3	Language acquisition and communication development
4	Infant and toddler development
5	Screening, evaluation, and assessment
6	Auditory, visual, and tactile technologies
7	Planning and implementation of services
8	Collaboration and interdisciplinary practices
9	Professional and ethical behavior, legislation, policies, and research

The legislation encourages families and professionals to consider the child's "natural environments" when identifying settings in which services are provided.

The Supplement to the JCIH 2007 Position Statement (JCIH, 2013) provides the complete set of knowledge and skill statements.

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). 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 learner(s) [i.e., family, child(ren)] and be provided in settings that are most appropriate (i.e., 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.

A traditional approach to services involves a professional visiting with a family in their home 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). This approach may create challenges for families who have limited time and may result in overlapping or conflicting information and services. Professionals may provide more effective and integrated services by asking the family what works best for them and how they can enhance services and communication among the team.

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 often been interpreted as a prohibition against center-based services for young children and their families, but 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 come to the school or center for services rather than, or in addition to, receiving services in their home or community. School or center-based programming provides families with the opportunity to meet other children and families, interact with specialists, and meet adults who are D/HH. Playgroups with D/HH and hearing siblings and peers provide a context for young children to develop communication and social skills. To support the involvement of all family members and caregivers, programs must offer services during times when siblings, extended family members, and others may participate.

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. 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).

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. Professionals, including those who are D/HH, should develop partnerships with families and implement culturally responsive practices that reflect the family’s values and strengths. 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 the entire educational process.

NOTE: Portions of this chapter were drawn from Sass-Lehrer, M. (2011). Early intervention: Birth to 3. In M. Marschark & P. E. Spencer (Eds.), *The Oxford handbook of deaf studies, language, and education, Volume 1* (2nd ed.). New York: Oxford University Press.

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