

**United States Government Accountability Office** 

Report to the Ranking Member, Committee on Education and the Workforce, House of Representatives

July 2014

# SPECIAL EDUCATION

Additional Federal Actions Could Help Address Unique Challenges of Educating Children in Nursing Homes

# GAO Highlights

Highlights of GAO-14-585, a report to the Ranking Member, Committee on Education and the Workforce, House of Representatives

### Why GAO Did This Study

Although nursing homes typically care for elderly or disabled adults, some children with disabilities also live in these homes. Because these children live away from their families, they may be less connected to local schools and may not receive the education benefits to which they are entitled. GAO was asked to study the delivery of education to children in nursing homes.

GAO examined (1) the characteristics of children in nursing homes, (2) how such children are referred for and receive education, (3) the challenges in delivering services to these children, and (4) monitoring of the education of children in nursing homes. GAO analyzed national nursing home data on children, surveyed all state special education directors, reviewed relevant federal laws and regulations, and interviewed federal officials. GAO also visited nursing homes and school districts in three states selected to include a large percentage (42 percent) of children in nursing homes nationwide.

#### What GAO Recommends

GAO recommends that Education develop information sharing mechanisms for teachers of these children and that Education and HHS strengthen their monitoring efforts. Education agreed with the first recommendation. For the second, Education and HHS agreed to further collaborate, but expressed concerns about creating an oversight structure. However, GAO recommends using existing means of oversight.

View GAO-14-585. For more information, contact Melissa Emrey-Arras at (617) 788-0534 or emreyarrasm@gao.gov.

### SPECIAL EDUCATION

### Additional Federal Actions Could Help Address Unique Challenges of Educating Children in Nursing Homes

### What GAO Found

Children in nursing homes represent a relatively small group of children whose medically complex conditions often present unique educational challenges. Of the nearly 5,000 school-age children in nursing homes nationwide, about 40 percent needed a feeding tube for nutrition and one-third needed oxygen therapy to help them breathe, according to GAO's analysis of 2012 data—the most recent data available—from the Department of Health and Human Services (HHS). Consistent with 2012 data, GAO observed on recent site visits that these children also had conditions that affected learning. For example, many children GAO observed at the nursing homes were nonverbal and minimally responsive. Because of their complex medical needs, these children often stayed in nursing homes for long periods of time—about one-third of them for more than a year, according to GAO's analysis of HHS data.

States GAO visited required nursing homes to refer children to school districts for educational services, and in nursing homes GAO visited, staff typically collaborated with school district officials to help them understand the children's needs. Because of the children's medical fragility, education services were delivered primarily in classrooms at the nursing homes or one-on-one (often bedside), with a few children transported to local schools. Teachers that GAO observed used assistive technology and other methods to aid instruction.

State and local school officials reported challenges to serving children living in nursing homes, including curricula development and teacher training. In GAO's nationwide survey, 31 states indicated having adequate training for teachers was a challenge. According to school officials GAO interviewed, teachers may not be fully prepared to teach children with profound disabilities, and several teachers said they could benefit from the experiences of other teachers about how best to serve these children. While the Individuals with Disabilities Education Act (IDEA) recognizes the importance of information sharing to improve educational results for children, current technical assistance efforts supported by the Department of Education (Education) do not include mechanisms for teachers to share best practices about how to serve children with significant cognitive and multiple disabilities. Such information sharing about effective approaches and strategies could help teachers of children in nursing homes be more fully prepared to provide children with education commensurate with their unique needs.

Education and HHS have different, yet complementary, monitoring responsibilities with respect to children in nursing homes. Education monitors state compliance with the IDEA requirement to provide a free appropriate public education in the least restrictive environment, and HHS oversees state nursing home inspections. Although collaboration between agencies with a common interest is a key practice, these agencies do not coordinate their monitoring efforts with respect to the education of these children. The relatively small size of this population makes it difficult for Education and states to gather information on whether these children receive education that meets IDEA requirements. Coordinated efforts between the two agencies could help close any potential gaps in Education's monitoring and help ensure that all children in nursing homes receive an education.

# Contents

Letter		1
	Background School-Age Children in Nursing Homes Are a Relatively Small, Medically Complex Population Who Often Stay in Homes for	4
	Long Periods of Time Nursing Homes We Visited Referred Children for Special Education and Children Typically Received Educational	12
	Services On-Site State and Local Officials Cite Challenges in Teaching and Paying	19
	for Special Education Services for Children in Nursing Homes The Relatively Small, Dispersed Population of Children in Nursing Homes Complicates State and Federal Monitoring under IDEA	27 33
	Conclusions	37
	Recommendations	37
	Agency Comments and Our Evaluation	38
Appendix I	Objectives, Scope, and Methodology	41
Appendix II	Number of School-Age (6 through 21) Children Living in Nursing Homes by State, Calendar Year 2012	47
Appendix III	State Performance Report Indicators and Data Collection Topics Used by Education to Monitor Compliance with Part B of the Individuals with Disabilities Education Act	49
	Data Collection Topics for States' Direct Reporting of Special Education Monitoring Data	50
Appendix IV	Comments from the Department of Education	51
Appendix V	Comments from the Department of Health and Human Services	54
Appendix VI	GAO Contact and Staff Acknowledgments	56

#### Tables

Table 1: Key Roles of the Department of Education and the	
Centers for Medicare & Medicaid Services with Respect to Children in Nursing Homes	6
Table 2: Educational Environment Categories and Definitions used by Education in Individuals with Disabilities	
Education Act Monitoring	10
Table 3: Selected Medical Conditions of School-Age Children	
(6 through 21) in Nursing Homes, Calendar Year 2012	15
Table 4: Selected Special Medical Devices and Treatments of	
School-Age Children (6 through 21) in Nursing Homes,	
Calendar Year 2012	16
Table 5: Centers for Medicare & Medicaid Services Select Nursing         Home Regulations and Guidance on Quality of Life and	
Activities	35
Table 6: Indicators and Definitions Used in State Performance	
Plans and Annual Performance Reports	49

### Figures

FIgure 1: Key Federal, State, and Local Responsibilities under the Individuals with Disabilities Education Act	9
Figure 2: Total Number of School-Age Children (6 through 21) in Nursing Homes by Age Groupings, Calendar Year 2012	13
Figure 3: Distribution of Number of School-Age Children (6 through 21) in Nursing Homes across States, Calendar	
Year 2012	14
Figure 4: Illustration of How Nursing Homes Assist School Districts in Referring Children for Special Education Services in	
the Nursing Homes We Visited	20
Figure 5: Where Children Living in Nursing Homes We Visited	
Receive Educational Services	22
Figure 6: Setting Where Educational Services Are Provided to Majority of Children Living in Nursing Homes, According	
to Survey of State Special Education Directors	23
Figure 7: Example of Sensory Box in a Lesson on Seasons for	
Children in Nursing Home We Visited	25
Figure 8: Teaching Challenges to Serving Children Living in Nursing Homes, According to Survey of State Special	
Education Directors	28

