## What is the *"IDEA"* behind *EHDI*?

The ultimate effectiveness of early identification of children who are deaf or hard-of-hearing (DHH) rests in what happens after the initial identification has been completed. The Early Hearing Detection and Intervention (EHDI) system focuses on early identification and then bridges to the early



intervention special education system that is supported by a law called the Individuals with Disabilities Education Act (IDEA). The link between the two systems is the shared recognition of the child as a unique individual whose strengths and needs must be clearly and accurately identified and whose family is empowered to express their questions, concerns, knowledge, hopes, and dreams that ultimately inform decisions made by the family. As a family member of a child who is DHH, or as a professional working within the EHDI system, it is important to understand how these two systems need to work together to enable each child to reach his or her full potential.

The term **Early Hearing Detection and Intervention** (**EHDI**) is commonly used to refer to the system of early identification and referral to diagnostic and intervention services focused on identifying children who are DHH. Historically, EHDI systems have focused on newborn hearing screening programs. The EHDI Act of 2017 (Public Law 115-71 of 2017) authorizes three U.S. Health and Human Services agencies to partner in coordinating the advancement of a national program for the early screening and diagnosis of infants and young children who are DHH. For the first time the law encouraged the identification of young children who experience late onset hearing loss. The three agencies involved include: Health Resources and Services Administration (HRSA), the Centers for Disease Control and Prevention (CDC), and the National Institutes of Health (NIH), each with a unique EHDI-related focus. HRSA, awards grants to states and territories to support continuous improvement of EHDI programs including addressing screening, loss to follow-up services, referral to early intervention services, family-centered medical home, and family engagement.

The Individuals with Disabilities Education Act (known as "IDEA") is a federal law administered by the Office of Special Education Programs (OSEP) in the U.S. Department of Education that ensures a free and appropriate public education to eligible individuals with disabilities 3-21 years of age throughout the nation. The Program for Infants and Toddlers with Disabilities (Part C of IDEA) is a federal grant program that assists states in operating a comprehensive statewide program of early intervention services for infants and toddlers with disabilities, ages birth through age 2 years, and their families. In order for a state to participate in the Part C program it must assure that early intervention will be available to every eligible child and its family. Currently, all states

and eligible territories are participating in the Part C program.

Annual funding to each state is based upon census figures of the number of children, birth through 2. Each state determines the specific eligibility criteria for children birth through two years of age and must have a Comprehensive Child Find System (Child Find). Child Find is a process of identifying, locating, and evaluating, as early as possible, all infants and toddlers with disabilities, birth to age three, who may require early intervention services (EIS). Part C regulations require that each State must have a statewide comprehensive, coordinated, multidisciplinary interagency system to provide early intervention services for infants and toddlers with disabilities and their families. To ensure a State has a comprehensive system, it is required that a State links their Part C program with all other major efforts to locate and identify young children by other State agencies and programs, including systems like EHDI.

The Individualized Family Service Plan (IFSP) refers to both a process and a document to which families of children with disabilities birth to three years of age are legally entitled under IDEA. The IFSP is developed collaboratively between a family and professionals and reflects the *individual* strengths and needs of the child. This plan, which can be modified at any time if the family so desires, serves as a road map for individualized early intervention services specifically designed for that child. This legal entitlement and many others that guide the delivery of services to children with disabilities under 3 years of age is included in Part C of IDEA.

The Individualized Education Plan (IEP) is also both a process and a document specifying a plan for special education and related services legally required by IDEA pertaining to the needs of individuals with disabilities 3-21 years of age. Like the IFSP, the IEP serves as a road map for special education services designed specifically for that individual. Special Education services for children 3 - 5 years of age are stipulated in Part B, section 619 of IDEA. This is why these programs are sometimes referred to as "Part B-619 programs."

## The Bridge Between EHDI and IDEA Services

Under the EHDI Act of 2017, HRSA funds the development of comprehensive, coordinated, statewide public health EHDI systems ensuring that newborns, infants and young children receive timely and appropriate screening, evaluation, and diagnostic services. These identification steps constitute the primary focus of most state EHDI programs. When a child completes the screening and diagnostic process and is found to be DHH, the child and family are referred to the Part C IDEA program in the state for early intervention services. This is where the "I" in EHDI comes in (referral to *intervention*). These intervention services are not directly supported or operated under the auspices of the HRSA-funded EHDI system. However, those involved in the EHDI screening and diagnostic activities help the family complete the identification process and transition to early intervention. They do this by making sure the family has all of the information they need about their child's hearing-related diagnosis, opportunities to learn about options pertaining to addressing their child's needs, support in expressing their concerns and ideas, and guidance in how to take the next step toward accessing early intervention services under IDEA. Part C is considered the "payor of last resort" for services, which means that Part C funds cannot be used to satisfy a financial commitment for services that would otherwise have been paid for by another public or private source.

After a child is referred to the state's Part C early intervention system, one of the first steps for the family is to play an active role in the development of the required Individualized Family Service Plan (IFSP), or the IEP if the child is 3 years of age or older. The "*I*" in EHDI bridges to and overlaps with the "*I*" in IDEA around the tangible development of an *individualized intervention* plan. This was not always the case, however. Historically children identified with disabilities were often served categorically, grouped by condition in segregated settings, using prescribed one-size-fits-all intervention solutions. IDEA, however, protects the right of all children to receive an individualized intervention/education plan reflecting the specific strengths and needs of the child as well as the desires of the family who is recognized under the law as the key decision maker for the child. No longer is it acceptable to prescribe programming or intervention strategies solely on the basis of a specific condition. Families are supported in considering options and opportunities based on what they know about and want for their child and family as they prepare for the IFSP/IEP process. By recognizing that individualized services are the ultimate goal for children who are identified. EHDI professionals support the family from the very beginning of the screening and diagnostic process as key decision makers for their child whom they know better than anyone else. By doing this, the transition from EHDI to IDEA services can be smooth; the two systems are bridged by the emphasis placed on the "I" which stands for intervention that is individualized. To achieve individualization, families must be active participants and the ultimate decision makers - a role that IDEA stipulates family members have the right and responsibility to play.

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