

Report to Congressional Requesters

**May 2011** 

# DEAF AND HARD OF HEARING CHILDREN

Federal Support for Developing Language and Literacy





Highlights of GAO-11-357, a report to congressional requesters

#### Why GAO Did This Study

Deaf and hard of hearing children can face significant challenges developing the language and literacy skills needed to succeed in school and become self-sufficient adults. The federal government supports these children through the Early Hearing Detection and Intervention (EHDI) program, which awards grants to states to develop systems to screen and diagnose newborns and infants for hearing loss and refer them for appropriate interventions. Also, the Individuals with Disabilities Education Act (IDEA) supports and funds early intervention and special education services for children with disabilities, including deafness and hearing loss.

To better understand how federal programs support deaf and hard of hearing children, GAO was asked to examine the: (1) extent of hearing loss among children, (2) settings in which these children are educated, (3) factors that help deaf and hard of hearing children acquire language and literacy skills, and (4) challenges to providing appropriate interventions for these children. GAO analyzed data on hearing loss; reviewed research literature; interviewed educators, national organizations, parents, and state and federal officials; and examined relevant federal laws and regulations. A draft of this report was provided to the Departments of Education and Health and Human Services for review and comment. Each provided technical comments, which were incorporated into the report, as appropriate. GAO makes no recommendations in this report.

View GAO-11-357 or key components. For more information, contact George A. Scott at (202) 512-7215 or scottg@gao.gov.

### DEAF AND HARD OF HEARING CHILDREN

## Federal Support for Developing Language and Literacy

#### What GAO Found

Available data indicate hearing loss affects a small percentage of children. In 2008, the prevalence of hearing loss among infants under 12 months was 0.1 percent, or about 1 diagnosed case per 1,000 screened. While the Centers for Disease Control and Prevention (CDC) does not collect hearing test data for children under age 12, other than EHDI data, federal surveys conducted from 2005 to 2009 estimated 3 percent or fewer of children nationwide under age 12 had hearing problems. Based on nationwide hearing examination data for youth aged 12–17 from 2005 to 2008, an estimated 1 percent had at least moderate hearing loss in one or both ears.

Deaf and hard of hearing children are educated in a variety of settings, from regular classrooms to separate schools for the deaf. Data from the U.S. Department of Education (Education) indicate that in fall 2008 the majority of these children who received special education did so in regular early childhood programs or regular classrooms for at least part of their day.

Experts GAO interviewed agreed that several key factors are critical for helping deaf and hard of hearing children acquire language and literacy skills. Early exposure to language—either spoken or signed—is critical because during the first few years of life it is easiest for children to learn language. Also, parents need to have information on the full range of communication options available so that they can make informed choices to meet their children's individual needs. Similarly, experts told GAO that education for these children should be individualized and that there should not be one standard approach for educating them. Additionally, having skilled professionals, such as qualified interpreters in regular classrooms, is important for ensuring that children with hearing loss receive the same information as their hearing classmates.

Limited information and resources are challenges to providing deaf and hard of hearing children with appropriate interventions. Experts indicated that parents may not always receive information on the full range of communication options available, and may not understand the importance of enrolling their children in early intervention services. Additionally, a lack of data can limit efforts to evaluate early intervention outcomes. The EHDI law calls for CDC and the Health Resources and Services Administration in the Department of Health and Human Services (HHS) to support states in the evaluation of early intervention efforts—programs that are, in part, provided under IDEA. These agencies suggested that privacy requirements may restrict the information that EHDI and early intervention programs can share, limiting efforts to evaluate outcomes for children. However, HHS and Education are taking a number of steps to identify best practices for sharing data and tracking the outcomes of deaf and hard of hearing children who receive early intervention services. Experts also cited a shortage of qualified teachers and interpreters as a major challenge. Moreover, providing services for these students can be costly and it is difficult for schools to provide a variety of options, especially in rural areas.

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#### **Abbreviations**

CDC Centers for Disease Control and Prevention

Education U.S. Department of Education

EHDI Early Hearing Detection and Intervention

HHS U.S. Department of Health and Human Services HRSA Health Resources and Services Administration IDEA Individuals with Disabilities Education Act

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## United States Government Accountability Office Washington, DC 20548

May 25, 2011

The Honorable Tom Harkin Chairman Committee on Health, Education, Labor, and Pensions United States Senate

The Honorable George Miller Ranking Member Committee on Education and the Workforce House of Representatives

Children who are deaf or hard of hearing¹ can face considerable challenges developing the language and literacy skills they need to succeed in school and become self-sufficient, productive adults. Although experts suggest that deaf and hard of hearing children who receive appropriate educational and other services can successfully transition to adulthood, research indicates that many do not receive the necessary support early on or during their school years to keep up with their hearing peers. For example, according to one study, the median reading comprehension score of deaf or hard of hearing students at age 18 was below the median of fourth-grade hearing students.²

In response to your interest in how federal programs support deaf and hard of hearing children, this report provides information on: (1) the extent of hearing loss among children in the United States, (2) the settings in which these children are educated, (3) factors that have been shown to help deaf and hard of hearing children acquire language and literacy skills, and (4) challenges that exist to providing appropriate interventions for these children.

<sup>&</sup>lt;sup>1</sup>The phrases "deaf and hard of hearing" and "children with hearing loss" are used interchangeably throughout the report.

<sup>&</sup>lt;sup>2</sup>Carol Bloomquist Traxler, "The Stanford Achievement test, 9<sup>th</sup> Edition: National Norming and Performance Standards for Deaf and Hard-of-Hearing Students," *Journal of Deaf Studies and Deaf Education*, vol. 5, no. 4 (fall 2000): 337–48.