Figure 9: Challenges Related to Cost and Availability of Special Education Service Providers for Children Living in Nursing Homes, According to Survey of State Special Education Directors

31

#### Abbreviations

- ADA Americans with Disabilities Act
- CMS Centers for Medicare & Medicaid Services
- HHS Department of Health and Human Services
- IDEA Individuals with Disabilities Education Act
- IEP Individualized Education Program
- MDS Minimum Data Set
- SSA Social Security Act
- SSI Supplemental Security Income

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U.S. GOVERNMENT ACCOUNTABILITY OFFICE

441 G St. N.W. Washington, DC 20548

July 16, 2014

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

Dear Mr. Miller:

Although nursing homes are medical facilities that typically care for elderly or disabled adults, a relatively small number of children (less than half a percent of nursing home residents) also live in these facilities. Children with disabilities who live in nursing homes are a vulnerable population about whom little is known. States are required under the Individuals with Disabilities Education Act (IDEA), administered by the Department of Education (Education), to make available to all children with disabilities a free appropriate public education that emphasizes special education and related services that, among other things, are designed to meet the unique needs of each child.<sup>1</sup> The law also requires states to ensure that children with disabilities are educated in the least restrictive environment, meaning, to the maximum extent appropriate, in classes with children who are not disabled.<sup>2</sup> Because these children live away from their families, and may enter nursing homes from a hospital or through a child welfare or health agency, there are concerns that these children may not always be connected to the educational system or receive the educational services required by IDEA. A September 2012 Department of Justice (Justice) investigation of children living in Florida nursing homes brought attention to the issue of children living in nursing

<sup>&</sup>lt;sup>1</sup> 20 U.S.C. § 1400(d)(1)(A). Related services are defined as transportation and such developmental, corrective, and other supportive services as may be required to assist a child with a disability to benefit from special education. Related services also include the early identification and assessment of disabling conditions in children. 20 U.S.C. § 1401(26)(A).

<sup>&</sup>lt;sup>2</sup> 20 U.S.C. § 1412(a)(5).

homes.<sup>3</sup> Although the focus of the Florida investigation was the state's compliance with the Americans with Disabilities Act (ADA), the investigation noted that many children were offered less than 1 hour per day of educational activities, raising questions regarding how Education and states ensure that children living in nursing homes are receiving educational services required under IDEA.

In light of these issues, the Ranking Member, House Committee on Education and the Workforce, asked for information on the educational services provided to children living in nursing homes. We examined (1) the characteristics of school-children who live in nursing homes, (2) how such children are referred for special education services and how services are delivered, (3) the challenges states and localities face in delivering special education services to these children in the least restrictive environment, and (4) the monitoring of the education of schoolage children in nursing homes.

We used multiple methodologies to address these objectives. To determine the characteristics of school-age children living in nursing homes, we analyzed administrative data on nursing home residents from the Department of Health and Human Services' (HHS) Minimum Data Set (MDS) for calendar year 2012. The MDS is part of the federally mandated process for clinical assessment of all residents in Medicare- and Medicaid-certified nursing homes. The data set provides demographic information about patients residing in Medicare- and Medicaid-certified nursing homes as well as information on residents' overall health and functionality. We used the MDS data to analyze the demographics of child residents as well as their health and functionality, such as active medical diagnoses, medical treatments, and duration of their residence in nursing homes. We assessed data reliability by reviewing existing information about the data system, conducting electronic testing, and interviewing federal and state health care agency officials. We determined that the data were sufficiently reliable for the purposes of this report. To obtain information on the monitoring of these children's education and

<sup>&</sup>lt;sup>3</sup> The Department of Justice report assessed the state's compliance with Title II of the Americans with Disabilities Act (ADA), as interpreted by the Supreme Court's decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999), which requires public entities to ensure that individuals with disabilities receive services in the most integrated setting appropriate to their needs. The report found that Florida failed to meet its obligations under Title II of the ADA by unnecessarily institutionalizing hundreds of children with disabilities in nursing homes. Compliance with the ADA is beyond the scope of this report.

information about challenges, we conducted a nationwide web-based survey of state special education directors from September to December 2013, and received responses from all 50 states and the District of Columbia. In addition, we reviewed relevant federal laws, regulations, and guidance and we interviewed federal officials at Education, HHS, and Justice. To obtain further information on children's characteristics and to assess educational services and any challenges, we visited three states—California, New York, and Texas—that collectively accounted for 42 percent of all children living in nursing homes in 2011.<sup>4</sup> Within these states, we visited two or three nursing homes as well as school districts in which the nursing homes were located. Our criteria for selecting states included the number of school-age children in special education, number and percentages of pediatric residents in nursing homes, and geographic location. We also selected a mix of nursing homes that serve only pediatric patients and those that serve both pediatric and geriatric patients. During these visits, we interviewed nursing home administrators and social workers, school district officials, special education teachers, and parents of children living in nursing homes, and we observed the educational instruction for these children. For each state we visited, we also interviewed state and local special education officials as well as the health agencies responsible for conducting nursing home inspections. In visiting nursing homes, we focused on the education of children under IDEA, not compliance with the Americans with Disabilities Act, which was beyond the scope of this report.<sup>5</sup> Finally, using our investigators, we posed undercover as the guardian of a child with complex medical conditions and called schools, school districts, and nursing homes.<sup>6</sup> Our goal in making these undercover calls was to explore the kinds of responses a parent might receive when trying to obtain information about the educational services provided to children who lived in nursing homes.

<sup>&</sup>lt;sup>4</sup> GAO analysis of 2011 data from the Department of Health and Human Services' (HHS) Centers for Medicare & Medicaid Services' (CMS) *Nursing Home Data Compendium*, 2012, the latest compendium data available.

<sup>&</sup>lt;sup>5</sup> The Americans with Disabilities Act of 1990 prohibits discrimination against and ensures equal opportunity for persons with disabilities in employment, state and local government services, public accommodations, commercial facilities, and transportation. The Individuals with Disabilities Education Act (IDEA) generally provides funding to states and school districts for early intervention and special education and related services for children with disabilities.

<sup>&</sup>lt;sup>6</sup> We primarily called nursing homes that we visited as well as selected other nursing homes.

In particular, we were interested in learning the educational setting suggested for the child, as well as the types of educational and related services the child might receive in a local school or the nursing home. (See app. I for more information on our methodology.)

We conducted this performance audit from March 2013 through July 2014 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. We conducted our related investigative work in accordance with standards prescribed by the Council of Inspectors General on Integrity and Efficiency.

### Background

Children in Nursing Homes	Although nursing homes are medical facilities that typically care for elderly or disabled adults, a relatively small number of children also live in these facilities. According to the Department of Health and Human Services (HHS), children represented less than a half a percent (0.2 percent) of the more than 1.4 million nursing home residents in the United States as of December 31, 2011. <sup>7</sup> Medicaid, the joint federal-state financing program for health care services for certain low-income		
	individuals, is the primary payer for long-term services and supports, including nursing home care. Medicaid accounted for about \$134 billion, or 61 percent, of spending for such long-term care services and supports for adults and children in 2012. <sup>8</sup> In all states, Medicaid covers the cost of		

<sup>&</sup>lt;sup>7</sup> HHS's Centers for Medicare & Medicaid Services' *Nursing Home Data Compendium*, 2012, which is the most recent data available.

<sup>&</sup>lt;sup>8</sup> National Health Policy Forum, *The Basics: National Spending for Long-Term Services and Supports (LTSS), 2012*, (The George Washington University, March 27, 2014). This total for long-term care services and supports excludes Medicare payments. Medicare generally does not cover long-term care stays in nursing homes, although Medicare may cover skilled nursing facility (SNF) care for a limited time after a qualifying hospital inpatient stay.

	nursing facility services for eligible children under age 21. <sup>9</sup> To qualify for Medicaid coverage for nursing home care, individuals, including children, must meet financial and other eligibility criteria. Financial eligibility is commonly established by receipt of Supplemental Security Income (SSI), <sup>10</sup> a federal program that provides cash benefits to low-income blind and disabled persons—including adults and children—who meet financial eligibility requirements and the program's definition of disability. <sup>11</sup> Many children living in nursing homes may receive SSI. Generally, they receive no more than \$30 a month in SSI benefits, though some states supplement that amount.
Monitoring and Oversight of Children in Nursing Homes	Education and the Centers for Medicare & Medicaid Services (CMS) within HHS both have monitoring and oversight responsibilities pertaining to the care of, and services provided to, children in nursing homes. Within Education, the Office of Special Education Programs is responsible for administering and monitoring IDEA, the primary federal law that addresses the special education and related service needs of children with disabilities, from birth through age 21. In addition, CMS is responsible for oversight of the quality of services for residents of Medicare- and Medicaid-certified nursing homes. CMS contracts with state health agencies to inspect these nursing homes for compliance with program requirements laid out in the Social Security Act and in CMS regulations. CMS's protocols for these state surveys assess not only nursing homes' adherence to medical standards, but also quality of life standards. Finally, Education is also responsible for enforcing certain civil rights laws that could affect the provision of education to children in nursing homes. <sup>12</sup>
	<sup>9</sup> Coverage for children in nursing homes is an optional service under Medicaid, although all states provide this service.
	<sup>10</sup> Not all Supplemental Security Income (SSI) recipients automatically qualify for Medicaid. Under Section 1902(f) of the Social Security Act, a state may use more restrictive Medicaid eligibility standards than SSI's standards, provided the standards are no more restrictive than those the state had in place as of January 1, 1972. 42 U.S.C. § 1396a(f)

<sup>11</sup> Eligibility may also be established by "spending down" family income on the child's medical costs to meet the state-determined income eligibility limit.

<sup>12</sup> The Department of Justice also enforces some civil rights laws that could affect these children. Compliance with civil rights laws, such as the Americans with Disabilities Act, is beyond the scope of this report.

Table 1: Key Roles of the Department of Education and the Centers for Medicare &
Medicaid Services with Respect to Children in Nursing Homes

	Agency	Responsibilities	
	Department of Education—Office of Special Education Programs	Monitors state compliance with Individuals with Disabilities Education Act (IDEA) <sup>a</sup> for children with disabilities in all educational settings	
	Department of Health and Human Services—Centers for Medicare & Medicaid Services	Contracts with states to inspect Medicare- and Medicaid-certified nursing homes <sup>b</sup>	
	Source: GAO analysis of information provided by the Dep	artments of Education and Health and Human Services.   GAO-14-585	
	Note: In addition, the Department of Education's Office for Civil Rights and the Department of Justice's Civil Rights Division play a role in enforcing civil rights laws for education programs.		
	<sup>a</sup> Codified at 20 U.S.C. § 1400 et seq.		
	<sup>b</sup> The Social Security Act (SSA) establishes requirements that nursing homes must meet in order to participate in Medicare and Medicaid, including promoting residents' quality of life. 42 U.S.C. §§ 1395i-3, 1396r.		
Special Education under IDEA	<ul> <li>\$12.6 billion was appropriated f authorizes grants to states under districts to provide services to s 21.<sup>13</sup> Under IDEA, Part D, Educt things, disseminate information to improve educational results f</li> <li>An essential component of IDEA the ages of 3 and 21 who meet to a free appropriate public edu</li> </ul>	A is that children with disabilities between IDEA's eligibility requirements are entitled	
	<sup>13</sup> For the purposes of the grants to states program under section 611 of the Individuals with Disabilities Education Act (IDEA) (20 U.S.C. § 1411), Education identifies school-age children as those ages 6 to 21. Section 619 of IDEA (20 U.S.C. § 1419) authorizes grants for preschool programs serving children with disabilities ages three through five. In addition, IDEA Part C authorizes Education to provide grants to states for early intervention services for infants and toddlers with disabilities (20 U.S.C. §§ 1431-1444), but those children are a population broader than those within the scope of this report.		
	<sup>14</sup> 20 U.S.C. §§ 1451(a), 1453(b)(5).		
	$^{15}$ In order to receive services under IDEA, a child must have a disability as defined in the Act. 20 U.S.C. § 1401(3).		

appropriate, these children are to be educated with other children who are not disabled.<sup>16</sup> Further, special classes, separate schooling, or other removal of children with disabilities from the regular classroom can occur only when the nature or severity of the child's disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily. School districts are also required to provide a continuum of educational environments, including regular classrooms, special classrooms, special schools, and instruction in other environments such as residential facilities, home, or hospital settings, or correctional facilities.<sup>17</sup> Students receive special education and related services, such as physical therapy, tailored to their needs based on an individualized education program (IEP).<sup>18</sup> An IEP is a written statement developed by a team of educational professionals, parents, and interested parties that includes a statement of the child's present levels of academic achievement, goals for progress, and a statement of the special education and related services needed to attain those goals.

The first step in providing a free appropriate public education to children with disabilities is identifying them. Each state must have in effect policies and procedures to ensure that all children with disabilities residing in the state who are in need of special education and related services are identified, located, and evaluated. These policies and procedures are referred to in statute as "Child Find."<sup>19</sup> School districts are responsible under Child Find for identifying students who may have a disability in the district by engaging in activities such as distributing informational brochures, providing public service announcements, and staffing exhibits at community events. School districts are also responsible for evaluating children's educational needs.

<sup>&</sup>lt;sup>16</sup> 20 U.S.C. § 1412(a)(5)(A). Least restrictive environment is determined individually for each child served under IDEA.

<sup>&</sup>lt;sup>17</sup> 34 C.F.R. §§ 300.39(a)(1)(i), 300.115(b)(1).

<sup>&</sup>lt;sup>18</sup> In general, related services under IDEA are transportation and those developmental, corrective, and other supportive services needed to help a child with a disability to benefit from special education. 20 U.S.C. § 1401(26). Related services include speech-language pathology services, physical and occupational therapy, and school nurse services, among others.

<sup>&</sup>lt;sup>19</sup> 20 U.S.C. § 1412(a)(3).