To respond to the first objective, we analyzed available data from hearing tests and several national surveys conducted from 2005 to 2009. We assessed the reliability of the survey data by (1) performing electronic testing of required data elements, (2) reviewing existing information about the data and the system that produced them, and (3) interviewing agency officials knowledgeable about the data. We determined that the data were sufficiently reliable for the purposes of this report. To address the second objective, we analyzed 2008 special education data—the most recent data available—on the Individuals with Disabilities Education Act reported to the U.S. Department of Education (Education). For our third objective, we interviewed experts from national organizations representing educators, parents, and the deaf community to obtain their views on the acquisition of language and literacy skills in deaf and hard of hearing children. We also reviewed published literature from 2005 to 2010 to identify factors associated with deaf and hard of hearing students' language and literacy development. To address our fourth objective, we reviewed federal supports for children with hearing loss—such as the Early Hearing Detection and Intervention program and programs under the Individuals with Disabilities Education Act that serve children with disabilities—and relevant federal laws, regulations, and guidance. We interviewed officials from Education and the U.S. Department of Health and Human Services (HHS) responsible for administering these programs and experts from national organizations. We also conducted site visits to Colorado, Massachusetts, and Washington—states which varied in the percentage of children with hearing loss educated in regular classrooms and in the characteristics of their state schools for the deaf. During the visits we spoke with state, school district, and school officials about state and local efforts to provide educational services to deaf and hard of hearing children, as well as any challenges and gaps in services for these students. We also interviewed parents of deaf and hard of hearing children about their views on their children's educational experiences. See appendix I for additional information on our scope and methodology.

We conducted this performance audit from March 2010 to May 2011 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

### Background

#### Hearing Loss among Children

Hearing loss can vary by type, level of severity, age at onset, and cause. Experts generally agree on the major types of hearing loss: conductive, sensorineural, and mixed (see table 1).<sup>3</sup>

| Table 1: Types of Hearing Loss |  |  |  |
|--------------------------------|--|--|--|
| Type of hearing loss           | Description  |  |  |
| Conductive                     | Conductive hearing loss results when sounds are prevented from going through the outer or middle ear, such as by a malformation of part of the ear or ear infections. This type of hearing loss can often be corrected with medicine or surgery. |  |  |
| Sensorineural                  | Sensorineural hearing loss occurs when there is a problem in the way the inner ear or hearing nerve works, such as from illness or noise exposure.   |  |  |
| Mixed                          | Mixed hearing loss includes both conductive and sensorineural hearing loss.  |  |  |

Sources: Centers for Disease Control and Prevention and the American Speech-Language-Hearing Association.

Hearing loss can also be classified by its level of severity and whether one or both ears are affected. The level of loss can range from slight to profound.<sup>4</sup> Hearing loss may be present in one ear (unilateral) or in both ears (bilateral). The level of loss in the two ears may be the same or different.

Hearing loss may be present at birth or may develop later. It can also be described as sudden or progressive (worsening over time), and stable or

<sup>&</sup>lt;sup>3</sup>Experts include the Centers for Disease Control and Prevention (CDC), American Speech-Language-Hearing Association, Boys Town National Research Hospital, and Johns Hopkins Medicine. CDC also identifies a fourth type of hearing loss—Auditory Neuropathy Spectrum Disorder, where damage to the inner ear or hearing nerve prevents sound that enters the ear normally from being easily understood by the brain.

<sup>&</sup>lt;sup>4</sup>The American Speech-Language-Hearing Association cites the following hearing loss classification system, with loss measured in decibels (dB HL): normal hearing loss falls from negative 10 to 15 dB HL, slight loss from 16 to 25 dB HL, mild loss from 26 to 40 dB HL, moderate loss from 41 to 55 dB HL, moderately severe loss from 56 to 70 dB HL, severe loss from 71 to 90 dB HL, and profound loss of 91 dB HL or more. According to the Centers for Disease Control and Prevention, a person with mild hearing loss may hear some speech sounds but find soft sounds difficult to hear whereas someone with profound hearing loss will not hear any speech and only very loud sounds.

fluctuating. The National Institute on Deafness and Other Communication Disorders reports that about 50–60 percent of severe to profound cases of childhood hearing loss are due to genetic causes. However, about 90 percent of infants who are born deaf are born to hearing parents. Experts also suggest nearly 25 percent of children with hearing loss have one or more other developmental disability, such as cerebral palsy or vision loss.

There are two primary types of personal assistive devices used to improve children's hearing—hearing aids and cochlear implants. Hearing aids amplify sound and can be worn by children as young as infants. According to the Centers for Disease Control and Prevention, children with severe to profound hearing loss may benefit from a cochlear implant. Unlike hearing aids, cochlear implants are surgically implanted devices that process sound from the environment and ultimately signal the brain, which can learn to recognize these signals in a meaningful way. According to available data from the U.S. Food and Drug Administration, as of April 2009, about 25,500 children in the United States had received cochlear implants.

### Communication Modes for Deaf and Hard of Hearing Children

Deaf and hard of hearing children can communicate in a variety of ways, including signing and speaking. Signing can take many forms, including American Sign Language, which is a complete and complex language with its own syntax and grammar that uses a combination of signs made with the hands and other movements, such as facial expressions and postures of the body. Other forms of visual communication are based on spoken language, such as Cued Speech—which uses hand shapes to represent different sounds in the English language, for example—and can aid lipreading. Signing Exact English is a sign system that corresponds to literal English. A communication mode may also combine the use of signing with speech. A survey of deaf and hard of hearing students in 2007–2008 found

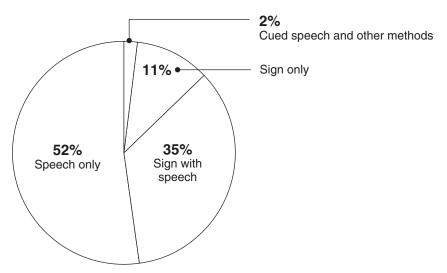
<sup>&</sup>lt;sup>5</sup>Testimony of James F. Battey Jr., M.D., Ph.D., Director, National Institute on Deafness and Other Communication Disorders, before the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies, U.S. Senate Committee on Appropriations (Mar. 26, 2007).

<sup>&</sup>lt;sup>6</sup>Other assistive technologies, such as an FM system, can help deaf and hard of hearing children communicate in the classroom by sending sound from someone speaking into a microphone to a person wearing the receiver, and can be used in conjunction with hearing aids.

<sup>&</sup>lt;sup>7</sup>Bone-anchored hearing aids may be used by children who are unable to wear a hearing aid in or behind the ear.

that more than half, nationwide, learned in speech-only environments (see figure 1).