	Special education funding is used, among other things, to employ special education teachers; related service providers (such as physical or occupational therapists); and special education administrators; as well as spending on special transportation services and nonpersonnel items (such as materials, supplies, and technological supports). As reported in 2004, expenditures for special education nationwide for the 1999-2000 school year—the latest national data available—were estimated to be about twice the average spent on students without disabilities, and the cost of providing services to a child with disabilities tends to escalate for children who have multiple disabilities. <sup>20</sup> According to a recent report about special education in California, the average annual costs of educating a student with disabilities were more than double those of a nondisabled student in school year 2010-2011—approximately \$22,300 compared to \$9,600, and some students require intensive interventions that cost notably more than \$22,300 per year. <sup>21</sup> The 2004 IDEA reauthorization established high-cost funds—or risk pools—for high-need children with disabilities. States that decide to establish such a fund must reserve 10 percent of the IDEA funds reserved for other state activities to establish and maintain a risk pool to assist school districts serving high-need children. <sup>22</sup>
Monitoring States' Compliance with IDEA	Education monitors state compliance with IDEA, including ensuring compliance with the requirement to provide students with a free, appropriate public education in the least restrictive environment—one of three priority areas for Education's monitoring of IDEA. <sup>23</sup> In turn, states (generally state educational agencies) are required to monitor each of their school districts for IDEA compliance in both school and out-of-school educational environments and to report monitoring data to Education. States receive such required data from their school districts (see fig. 1).
	<sup>20</sup> American Institutes for Research, Special Education Expenditure Project, <i>What Are We Spending on Special Education Services in the United States, 1999-2000?,</i> June 2004. The Special Education Expenditure Project reports provide the latest national data available on special education spending.
	<sup>21</sup> Mac Taylor, Overview of Special Education in California, California Legislative Analyst's Office, January 3, 2013. www.lao.ca.gov
	<sup>22</sup> 20 U.S.C. § 1411(e)(3).
	<sup>23</sup> 20 U.S.C. § 1416(a)(3). The other two priority areas for monitoring are state exercise of general supervisory authority—which includes child find and effective monitoring—and the disproportionate representation of racial and ethnic groups in special education and related services.

### Figure 1: Key Federal, State, and Local Responsibilities under the Individuals with Disabilities Education Act



The Individuals with Disabilities Education Act (IDEA), Part B: Key Statutory and Regulatory Provisions, R41833 (Washington, DC: January 7, 2013). | GAO-14-585

<sup>a</sup> Under IDEA, the Department of Education may determine that a state needs intervention or substantial intervention, but we have combined these categories for simplicity.

<sup>b</sup> In addition to reporting to the Department of Education, states are required to report annually to the public on districts' performance.

Education has two key mechanisms to collect and review information on states' annual performance under IDEA: (1) direct reporting by states of detailed IDEA data through Education's data system and (2) performance reports that states submit to Education, providing an overview of state performance that year. Through the data system, states report data on several topics—such as child counts, educational environment, and

discipline—required under the law. <sup>24</sup> In the performance reports, states evaluate their IDEA performance against targets they set for each of 17 indicators.<sup>25</sup> (See app. III for a list of IDEA data collections and performance report indicators.) Each year, Education receives these IDEA data and performance reports from states.

For both types of reporting, data on the environments in which children receive education are a key tool for state and federal monitoring of the least restrictive environment requirement under IDEA.<sup>26</sup> Educational environment categories cover a range of regular classroom and out-of-school environments (see table 2).

# Table 2: Educational Environment Categories and Definitions used by Education in Individuals with Disabilities Education Act Monitoring

Reporting category	Description of children with disabilities included in category
Inside regular classroom 80 percent or more of the day	Children who receive special education and related services inside age-appropriate regular classrooms or community-based settings that include individuals with and without disabilities for 80 percent or more of the school day.
Inside regular classroom 40 percent to 79 percent of the day	Children who receive special education and related services inside age-appropriate regular classrooms or community-based settings that include individuals with and without disabilities for no more than 79 percent but no less than 40 percent of the school day.
Inside regular classroom less than 40 percent of the day	Children who receive special education and related services inside age-appropriate regular classrooms or community-based settings that include individuals with and without disabilities for less than 40 percent of the school day.

<sup>24</sup> 20 U.S.C. § 1418(a). States report these data in what is known as the "618 data collection," using the Department of Education's EDFacts data system. One of the topics on which states report data is children's educational environments.

<sup>25</sup> These 17 indicators are designed to measure state performance on the three IDEA priority areas. IDEA requires states to report annually on the state's performance under the state performance plan, which evaluates a state's efforts to implement the requirements and purposes of IDEA and describes how the state will improve implementation. 20 U.S.C. § 1416(b). Some, but not all, of the indicators use data also included in states' direct reporting of IDEA data.

<sup>26</sup> Least restrictive environment is determined on an individual basis by each child's individualized education program team.

Reporting category	Description of children with disabilities included in category
Parentally Placed in Private School	Children who have been enrolled by their parents or guardians in regular parochial or other private schools and whose basic education is paid through private resources and who receive special education and related services at public expense from a local educational agency or intermediate educational unit under a service plan.
Correctional Facility	Children receiving special education and related services in short-term detention facilities or correctional facilities.
Separate School	Children with disabilities receiving special education and related services, at public expense, for greater than 50 percent of the school day in public or private separate day schools for students with disabilities.
Homebound/Hospital	Children receiving special education and related services in hospital programs or homebound programs. Does not include children whose parents have opted to home-school them and who receive special education at the public expense.
Residential Facility	Children with disabilities receiving special education and related services, at public expense, for greater than 50 percent of the school day in public or private residential facilities, and who live at those facilities.

Source: Documentation provided by the Department of Education. | GAO-14-585

Education uses state performance reports and IDEA data—along with monitoring visits to states and other information<sup>27</sup>—to determine whether the state meets IDEA requirements or whether it needs assistance or intervention. Education also examines whether states have appropriate procedures in place to monitor school district compliance with IDEA. Education is currently undertaking a new initiative called Results-Driven Accountability, which is intended to increase focus on educational outcomes for students with disabilities. Education began soliciting

<sup>&</sup>lt;sup>27</sup> Education officials said they have conducted state monitoring visits in some form since 1977, but conducted what they called verification and continuous improvement visits from 1999 through 2011. Education is currently undertaking a new monitoring initiative and has most recently conducted pilot visits to select states as part of this initiative.

stakeholder input on this effort in 2012 and states will begin submitting performance plans and reports under this new initiative in 2015.<sup>28</sup>