Figure 1: Percentage of Deaf and Hard of Hearing Students by Primary Communication Mode Used for Instruction

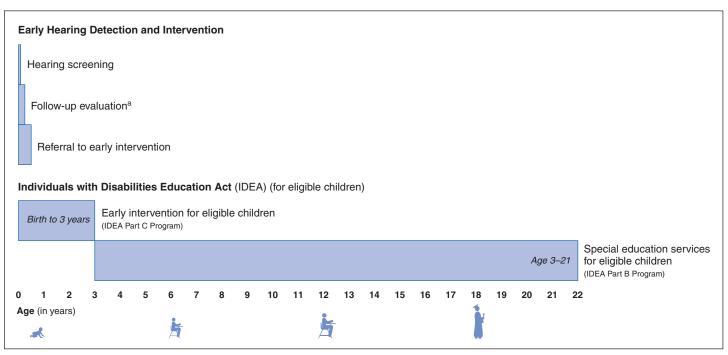


Source: Gallaudet Research Institute (November 2008). Regional and National Summary Report of Data from the 2007-08 Annual Survey of Deaf and Hard of Hearing Children and Youth. Washington, DC: GRI, Gallaudet University.

Federal Support for Children with Hearing Loss

From birth through age 21, the federal government supports the educational needs of deaf and hard of hearing children, and other children with disabilities, through a variety of means (see figure 2).

Figure 2: Federal Support for Children with Hearing Loss



Source: GAO analysis of select federal laws and programs.

<sup>a</sup>For infants who screen positive for hearing loss

**Early Hearing Detection and Intervention (EHDI)**. HHS, through its Centers for Disease Control and Prevention (CDC) and Health Resources and Services Administration (HRSA), provides grants and assistance to states to develop, monitor, and collect data on early hearing screening, evaluation, and intervention programs and systems. The Joint Committee on Infant Hearing developed national program goals for early screening and intervention that aim to ensure that all newborns are screened for hearing loss before 1 month of age, that infants who do not pass the

 $<sup>^842</sup>$  U.S.C.  $\S$  280g-1. CDC was appropriated about \$10.9 million for EHDI in fiscal year 2009. The same year, HRSA's hearing screening and intervention program was funded at \$19 million.

<sup>&</sup>lt;sup>9</sup>The committee is composed of members of the Alexander Graham Bell Association for the Deaf and Hard of Hearing, the American Academy of Pediatrics, the American Academy of Audiology, the American Academy of Otolaryngology-Head and Neck Surgery, the American Speech-Language-Hearing Association, the Council on Education of the Deaf, and the Directors of Speech and Hearing Programs in State Health and Welfare Agencies.

screening receive a full evaluation before 3 months, and that those identified with hearing loss receive early intervention services before 6 months. Ongress reauthorized the EHDI program in December 2010, with amendments specifying that the purpose of the grants is to help states develop programs to ensure that children who are referred from state screening programs receive prompt evaluation and diagnosis and the appropriate educational, audiological, and medical interventions.

Individuals with Disabilities Education Act (IDEA). To support the educational needs of children with disabilities, including those who are deaf or hard of hearing, Congress originally enacted IDEA in 1975, 12 most recently reauthorizing and amending it in 2004. IDEA authorizes federal funding for early intervention and special education and related services for children with disabilities through two main programs: the Infants and Toddlers with Disabilities (Part C) program, 14 which supports early intervention services for children younger than 3 years of age, and the Assistance for Education of All Children with Disabilities (Part B) program, 15 which supports the special education needs of children aged 3–21 (see appendix II). 16 While IDEA Part C and B programs have different

<sup>&</sup>lt;sup>10</sup>According to the CDC, the agency does not establish criteria for passing the hearing screening.

<sup>&</sup>lt;sup>11</sup>Early Hearing Detection and Intervention Act of 2010, Pub. L. No. 111-337, 124 Stat. 3588. The program also aims to develop efficient models to ensure that newborns and infants who are identified with a hearing loss through screening receive follow-up by a qualified health care provider. The EHDI law was first enacted as part of the Departments of Labor, Health and Human Services, and Education Fiscal Year 2000 Appropriations Act, Pub. L. No. 106-113, Appendix D, Title VI, 113 Stat. 1501, 1501A-276 (1999) and was subsequently added as amendment to the Public Health Service Act by section 702 of the Children's Health Act of 2000, Pub. L. No. 106-310, Div. A, Title VII, 114 Stat. 1101, 1120.

 $<sup>^{12}\</sup>mbox{IDEA}$  was originally enacted as the Education for All Handicapped Children Act, Pub. L. No. 94-142, 89 Stat. 773.

 $<sup>^{13}</sup>$ Individuals with Disabilities Education Improvement Act of 2004, Pub. L. No. 108-446, 118 Stat. 2647. IDEA, as amended, is codified at 20 U.S.C.  $\S$  1400 et seq.

<sup>&</sup>lt;sup>14</sup>In fiscal year 2008, the Part C program was funded at \$436 million.

<sup>&</sup>lt;sup>15</sup>In fiscal year 2008, the Part B program was funded at \$10.95 billion.

<sup>&</sup>lt;sup>16</sup>In addition to IDEA, other laws support the educational needs of children with disabilities, including children who are deaf or hard of hearing. Section 504 of the Rehabilitation Act of 1973 (Section 504) prohibits entities that receive federal financial assistance, including public schools, from discriminating against otherwise qualified individuals with disabilities. Title II of the Americans with Disabilities Act of 1990, as amended, prohibits discrimination on the basis of disability by public entities, including public schools, regardless of whether they receive federal financial assistance. In general, Section 504 and Title II requirements are similar.

eligibility criteria and children are evaluated for each program separately, Education considers the effective transition between the programs a priority and requires states to support families through a timely transition process. <sup>17</sup> States are also required by IDEA to develop transition plans for children exiting the Part C program.

As a condition of receiving IDEA funds, states must meet several requirements, including:

- identifying and evaluating all children with disabilities to determine whether they are eligible for early intervention or special education and related services;
- providing early intervention in accordance with an individualized family service plan<sup>18</sup> (Part C) or special education and services in accordance with an individualized education program<sup>19</sup> (Part B), as developed by a team that includes the parent and qualified professionals; and,
- to the maximum extent appropriate, providing early intervention services in a natural environment and educating children with disabilities with children who are not disabled.<sup>20</sup>

As of fall 2008, more than 78,000 deaf and hard of hearing children aged 3–21 in the 50 states received services under IDEA Part B,<sup>21</sup> or about 1 percent of all students served by IDEA Part B nationwide (see figure 3).