School-Age Children in Nursing Homes Are a Relatively Small, Medically Complex Population Who Often Stay in Homes for Long Periods of Time	
School-Age Children in Nursing Homes Are a Small, Medically Complex Population	Although children in nursing homes represent a relatively small group of children, their medically complex conditions make them a unique population to educate. While children in nursing homes include children as young as infants and toddlers, of all children staying in nursing homes at any time during calendar year 2012, about half—nearly 5,000 children—were school-age children from ages 6 through 21, according to our analysis of CMS data. <sup>29</sup> School-age children living in nursing homes, the focus of this study, accounted for less than half a percent of all children with disabilities under IDEA for school year 2011-2012. <sup>30</sup> There
	<sup>28</sup> In technical comments provided to GAO on this report, Education officials said that under this new initiative, their latest round of state determinations, issued on June 23, 2014, focused on student outcomes in addition to compliance with requirements in the Individuals with Disabilities Education Act. Education will also require states to submit State Systematic Improvement Plans beginning in 2015.
	<sup>29</sup> A total of nearly 10,000 children lived in nursing homes at any time during calendar year 2012. Of those children, infants and toddlers aged birth to 2 years accounted for nearly half, or 4,650, children. Children aged 3 through 5 years accounted for nearly 5 percent, or 470 of children living in nursing homes in calendar year 2012. These figures are based on our analysis of CMS's Minimum Data Set (MDS) for calendar year 2012.
	<sup>30</sup> In the 2011-2012 school year, there were approximately 5.6 million children aged 6 through 21 years served under IDEA Part B, accounting for nearly 10 percent of children in that age group enrolled in school. The number of children served under IDEA is a point-in-time count in school-year 2011-2012, whereas our CMS analysis is an annual cumulative total anytime during calendar year 2012.

was almost an even split between the number of school-age children in nursing homes who were aged 6 through 18 years old-the age range generally considered as school age-and those who were 19 through 21.<sup>31</sup> (See fig. 2).

#### Figure 2: Total Number of School-Age Children (6 through 21) in Nursing Homes by Age Groupings, Calendar Year 2012



Source: GAO analysis of Centers for Medicare & Medicaid Services Minimum Data Set 3.0. | GAO-14-585

These children were spread out among nursing homes throughout the country. In calendar year 2012, eight states had 10 or fewer children living in nursing homes, according to our analysis of CMS data. Seven states, which tended to have the largest state populations, had more than 200 children in nursing homes, ranging from 210 in Indiana to 908 children in California. (See fig. 3.) (For individual state breakouts, see app. II.) In all of the nursing homes we visited, staff told us the children who lived in their home typically were residents of their state.

 $<sup>^{31}</sup>$  We are including children over the age of 18 in this study because services under IDEA are generally available to eligible students ages 3 through 21.

# Figure 3: Distribution of Number of School-Age Children (6 through 21) in Nursing Homes across States, Calendar Year 2012



Source: GAO analysis of Centers for Medicare & Medicaid Services Minimum Data Set 3.0. | GAO-14-585

School-age children living in nursing homes were often medically fragile and had complex, chronic medical conditions, with nearly 71 percent having at least two active disease diagnoses, according to our analysis of CMS data.<sup>32</sup> For example, nearly 37 percent of the children had seizures and 21 percent had cerebral palsy, both of which may be caused by brain abnormalities and result in conditions that range in severity from disabling, to ones that can be controlled with medications and supportive treatments. (See table 3.) Nursing home staff described children in the homes as having chronic conditions often resulting from genetic

<sup>&</sup>lt;sup>32</sup> The data field used in this analysis—"Active Disease Diagnosis"—requires a diagnosis documented by a physician (or by a nurse practitioner, physician assistant, or clinical nurse specialist if allowable under state licensure laws) in the last 60 days of an assessment. Once the diagnosis is identified, it must be determined if the disease is active within the last 7 days. Our analysis tested all assessment records for each child to determine whether the child had been diagnosed with a disease at any point of time from date of admission to a cut-off date of December 31, 2012.

disorders, birth trauma, a catastrophic accident, or the onset of a disease such as cancer.

## Table 3: Selected Medical Conditions of School-Age Children (6 through 21) in Nursing Homes, Calendar Year 2012

Medical Conditions <sup>a</sup>	Number of Children	Percent of Total <sup>b</sup>
Seizure or Epilepsy: chronic neurological disorder characterized by recurrent, unprovoked seizures	1,764	37
<b>Cerebral Palsy:</b> group of neurological disorders that appear in infancy or early childhood and permanently affect body movement and muscle coordination	1,021	21
<b>Respiratory Failure:</b> condition where not enough oxygen passes from lungs into blood or if the lungs cannot remove carbon dioxide from blood	621	13
Quadriplegia: paralysis of arms and legs	502	10
<b>Comatose:</b> state in which neither arousal (wakefulness, alertness) nor awareness exists	317	7
<b>Traumatic Brain Injury:</b> sudden trauma that causes damage to the brain	297	6

Source: GAO analysis of Centers for Medicare & Medicaid Services' Minimum Data Set 3.0. GAO-14-585

<sup>a</sup> The Individuals with Disabilities Education Act requires that states and school districts make available a free appropriate public education to all children with disabilities.

<sup>b</sup> Percents do not add up to a 100 percent because children could have more than one diagnosis.

In addition, children in nursing homes often needed special treatments or procedures to help them breathe and to prevent them from choking. For example, 25 percent of the children required the use of a tracheostomy tube and 32 percent needed oxygen therapy to help breathe, according to our analysis of CMS data.<sup>33</sup> (See table 4.) In nearly all of the nursing homes we visited, staff told us that their children had tracheostomy tubes and/or needed respiratory care to support breathing, as well as frequent suctioning to remove excess fluids and saliva to prevent choking. Staff at two nursing homes said that the children are prone to infections, which

<sup>&</sup>lt;sup>33</sup> A tracheostomy or trach tube is usually placed through the opening of the neck into the trachea (windpipe) to provide an airway and to remove secretions from the lungs. A tracheotomy may be done if the airway is blocked or because of a condition that makes it hard to breathe, such as paralysis of the muscles that affect swallowing or severe neck or mouth injuries.

could cause children to be isolated in their room without a roommate and require all services to be brought to the room.

## Table 4: Selected Special Medical Devices and Treatments of School-Age Children (6 through 21) in Nursing Homes, Calendar Year 2012

Special Treatments	Number of Children	Percent of Total
Oxygen therapy: continuous or intermittent oxygen administered via mask	1,517	32
<b>Suctioning:</b> removal of secretions (phlegm or mucus) or drainage from the patient's airway (trachea) or other part of the body	1,310	27
<b>Tracheostomy Care:</b> cleaning of trach tube used to provide an airway to help support breathing and secretion from the lungs	1,214	25
Ventilator: a machine used to support breathing by providing oxygen to lungs and removing carbon dioxide	681	14

Source: GAO analysis of Centers for Medicare & Medicaid Services' Minimum Data Set 3.0. | GAO-14-585

Note: Percents do not add up to a 100 percent because some children require the use of more than one medical device or treatment.

Because of their medical conditions, nearly 80 percent of the children needed extensive help or were totally dependent in carrying out at least one activity of daily living, according to our analysis of CMS data. For example, 72 percent could not use the toilet without extensive assistance from someone else; 69 percent could not move from one location to another (e.g., from bed to standing); and about 69 percent needed wheelchairs to move around. Further, 43 percent of the children required a feeding tube (such as a gastrostomy tube) to provide food, nutritional substances, fluids, or medicine into their bodies.