<sup>&</sup>lt;sup>17</sup>Education requires state Part C programs to report on, among other things, the percentage of children exiting Part C who receive timely transition planning to support the child's transition to preschool and other community services by the age of 3. Transition planning includes documentation of appropriate transition steps and services for a child, as well as notification of school districts and a transition conference for children potentially eligible for Part B services. Part B programs are required to report to Education on the percentage of children referred by Part C prior to age 3, who are found eligible for Part B, and who have an individualized education program developed and implemented by their third birthdays.

<sup>&</sup>lt;sup>18</sup>20 U.S.C. § 1436 and 34 C.F.R. § 303.342 and § 303.343.

<sup>&</sup>lt;sup>19</sup>20 U.S.C. § 1414(d)(1) and 34 C.F.R. § 300.321 and § 300.324.

<sup>&</sup>lt;sup>20</sup>States must also include procedural safeguards in their programs, such as a right to due process hearings and the right to appeal to federal district court.

<sup>&</sup>lt;sup>21</sup>These data represent the 50 states only. More than 79,000 deaf and hard of hearing children in the 50 states, the District of Columbia, schools of the Bureau of Indian Education, and the U.S. territories received IDEA Part B services as of fall 2008.

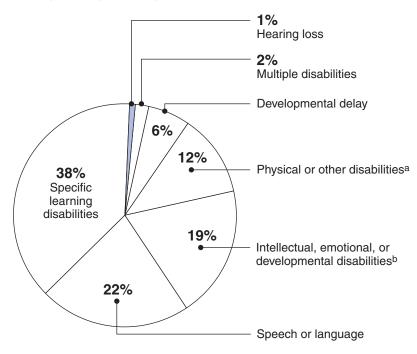


Figure 3: Percentage of All Students Aged 3–21 in the 50 States Served by IDEA in 2008 by Primary Disability

Source: U.S. Department of Education data from www.ideadata.org.

Note: This figure likely represents an undercount of all children 3–21 with hearing loss served under IDEA, as data are collected by primary disability. According to Education, data for children up to age 3 are not available by disability category under the Part C program.

<sup>a</sup>Physical or other disabilities category includes orthopedic impairments, visual impairments, deafblindness, traumatic brain injury, and other health impairments.

<sup>b</sup>Intellectual, emotional, or developmental disabilities category includes intellectual disabilities, emotional disturbance, and autism.

## Hearing Loss Affects a Small Percentage of Children

According to the most recent hearing screening data available from CDC's EHDI program, the prevalence of hearing loss among newborns and infants younger than 12 months in 2008 was approximately 0.1 percent, or about 1 diagnosed case for every 1.000 screened. 22 That year, more than 3 million infants, or 97 percent of births nationwide, were screened for hearing loss. Of those screened, 2 percent failed.<sup>23</sup> Further audiological testing for those infants who failed a screening revealed that about 7 percent were subsequently diagnosed with hearing loss and about 41 percent were diagnosed with normal hearing. However, further information on the hearing status for the majority (53 percent) of these children was unavailable to CDC for a variety of reasons; most often, states reported that families could not be contacted or were unresponsive.<sup>24</sup> As a result there is no information available to CDC to confirm hearing loss in more than half of infants who failed their hearing screening test that year. It should be noted that the recent reauthorization of the EHDI program included a provision that may help remedy this problem. Specifically, the reauthorization amended the EHDI law to provide that funding to states can be used to develop efficient models to ensure that those who fail an initial screening receive follow-up care by a qualified health care provider and that states will be encouraged to adopt models to increase the rate of follow-up for these children.<sup>25</sup>

Data on children beyond infancy similarly suggest a low prevalence of hearing loss. While the CDC does not currently collect hearing test data for children younger than the age of 12, apart from the data collected under the EHDI program, <sup>26</sup> HHS surveys from 2005 to 2009 indicate an estimated

<sup>&</sup>lt;sup>22</sup>This statistic represents prevalence in the 45 states for which data were available. Alabama, California, Georgia, Nevada, and New York were not included in this analysis.

<sup>&</sup>lt;sup>23</sup>Infants may be screened for hearing loss more than once; for infants who received multiple screenings, this statistic is based on the results of their most recent screening test.

<sup>&</sup>lt;sup>24</sup>The families of most infants without a documented diagnosis could not be contacted or were unresponsive (about 82 percent), while other infants had a diagnosis in process (about 9 percent), died or had a parent who refused further testing (about 5 percent), or were nonresidents or moved out of state (about 4 percent).

<sup>&</sup>lt;sup>25</sup>Pub. L. No. 111-337, § 2, 124 Stat. 3588 (codified at 42 U.S.C. 280g-1(a)(3)).

<sup>&</sup>lt;sup>26</sup>The most recent year for which hearing test data are available for children in this age range is 1994, when data were collected on children aged 6 to 19. Although existing federal hearing screening and testing programs do not currently cover children of all ages, states may mandate hearing tests for these children. For example, according to the Colorado Department of Education, Colorado requires that children in kindergarten and grades 1–3, 5, 7, and 9 are tested for hearing loss.

3 percent or fewer of children nationwide in this age range had hearing problems. <sup>27</sup> (See appendix III for more information.) In addition to the EHDI program, the CDC sponsors hearing examinations of youth from ages 12 through 19 through the National Health and Nutrition Examination Survey. <sup>28</sup> Based on these examinations from 2005 to 2008, an estimated 1 percent of 12–17 year olds nationwide had at least moderate hearing loss in one or both ears. <sup>29</sup> When we compared the demographic characteristics of those with moderate to moderately-severe hearing loss to those with normal hearing to mild loss, we found no statistically significant differences in the distributions of sex, race, or poverty status <sup>30</sup> between the two groups.

## Most Deaf and Hard of Hearing Children are Educated in Regular Classrooms

Children who are deaf or hard of hearing are educated in a variety of settings, ranging from regular classrooms alongside hearing peers to separate schools and residential facilities for children with hearing loss. According to data from Education, the majority of deaf and hard of hearing children who received special education through IDEA Part B in fall 2008 did so in regular early childhood programs or regular classrooms, for at least part of their day (see table 2).