Compounding their complex medical needs, these children often also had conditions that affect learning. For example, about 21 percent of the children had at least one condition related to intellectual disability or developmental delay, such as Down syndrome; autism; epilepsy; or other intellectual disabilities, such as those resulting from other medical conditions incurred during pregnancy or birth. Further, many of the children also had difficulties communicating. Half of the children had difficulties being understood because they could not speak or their words were slurred or mumbled, according to our analysis of CMS data. In addition, half of the children also had difficulties understanding others.<sup>34</sup> Many children we observed at the nursing homes were non-verbal; were minimally responsive to others; and needed to use hand or arm gestures, eye movements, or assistive devices (such as switch buttons) to help them communicate. Several nursing home staff told us that it was difficult to know if many of the children were absorbing what they were being taught because they didn't show any response.

Because of the severity and costliness of their medical needs, children in nursing homes are likely to be eligible for Medicaid. In the nursing homes we visited, almost all of the children were on Medicaid, according to nursing home staff. Several nursing homes told us the children often become eligible for Medicaid because their families have low-incomes or they have reached the limit for services or number of days under private insurance because of the costliness of the child's medical condition. Staff from two nursing homes also told us that the children were generally from low-income families and that the families' income levels, according to one nursing home, may have diminished as a result of the child's medical costs. According to nursing home staff in three of the nursing homes we visited, some children were also eligible for Supplemental Security Income (SSI) payments for their disability.<sup>35</sup>

School-Age Children in Nursing Homes Often Stayed for Extended Periods of Time and Level of Parental Involvement Varied

<sup>&</sup>lt;sup>34</sup> According to the CMS definition, "difficulty understanding others" may be described in one of the following ways: (1) misses some part or intent of the message but comprehends most conversation; (2) sometimes understands by responding adequately to simple, direct communication only; and (3) rarely or never understands.

<sup>&</sup>lt;sup>35</sup> SSI payments are limited to \$30 monthly when a child is in a medical facility where health insurance pays for his or her care.

than a year and those spending most of their childhood in nursing homes.  $^{\rm 36}$ 

In some instances, these children were disconnected from their families. while in other instances parents were very involved, with frequent visits to and communication with the nursing homes, according to nursing homes we visited. Nursing home staff told us that for some parents, their jobs, the need to care for other siblings, or language barriers make it difficult to regularly visit their child or communicate with the nursing home. Staff at one nursing home we visited told us that half of the parents do not visit regularly, on holidays, or for major life events. In nearly all of the nursing homes, a small number of children were also under the supervision of child welfare authorities. According to nursing home staff, in some cases, the parents retained their rights to make decisions for their children subject to court approval, while in others a social worker represented the child's interests because of parental neglect or abuse. In one nursing home, many children were involved with child welfare authorities because of previous abuse or neglect. Further, staff from one nursing home told us that child protective services may close a case once a child is admitted to a nursing home because it is considered a safe location. In other instances, parents were very involved in their children's daily lives. For example, nursing home staff described other parents as highly involved with their children, either frequently visiting their child and/or regularly communicating with the nursing home. For example, in one nursing home we visited, the parents of one child visited their child twice a week even though they lived out of state. In another nursing home, parents organized successfully to keep their children from being relocated to other nursing homes because of concerns about how relocation would have affected the continuity of care their children received.

<sup>&</sup>lt;sup>36</sup> According to staff at several nursing homes we visited, school-age children can live in a pediatric nursing home or in a mixed geriatric and pediatric nursing home. If children need further care after they age out of the pediatric unit (typically at 18 or 21), they may be transferred to nursing homes that care for geriatric patients, or remain at their current nursing home.

Nursing Homes We Visited Referred Children for Special Education and Children Typically Received Educational Services On-Site

Nursing Home Staff on Our Site Visits Coordinated with School Districts to Refer Children for Special Education Services When a child is admitted to a nursing home, all three states we visited had regulations or other guidance requiring nursing homes to refer children to the appropriate school districts for educational services,<sup>37</sup> and nursing home staff we spoke with in those states often collaborated with school district officials to notify them about the children and help them understand the child's needs. (See fig. 4.) For example, Texas-which has a relatively high number of children in nursing homes-requires nursing home staff to notify the school district within 3 days of a child being admitted. Texas also requires nursing homes to share with the school district the child's educational history, vision and hearing screenings, and educational assessments within 14 days of admission to the nursing home. The state further allows nursing home staff to provide input into the child's IEP, which describes special education services the child is to receive. The state also requires nursing homes to document educational objectives in the child's nursing home care plan, which describes the services the nursing home will provide to maintain the resident's well-being.<sup>38</sup> California, which has the highest concentration of

<sup>&</sup>lt;sup>37</sup> In the three states we visited, written requirements obligated the nursing homes to refer pediatric residents to the school district for educational services. In our survey of state special education directors, we found that the Child Find requirement under IDEA and the responsibility for providing special education services was divided generally evenly among the states between the school district where the child's family resides and the school district in where the nursing home is located. For example, in New York, the school district in which a child's family resides is responsible, while in California and Texas, responsibility lies with the school district in which the nursing home is located.

<sup>&</sup>lt;sup>38</sup> Under federal requirements for nursing homes receiving payment under Medicare or Medicaid, nursing homes must develop a comprehensive care plan for each resident that includes the services necessary for the resident to attain or maintain the highest practicable physical, mental, and psychosocial well-being.

children in nursing homes, also has requirements that the nursing homes and school districts collaborate to develop and implement the IEP and incorporate the activities identified in the IEP into the child's care plan. In the nursing homes we visited, the social worker on staff typically carried out the responsibilities for collaborating with the school districts; and in some cases the teacher on-site was also involved in this process. Further, some of the nursing home officials we spoke to said that they held regular meetings with the teacher to discuss each child's medical needs and care.

# Figure 4: Illustration of How Nursing Homes Assist School Districts in Referring Children for Special Education Services in the Nursing Homes We Visited



Source: GAO. | GAO-14-585

### Medical Condition Largely Drove Educational Setting and Services in Nursing Homes Visited

According to officials in the nursing homes we visited, because of their medical fragility, children primarily received educational services on-site at the nursing homes. (See fig. 5). While instruction was generally conducted in classrooms in the nursing homes, some children received one-on-one tutoring, often bedside, when the children were too fragile to be moved. A child's physician made the determination as to whether the child was too fragile to go to a local school and considered factors such as the child's ventilator dependency, frequency of seizures, tolerance for being on a bus and sitting for extended periods of time, and the local schools' capacity to meet the medical needs of the child, according to school administrators and nursing home staff. For example, in one nursing home, children who had unstable respiratory systems received education in the nursing home because they needed to have a respiratory therapist nearby. When our undercover investigator inquired about the

educational environment for a child living in a nursing home, staff within nearly all the nursing homes and school districts explained that the setting would depend on the child's medical stability and individual needs.<sup>39</sup> These responses corroborated information we heard on site visits about a child's medical fragility determining the setting of the child's educational services. Further, some of the parents we spoke with preferred having their child receive education and other services in the nursing home. One parent whose child suffered from seizures told us he did not feel comfortable having his child away from the medical team at the nursing home, while another parent, whose child had previously attended school outside the nursing home, said that her child had cried every day at school because sitting was painful for him. The child currently receives education services in the nursing home. These concerns regarding the well-being of children are consistent with our survey findings in which 31 states considered balancing children's safety needs while providing education in the least restrictive environment a challenge. Some nursing homes and school district officials we interviewed said that the school district's capacity to attend to the child's medical needs while in school was also weighed. For example, several nursing home officials said some schools do not have staff trained to handle tracheostomy suctioning; in contrast, a few school districts we visited had nurses or other staff trained to provide for tracheostomy care while children attended school.