<sup>&</sup>lt;sup>27</sup>The surveys include the National Health Interview Survey (NHIS), National Survey of Children's Health (NSCH), and National Health and Nutrition Examination Survey (NHANES) household interview data. For NHIS and NSCH, a responsible adult, such as a parent or guardian who is knowledgeable about a child's health status, served as the survey respondent. For NHANES, an adult reported information on behalf of children younger than the age of 16.

<sup>&</sup>lt;sup>28</sup>The National Health and Nutrition Examination Survey is used to assess the health and nutritional status of children and adults in the United States through a combination of interviews and physical examinations. For the purposes of examining data on children, we limited our analysis to 12–17 year olds only. See appendix I for more information.

<sup>&</sup>lt;sup>29</sup>An estimated 99 percent of 12–17 year olds had hearing ranging from normal to mild loss and less than an estimated 1 percent experienced severe or profound loss.

<sup>&</sup>lt;sup>30</sup>For poverty status, we compared 12–17 year olds from families with income below 200 percent of federal poverty guidelines and at or above 200 percent of the guidelines. For race, we compared non-Hispanic white children and non-Hispanic African-American children. We selected these races due to the limited sample sizes available by race.

Table 2: Educational Settings of Children with Hearing Loss in the 50 States Served Under IDEA Part B in Fall 2008

| Educational setting for children ages 3–5                | Percentage<br>of children<br>ages 3–5 | Educational setting<br>for children ages<br>6–21 | Percentage<br>of children<br>ages 6–21 |
|--|---------------------------------------|--|--|
| In regular early childhood program more than 80% of time | 32.9%                                 | In regular classroom<br>more than 80% of<br>time | 53.3%                                  |
| In regular early childhood program 40–79% of time        | 6.7                                   | In regular classroom<br>40–79% of time           | 17.2                                   |
| In regular early childhood program less than 40% of time | 13                                    | In regular classroom<br>less than 40% of time    | 15.8                                   |
| Separate classroom <sup>a</sup>                          | 26.6                                  | n/a  | n/a                                    |
| Separate school  | 13.5                                  | Separate school                                  | 8.2                                    |
| Other <sup>b</sup>                                       | 4                                     | Other <sup>b</sup>                               | 4.7                                    |
| Data unavailable <sup>c</sup>                            | 3.4                                   | Data unavailable°                                | 0.9                                    |

Source: GAO analysis of Education data from www.ideadata.org.

Note: Data in each column do not sum to 100 due to rounding.

Under IDEA, the degree of a child's hearing loss alone should not dictate a particular educational setting. According to the law, decisions about the setting in which deaf or hard of hearing children are educated should be based on consideration of a child's language and communication needs, opportunities for direct communication with peers, and access to instruction in the language and communication mode the child uses, among other factors. During our site visits, we observed deaf and hard of hearing students in regular classrooms with hearing students, aided by interpreters; in self-contained classrooms of deaf and hard of hearing children in local public schools; and in schools for the deaf. Students may also divide their time among multiple educational settings. We also observed students who spent most of their time in a self-contained classroom but attended some classes, such as art and music, with hearing peers, and met with students who divided their time between a deaf school and a regular classroom in a local public school. Students from deaf schools may choose to participate in other public school programs in order to take advantage of advanced placement courses or other course offerings not available in the deaf school.

<sup>&</sup>lt;sup>a</sup>Separate classroom is not an available category for students aged 6 to 21.

<sup>&</sup>lt;sup>b</sup>Other may include placement in a private school by parents or residential or correctional facilities, home or hospital environments, or service provider locations.

<sup>&</sup>lt;sup>c</sup>Data that are unavailable were either not reported to Education or suppressed to limit disclosure due to the small number of children

Early Exposure to Language and an Individually Tailored Education Are Vital to Developing Language and Literacy Skills

Early Access to Language Helps Deaf and Hard of Hearing Children Build Language and Literacy Skills Experts we spoke with stated that it is important to expose deaf and hard of hearing children to language as early as possible in life. They told us that the first few years of a child's life are the most critical for learning language because it is during this time when the brain is rapidly developing that it is easiest to learn language. Several educators we spoke with shared stories of deaf children who did not receive services until later in childhood and subsequently lagged behind. Officials at one school also said that the age at which children are first exposed to language is a good predictor of their future language skills. Research into language development bears this out. One study examining children with moderate to profound hearing loss compared those who were exposed to language through an early intervention program before they were 3 months of age with those who enrolled later. The study found that by the time these children were 12 to 16 months old, those who started earlier were already demonstrating more advanced language skills.<sup>31</sup>

The benefits of early language exposure are not tied to any one language or communication mode. Experts we interviewed agreed that early exposure aids deaf and hard of hearing children in the acquisition of language skills, whether the language is signed or spoken. A study focusing on children with cochlear implants found that those who received an implant before 2 ½ years of age developed speech more rapidly and had better pronunciation and vocabulary than children who

<sup>&</sup>lt;sup>31</sup>Marianne Ahlgren, Julie Jodoin-Krauzyk, Mary Jane Johnson, Deborah Topol, Richard Tucker, and Betty Vohr, "Early Language Outcomes of Early-Identified Infants With Permanent Hearing Loss at 12 to 16 Months of Age," *Pediatrics*, vol. 122, no. 3 (2008).

received an implant at an older age.<sup>32</sup> Similarly, research indicates that children exposed to sign language early and consistently develop larger vocabularies more quickly than those who are not.<sup>33</sup>

Experts and advocates we interviewed also indicated that it is important for parents to have access to information on the full range of communication options. They told us that informed parents are better able to make decisions about communication modes and assistive technologies that meet the needs of their children. In laying out principles for EHDI programs, the Joint Committee on Infant Hearing<sup>34</sup> in 2007 stated that families should be made aware of all communication modes and available assistive hearing technologies. The committee added that a family's decision-making process should be guided by informed choices and desired outcomes. Because children can benefit from early intervention regardless of their communication mode, knowing the range of options can help a family make a decision that best suits its needs.