<sup>&</sup>lt;sup>39</sup> Our investigator made calls to nursing homes and school districts posing as a child's guardian planning to admit the child to a nursing home to inquire about where educational services would be delivered and the types of educational services that would be provided. See appendix I for more information.



#### Figure 5: Where Children Living in Nursing Homes We Visited Receive Educational Services

Source: GAO. | GAO-14-585

In our survey of state special education directors, officials also reported that children in nursing homes primarily receive educational services in nursing homes. Specifically, 16 state special education directors indicated the majority of children living in nursing homes in their states are educated in the nursing homes through individual tutoring or class instruction (see fig. 6). Interestingly, however, nearly half (22) of states reported that they did not know where such children receive educational services, possibly indicating the population of children in nursing homes was small and difficult to track at the state level.



Figure 6: Setting Where Educational Services Are Provided to Majority of Children Living in Nursing Homes, According to Survey of State Special Education Directors

Source: GAO survey of state special education directors. | GAO-14-585

Note: States were asked to check one survey response. Six states responded "other" setting, but most indicated in their comments that either they do not have children residing in nursing homes or the children received educational services across the settings.

A child's medical fragility also affected the amount of instruction time they received, according to several teachers we interviewed. For example, in the nursing homes we visited, children who were able to handle instruction in a classroom generally received from 1 to 4 hours a day. In one of the facilities we visited, school district officials told us the children must be able to tolerate sitting for at least 30 minutes in order to participate in class instruction. In addition, teachers used some instruction time getting the child ready to learn. For example, some teachers said that compressing children's joints and massaging their arms and legs to increase blood circulation helped stimulate their brains and prepare them for the day's instruction. Similarly, in some nursing homes, children were pulled out of class for IDEA-related services—such as physical, occupational, and speech therapies—or providers came into the classroom to provide such services during instruction time.<sup>40</sup> Some

<sup>&</sup>lt;sup>40</sup> Under IDEA, related services may be provided to assist a child with a disability to benefit from special education. Examples of such services include physical and occupational therapy; recreation, including therapeutic recreation; orientation and mobility services; and medical services for diagnostic or evaluation purposes. Related services also include school health services and school nurse services, social work services in schools, and parent counseling and training. 20 U.S.C. § 1401(26), 34 C.F.R. § 300.34(a).

teachers also said that many children are unable to be out of bed more than a few hours a day and may not be alert for longer periods of time. In nearly every nursing home we visited, we observed children who appeared to be asleep or had their eyes closed while instruction was being delivered. Further, some teachers we spoke with said that nursing home staff or teachers regularly check diapers and perform tracheostomy suctioning. Children with less tolerance for classroom instruction were typically provided with individual tutoring that lasted anywhere from 30 minutes to 2 hours a day in nursing homes we visited. We also observed children receiving individual tutoring because of illnesses, such as the flu. In our survey of state directors, 18 reported that their states had a minimum number of required hours of instruction for children in nursing homes, with the majority requiring between 4 and 10 hours per week. Several teachers we interviewed noted they followed the state or local requirements for hours of instruction time. For example, children receiving educational services through the tutoring program at one nursing home received 1 hour or 2 hours depending on their age, per guidance from the school district.

According to several teachers and local school administrators, teachers had to modify the schools' curriculum significantly, with emphasis on sensory methods for conveying the lessons, because of the children's cognitive and functioning needs. For example, in one nursing home, a 14year-old child functioning at a pre-kindergarten instructional level had a short-term educational goal of writing five lower-case letters with assistance and a long-term educational goal of holding a marker without assistance. An 18-year-old child had a short-term educational objective of touching the correct color when presented with two choices of color cards. Because many of the children were nonverbal and nonresponsive or minimally responsive to instruction, teachers we observed used sensory and assistive technology to aid instruction.<sup>41</sup> For example, some teachers used sensory boxes with objects that corresponded to lessons for the children to touch (see fig. 7), and another used multiple sensory means to teach eighth-grade earth science (see sidebar 1 for description of instruction).

<sup>&</sup>lt;sup>41</sup> Assistive technology is any item, piece of equipment, or product system that is used to increase, maintain, or improve functional capabilities of a child with a disability.





Source: GAO. | GAO-14-585

# 1. Example of Classroom Lesson Using Sensory Tools Observed at Nursing Facility

As a teacher read a story about rain, she moved around to each child to stimulate their senses and simulate actions from the book. For example, she:

- sprayed water on their arms or cheeks to simulate rain,
- brushed leaves on children's arms, and
- turned lights off to simulate night time and played night sounds.

Source: GAO observation of teaching at a nursing home | GAO-14-585

Note: This lesson was modified from an eighth-grade science curriculum. In earth science, eighthgraders in Texas are expected to learn how interactions in solar, weather, and ocean systems create changes in weather patterns and climate. Students are expected to identify how global patterns of atmospheric movement influence local weather using weather maps that show high and low pressures and fronts, and identify the role of the oceans in the formation of weather systems such as hurricanes.

Several teachers used an adaptive switch, which may look like a button, to elicit a response from the children (see sidebar 2 for description) and a few special education providers, such as vision or speech therapists, used a retinal (eye-gazing) communication device to enable children to communicate with their eyes.

#### 2. Example of Tutoring Using Assistive Technology

The child was sitting in a wheelchair, was nonverbal, and did not move his body or eyes. The subject of the lesson was Fall, and the teacher described Fall and showed the child pictures of pumpkins and trees. The teacher put a picture of a pumpkin into the child's hand and guided the hand to place the picture on a piece of paper (hand-over-hand technique in which the teacher guides the child's hand). To simulate Fall weather, the teacher turned a fan on so the child could feel a cool breeze on his face. The teacher also placed the child's hand around an adaptive switch, helped him activate the fan, and then asked the child to try to turn the fan on himself. A few minutes later, the child held the button down on his own, turning the fan on. The teacher repeated this activity with a recording of his voice, and after some time, the child pushed the switch independently. Each time the child pushed the switch, we observed his eyes open very wide, his head move slowly one way, and his other arm move slightly. We observed the instruction for 25 minutes.