Education Should Be Individualized, Including Delivery by Qualified Professionals with Knowledge of Hearing-Related Issues Educators and advocates we spoke with told us that deaf and hard of hearing children should have an education tailored to their individual abilities and needs. These experts told us that because the needs of deaf and hard of hearing children can vary widely, there should not be one standard approach for educating them. The provision of an individualized education for all children with disabilities based on their unique needs is a key requirement of IDEA. In addition, Education has issued guidance<sup>35</sup> to help ensure that the unique communication and related services needs of deaf and hard of children are addressed. We observed examples of schools providing individualized and flexible approaches during our visits to states. In one regional program in Massachusetts, students have the opportunity to take classes in regular classrooms with other high school students, but may spend part of their time in separate classrooms for

<sup>&</sup>lt;sup>32</sup>Carol McDonald Connor, Holly K. Craig, Krista Heavner, Stephen W. Raudenbush, and Teresa A. Zwolan, "The Age at Which Young Deaf Children Receive Cochlear Implants and Their Vocabulary and Speech-Production Growth: Is There an Added Value for Early Implantation?" *Ear and Hearing*, vol. 27, no. 6 (2006).

<sup>&</sup>lt;sup>33</sup>Amy R. Lederberg and Patricia E. Spencer, "Word-Learning Abilities in Deaf and Hard-of-Hearing Preschoolers: Effect of Lexicon Size and Language Modality," *Journal of Deaf Studies and Deaf Education*, vol. 14, no. 1 (2009).

<sup>&</sup>lt;sup>34</sup>For the committee's policy, see *Pediatrics*, vol. 120, no. 4 (2007).

<sup>&</sup>lt;sup>35</sup>Deaf Students Education Services; Policy Guidance, 57 Fed. Reg. 49,274 (Oct. 30, 1992).

subjects where they need extra help. Also, we visited a school in Colorado where children receive additional help in writing and vocabulary every other day in a resource center.

Educators and advocates also highlighted the importance of having staff with knowledge of hearing-related issues to provide services to deaf and hard of hearing students. Guidance from the National Association of State Directors of Special Education notes that it is important that audiologists in schools have specific training to work with these students and that teachers who work with this population also be trained in deaf education. Additionally, advocates noted that having skilled interpreters is especially important for deaf children in regular classrooms because they rely on these interpreters to accurately convey to them what is being taught in the classroom.

Limited Information and Resources are Challenges to Providing Appropriate Interventions to Children

Parents May Lack Information on How to Address the Specific Needs of Their Children Experts told us that parents do not always have access to information on the full range of available communication options. Several said that the first service provider with whom parents consult after their child is identified as having hearing loss can have a significant influence on the choices parents make, especially if they do not receive balanced information on a range of options. For example, if the family is first referred to an audiologist, experts were concerned that parents would choose a cochlear implant for their child rather than continue learning about other options such as sign language.

<sup>&</sup>lt;sup>36</sup>National Association of State Directors of Special Education, Inc., *Meeting the Needs of Students Who Are Deaf or Hard of Hearing: Educational Services Guidelines* (Alexandria, Va, July 2006).

Some experts we interviewed were also concerned that parents of deaf and hard of hearing children may struggle to understand the information needed to make language and communication decisions for their children. The majority of these children are born to hearing parents, and as such, experts commented that families often do not know how to address the specific needs of their children. For instance, several officials we spoke with noted that many parents do not understand the importance of enrolling their children in early intervention services. To illustrate, 2008 data from CDC show that about 24 percent of children with a hearing loss eligible for early intervention services did not enroll in them.<sup>37</sup> As noted previously, early intervention services can have a significant impact on the development of a child.

Efforts to help parents make informed decisions for their deaf and hard of hearing children vary. For example, Colorado officials said state law requires cases of infants identified with a hearing loss to be referred to a hearing resources coordinator. This coordinator may meet with the family, explain the communication and service options available to the child, and refer the child to follow-up services. Similarly, Washington state officials told us that their state uses family resource coordinators to provide families with objective information about options and help them access services. In contrast, a national group of educators told us that most states lack a centralized contact and do not track children to ensure they receive follow-up services after being identified.

In addition to state efforts, some federal requirements concerning educating parents also exist. IDEA requires each state to have a public awareness program focused on the early identification of infants and toddlers with disabilities and a central directory that includes information on early intervention services and resources in the state. Additionally, Education funds Parent Training and Information Centers across the nation to provide parents of children with disabilities—including those who are deaf and hard of hearing—with training and information on working with early intervention and special education providers to meet the needs of their children.

 $<sup>^{37}\!2008</sup>$  CDC EHDI Hearing Screening & Follow-up Survey. These data were reported from 44 states.

Agencies are Taking Steps to Address Data Limitations That Hinder Evaluation of Early Interventions

Limited data may hinder the ability of states to evaluate the effectiveness of early intervention programs for deaf and hard of hearing children. The EHDI law directs HRSA to award grants or form cooperative agreements with states to monitor, among other things, the effectiveness of early interventions for children with hearing loss. Similarly, the law calls on CDC to award grants or form cooperative agreements to provide technical assistance with data collection for EHDI programs and to study the effectiveness of early intervention programs. State EHDI programs currently collect some outcome data, such as the number of children who are eligible for and enroll in early intervention. However, because early intervention services are provided under IDEA Part C, EHDI programs generally do not have access to the information on individual children needed to evaluate these interventions. State IDEA Part C programs are required to collect some outcome data on the children they serve. For example, state Part C programs collect information on the acquisition and early use of language among infants and toddlers receiving services as well as the number of children who receive assistance to transition out of Part C early intervention into Part B special education services. According to the National Center for Hearing Assessment and Management (NCHAM), such data could help state EHDI programs evaluate early intervention outcomes, but federal privacy laws and regulations may prohibit state EHDI programs from obtaining these data from state Part C programs. For instance, NCHAM states that IDEA Part C regulations prohibit programs from sharing personal information about children with anyone who is not a participating Part C service provider without written consent from parents.<sup>38</sup>

Federal agencies are taking a number of steps to help state EHDI programs obtain data they need on early intervention outcomes. For example, CDC is funding a study in a limited number of states to explore the feasibility of creating data management systems that enable states to collect data on developmental outcomes for deaf and hard of hearing children. The results of this study should be published by the end of fiscal year 2011, and CDC told us that the principal investigator has applied for additional funding in order to continue work in this area. Additionally, CDC, HRSA, and Education have provided technical assistance to NCHAM in identifying a number of recommended practices for helping state EHDI and Part C programs share data in a manner that is consistent with

<sup>&</sup>lt;sup>38</sup>National Center for Hearing Assessment and Management, *The Impact of Privacy Regulations: How EHDI, Part C, & Health Providers Can Ensure that Children & Families Get Needed Services* (Logan, Utah, May 2008).

applicable privacy restrictions. These practices include implementing memorandums of agreement between EHDI and Part C programs specifying procedures for obtaining consent from parents to allow agencies to share data about their children.

Shortages of Qualified Professionals and the Availability of Resources May Hinder Schools from Providing Appropriate Services

Experts told us that early intervention service providers and schools have trouble attracting and retaining qualified staff. Several of them told us that schools and service providers have difficulty retaining teachers, interpreters, and other staff because these professionals can receive better pay outside of the education system. Experts also told us that there is a shortage of teachers for the deaf and that the number of training programs for these professionals is decreasing. Poorly trained interpreters can also be a barrier to student learning because not all states have proficiency requirements for interpreters. For example, officials in Colorado said the state requires educational interpreters to demonstrate competency by meeting a minimum score on a proficiency test, whereas officials in Washington state told us that they have no comparable requirement for interpreters. More generally, officials from the Registry of Interpreters for the Deaf (RID) told us that according to published research, only about 20 percent of individuals taking the Educational Interpreter Performance Assessment (EIPA)<sup>39</sup> meet state standards or RID's standards.

Parents, educators, and advocates agree that while decisions about a child's education should be based on his or her unique needs as required by IDEA, the cost or availability of services often determines what a child receives. Some of these stakeholders said that schools may be hesitant to provide particular special education services because the costs incurred are prohibitive. For example, a school district may have to pay tuition for a child if the child attends a program outside the school district in order to have his or her needs met. Also, educators and advocacy groups said schools may prefer to place children in a program the school already offers in order to keep down costs. However, IDEA requires schools to provide an individualized education to children and to obtain input from a team, including knowledgeable school staff and parents, when making decisions about how to meet a child's needs. Additionally, IDEA requires school districts and states to provide recourse for parents who do not

<sup>&</sup>lt;sup>30</sup>The EIPA test was developed by the Boys Town National Research Hospital and uses skilled deaf and hearing raters to provide diagnostic services for individual interpreters, states, educational settings and school districts. RID considers a score of 4.0 or higher on the EIPA as qualifying for RID certification.

agree with individualized education program decisions for their child, including the ability to seek a due process hearing.

Experts also noted that providing services in rural areas is especially challenging. Hearing loss occurs in a small percentage of children and as such, there may be few deaf children in a given area. One expert noted that in some rural areas, it is not uncommon to have only one or two deaf children per county. In these cases, children may not have access to the same level of expertise or services as children in urban areas. For example, a Washington state official said that a rural county in that state had only one special education teacher to serve children with a range of disabilities and the one available speech-language therapist did not have a background in hearing loss issues.

## Concluding Observations

The newly reauthorized EHDI law acknowledges the importance of early access to services for children with hearing loss, in part, by encouraging states to increase follow-up rates for newborns and infants who fail a hearing screening. Meeting the needs of deaf and hard of hearing children requires an approach that begins early and is tailored to each child's needs. Given the impact that early intervention can have on a child's development and future self-sufficiency, and the level of federal funding devoted to it, the evaluation of the effectiveness of early intervention is crucial. The federally funded effort to facilitate these state evaluations is an important step and may, over time, help inform the effectiveness of early interventions for deaf and hard of hearing children.

## **Agency Comments**

We provided a draft of this report to Education and HHS for review and comment. Both agencies provided technical comments, which we incorporated into the report, as appropriate.

We are sending copies of this report to the Secretaries of Education and HHS, relevant congressional committees, and other interested parties. In addition, the report will be available on GAO's Web site at <a href="http://www.gao.gov">http://www.gao.gov</a>.

If you or your staff have any questions about the report, please contact me at (202) 512-7215 or scottg@gao.gov. Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this report. GAO staff that made major contributions to this report are listed in appendix IV.

George A. Scott, Director Education, Workforce, and

Leonge A. Scott

Income Security Issues

## Appendix I: Scope and Methodology

To obtain information on the extent of hearing loss among children in the United States, we analyzed recent available data on hearing loss in children from hearing tests and three Department of Health and Human Services' (HHS) surveys from 2005 to 2009. Specifically, we analyzed hearing test data from the Early Hearing Detection and Intervention program on newborns and infants up to 12 months and from the National Health and Nutrition Examination Survey's hearing examinations of 12–17 year olds. We also analyzed survey data from the National Health Interview Survey, National Health and Nutrition Examination Survey, and the National Survey of Children's Health (see table 3). We evaluated these federal surveys for methodological rigor, as well as to determine the extent to which the data could be used to offer a national perspective on children with hearing loss. We determined that the data were sufficiently reliable for our purposes. Because the survey data were collected using generalizable, probability samples, this sample is only one of a large number of samples that might have been selected. Since each sample could provide different estimates, we have used 95 percent confidence intervals to show the precision of our results. All percentage estimates used in this report have 95 percent confidence intervals of within plus or minus 4 percentage points, unless otherwise noted.

| Survey   | Purpose  | Age group analyzed <sup>a</sup>   | Web sites, as of April 12, 2011         |
|--|--|---|---|
| National Health<br>Interview Survey                    | To serve as the principal source of information on the health of the civilian noninstitutionalized population of the United States                     | Children aged 0-17<br>years   | http://www.cdc.gov/nchs/nhis.htm        |
| National Health and<br>Nutrition Examination<br>Survey | To assess the health and nutritional status of adults and children in the United States, through a combination of interviews and physical examinations | Interview surveys of<br>children aged 0–17;<br>hearing examinations of<br>youth 12–17 years | http://www.cdc.gov/nchs/nhanes.htm      |
| National Survey of<br>Children's Health                | To examine the physical and emotional health of children   | Children aged 0-17<br>years   | http://www.cdc.gov/nchs/slaits/nsch.htm |

Source: GAO analysis of HHS surveys.

<sup>a</sup>For the purposes of our analysis.

To identify factors associated with the development of language and literacy for deaf and hard of hearing children, we spoke to a variety of national experts, representing educators, parents, and the deaf community, and solicited written comments from a variety of national organizations representing a spectrum of views on deaf education (see table 4).

| Table 4: Organizations | Interviewed or | Providing | Written II | nput |
|------------------------|----------------|-----------|------------|------|
|                        |                |           |            |      |

#### Organization

Alexander Graham Bell Association for the Deaf and Hard of Hearing

National Association of the Deaf

American Society for Deaf Children

National Cued Speech Association

Convention of American Instructors of the Deaf

Registry of Interpreters for the Deaf

National Association of State Directors of Special Education

Conference of Educational Administrators of Schools and Programs for the Deaf

American Speech-Language-Hearing Association

The Laurent Clerc National Deaf Education Center at Gallaudet University

Center for ASL/English Bilingual Education and Research

Hands & Voices

The Association of College Educators-Deaf and Hard of Hearing

American Academy of Audiology

Source: GAO.

We searched numerous databases—including the Education Resources Information Center, the Cumulative Index to Nursing and Allied Health Literature, Electronics Collections Online, ProQuest, and numerous social science and medical literature databases on the Dialog platform—in order to identify recent studies on factors that have been shown to promote language and literacy development for deaf and hard of hearing children. We also consulted with national experts to identify relevant studies. As a result, we identified 159 studies published from 2005 through 2010. We limited the scope of our work by looking at studies that met the following criteria: (1) original research published since 2005, (2) based in the United States, (3) included five or more participants, and (4) related to a single disability. Through further review, we found that 26 published studies fell within our scope. Therefore, our results are not an exhaustive or historical treatment of the topic. We conducted detailed reviews of these 26 studies. Our reviews entailed an assessment of each study's research methodology, including its research design, and analytic techniques, as well as a summary of each study's major findings and conclusions. We also assessed the extent to which each study's data and methods support its findings and conclusions.

To identify the challenges that exist to providing appropriate interventions for deaf and hard of hearing children, we reviewed relevant federal laws and regulations for the Early Hearing Detection and Intervention program and the Individuals with Disabilities Education Act (IDEA), and interviewed federal officials responsible for administering these programs. We also spoke to a variety of national organizations and conducted site visits to Colorado, Massachusetts, and Washington state to learn more about the experiences educators and others have had with educational and other services for deaf and hard of hearing children. We selected these states because they vary in terms of the percentage of deaf and hard of hearing children educated in regular classrooms, the educational focus of their state school for the deaf, and their geography. During these visits, we solicited input from a variety of groups and individuals, including state agencies responsible for overseeing IDEA Part C and Part B programs, school district and school administrators, and teachers. We visited a variety of schools encompassing differences in setting (residential, regional programs, children in self-contained classrooms, and children in regular classrooms) and mode of communication (sign language and auditory or oral). In addition, we interviewed 28 parents of deaf and hard of hearing students during our site visits to learn about their experiences and the challenges they face. Local organizations within the states we visited organized meetings of parents who volunteered to meet with us.

We conducted this performance audit from March 2010 to May 2011 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

<sup>&</sup>lt;sup>1</sup>Massachusetts does not have a state school for the deaf.

# Appendix II: Summary of Key Provisions of IDEA Part C and Part B Programs

|   | Part C  | Part B  |
|---|---|---|
| Who is eligible for services?   | An infant or toddler with a disability, under 3 years of age, who is experiencing a developmental delay or has a diagnosed condition that has a high probability of resulting in a developmental delay.   | A child, aged 3–21, with a disability that falls into at least 1 of 10 categories, including hearing impairments, that adversely affects the child's educational performance, and as a result is determined to require special education services. <sup>a</sup>                     |
| What is included in a child's individualized family service plan or individualized education program? | An individualized family service plan should include, among other things, a written assessment of the child's development, acknowledgment of the family's priorities, measurable outcomes and results for the child, and the specific early intervention services to be provided. | An individualized education program should include, among other things, a written assessment of the child's level of performance and academic achievement; measurable annual goals, including academic goals; and the special education services and accommodations to be provided. |
| Where does a child receive services?  | To the maximum extent appropriate, early intervention services should be provided in a child's natural environments, including the home, and community settings where children without disabilities participate.  | Under the principle of least restrictive environment, to the maximum extent appropriate, children with disabilities should be educated with children who are not disabled.  |

Source: GAO analysis of IDEA, as amended, and implementing regulations found at 34 C.F.R. Part 303 (Part C) and 34 C.F.R. Part 300 (Part B).

<sup>a</sup>The 10 categories are intellectual disabilities, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, and specific learning disabilities.

# Appendix III: National Survey Estimates of Hearing Loss for Children Aged 0–17

| Survey  | Years         | Survey question   | Percentage of children,<br>Aged 0–11, experiencing<br>at least a little trouble<br>hearing or told they had<br>hearing problems | Percentage of children,<br>Aged 12–17, experiencing<br>at least a little trouble<br>hearing or told they had<br>hearing problems |
|---|---------------|---|---|--|
| National Health<br>and Nutrition<br>Examination<br>Survey | 2005–<br>2008 | Which statement best describes {the sample child's} hearing (without a hearing aid)? Would you say {your/his/her} hearing is excellent, good, that {you have/s/he has} a little trouble, moderate trouble, a lot of trouble, or {are you/is s/he} deaf? | 3.3%  | 5.3%   |
| National Health<br>Interview Survey                       | 2008–<br>2009 | Which statement best describes {the sample child's} hearing without a hearing aid: Excellent, good, a little trouble hearing, moderate trouble, a lot of trouble, or is {the child} deaf?   | 2   | 2.5  |
| National Survey of<br>Children's Health                   | 2007          | Has a doctor or other health care provider ever told you that {the sample child} had hearing problems?  | 2.9   | 3.1  |

Source: GAO analysis of HHS surveys.

# Appendix IV: GAO Contact and Staff Acknowledgments

#### **GAO Contact**

George A. Scott, (202) 512-7215 or scottg@gao.gov

## Staff Acknowledgments

Clarita Mrena (Assistant Director), Avani Locke (Analyst-in-Charge), Daniel R. Concepcion, and Alana Miller made significant contributions to all aspects of this report. Jean McSween helped develop our methodology and reviewed relevant research. Ying Long, Karen O'Conor, and Vanessa Taylor analyzed data, and Leia Dickerson and Ashley McCall assisted with our literature search. Kathleen van Gelder provided writing assistance, and James Bennett helped develop our graphics. Also, Jessica Botsford provided legal assistance and Ashanta Williams verified the material in this report.

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