Source: GAO observation of teaching at a nursing home  $\mid$  GAO-14-585

Some children with relatively higher functional and cognitive capabilities received more advanced instruction. In one nursing home, for example, the teacher read books aloud to an 18-year-old with the cognitive level of a fifth grader, and had the child read back to her.

While most children received education services in the nursing homes, a small number of children attended local schools where they were either transported by bus or ambulance. Children must not only be medically stable, but must also be able to tolerate a longer school day and a nonhospital environment—such as normal odors and air quality—as one teacher told us. One nursing home administrator said the children must be up at 5:30 a.m. to be ready for the buses at 7:30 a.m. The teacher at the local school said the bus ride to school can overload the children's senses—as a result, she said, some children are crying when they arrive at school while others are asleep. In one local school's classroom, we

observed children from the nursing home who were educated in a selfcontained classroom. We observed them spending time out of their wheelchairs in a multi-sensory room. One child was lying on a mat exploring lights and chimes. Another child was in a swing as the teacher and teacher's aide swung her back and forth in order to simulate movement for the child who could not use her limbs. In another local school, we observed a child from the nursing home in a class with other children with moderate to severe disabilities listening to the teacher read a story aloud.

State and Local Officials Cite Challenges in Teaching and Paying for Special Education Services for Children in Nursing Homes

Officials Cited Developing Curriculum and Teacher Preparation as Challenges In our national survey of state special education directors and in discussions with teachers and school officials we visited, officials cited curricula development and teacher preparation as challenges confronting teachers who provide education for children with complex medical needs living in nursing homes (see fig. 8).

# Figure 8: Teaching Challenges to Serving Children Living in Nursing Homes, According to Survey of State Special Education Directors



Source: GAO analysis of state survey data. | GAO-14-585

Note: A number of states responded "don't know" to the survey questions on challenges to providing special education services to children living in nursing homes, possibly indicating the population of children in nursing homes was small and difficult to track at the state level.

#### **Developing Curricula**

For 29 states, developing curricula that effectively fits the needs of these students was a challenge, a sentiment echoed by several teachers and school administrators we spoke to during our site visits. For example, during one of our visits to nursing homes, one teacher with substantial teaching experience said that for years she struggled to find curricula that fit the needs of children with profound disabilities. Several teachers said that it is often difficult to determine what information the children are absorbing given the severity of their medical and cognitive impairments. Some local education officials questioned whether it would be more appropriate to focus instruction on functional life skills, such as learning to

feed themselves independently, rather than on a grade-level curriculum,<sup>42</sup> such as a modified version of algebra. Education is funding efforts to develop curriculum resources for teachers of children with the most significant cognitive disabilities.<sup>43</sup> Such resources are expected to be available by the 2014-2015 school year.

For 31 states, having adequate training for teachers was a challenge. Teacher Training Training and preparation was geared to teaching the broader special education population, rather than working with children with profound disabilities and complex medical conditions, according to some school district officials and teachers we interviewed. Further, some school officials we interviewed indicated teachers may not be fully prepared to teach this unique population, raising questions about the extent to which they can provide such children with special education services designed to meet the individualized needs of each child. For example, in New York, a school official said teachers sometimes arrive at the nursing home without sufficient preparation in how to work with the children with complex medical and cognitive needs. Likewise, in California, another school official said that although their teachers were certified to teach children with moderate and severe disabilities, this certification did not adequately prepare teachers for teaching children with profound

<sup>&</sup>lt;sup>42</sup> IDEA requires that IEPs include what is needed for the child to make progress toward the general education curriculum. 20 U.S.C. § 1414(d)(1)(A)(i)(IV)(bb). The Elementary and Secondary Education Act, as amended, requires that children with disabilities be included in statewide assessments and requires all students to be measured against academic achievement standards established by the states. 20 U.S.C. § 6311(b)(3)(C)(ix)(II). Students with severe cognitive disabilities may be assessed using alternate assessments that measure their achievement against grade-level standards or alternate academic achievement standards. 34 C.F.R. § 200.6(a)(2). States may include the advanced and proficient scores of such students in calculating a state's adequate yearly progress as long as the number based on the alternate standards does not exceed 1 percent of all students in the grades tested at the state or district level. 34 C.F.R. § 200.13(c).

<sup>&</sup>lt;sup>43</sup> The National Center and State Collaborative, a consortium of 19 states, is currently developing a comprehensive system that addresses the curriculum, instruction, and assessment needs of students with the most significant cognitive disabilities with grant funding from Education. The goal of the collaborative is to ensure that students with the most significant cognitive disabilities achieve increasingly higher academic outcomes and leave high school ready for postsecondary options. The collaborative has developed curriculum and instructional resources based on Common Core State Standards that can be used to support that goal. The system is expected to be operational for the 2014-2015 school year.

disabilities they encountered among children living in nursing homes.<sup>44</sup> During our site visits, several teachers said they could benefit from the experiences of other teachers about how best to serve this population of children. Further, on our site visits, some school officials noted that teachers of children in nursing homes are isolated and may have few opportunities to collaborate with other teachers. For example, one teacher said when she began teaching at the nursing home, she visited other facilities to observe more experienced teachers; however, because the population of children in nursing homes is relatively small and dispersed, many teachers may not have opportunities to learn from other teachers. IDEA authorizes Education to provide funding for personnel preparation. technical assistance, and information sharing,<sup>45</sup> and recognizes that teachers need information and technical assistance in a timely, coordinated, and accessible manner in order to improve educational results for children with disabilities.<sup>46</sup> However, current technical assistance efforts supported by Education do not facilitate the sharing of information among teachers of this population. Such information sharing about effective approaches and strategies could help teachers of children in nursing homes be more prepared to provide these children with education commensurate with their unique needs.

Cost of Providing IDEAAdServices Combined withsetLimited Availability ofsetSpecial EducationlivProviders Compoundedchallenges

According to state and local education officials, paying for costly IDEA services and a lack of available providers of special education services were key financial challenges to providing educational services in regular schools and classrooms—the least restrictive environment—for children living in nursing homes (see fig. 9).

<sup>46</sup> 20 U.S.C. § 1450(10).

<sup>&</sup>lt;sup>44</sup> The moderate/severe disability specialty area of California's Education Specialist Instruction Credential includes autism, deaf-blindness, moderate to severe mental retardation, multiple disabilities, and serious emotional disturbance.

<sup>&</sup>lt;sup>45</sup> IDEA permits such funding to be provided to eligible entities through grants, contracts, or cooperative agreements. 20 U.S.C. §§ 1461-63.

### Figure 9: Challenges Related to Cost and Availability of Special Education Service Providers for Children Living in Nursing Homes, According to Survey of State Special Education Directors



High costs of IDEA related services and equipment

Providing appropriate medical support to students during transportation to and from school

Having appropriate vehicles for transporting these students to and from school

Having sufficient numbers of special education teachers

Availability of providers of related services, such as physical and occupational therapy

Availability of school nurses to provide skilled care in schools

Source: GAO analysis of state survey data. | GAO-14-585

Note: A number of states responded "don't know" to the survey questions on challenges to providing special education services to children living in nursing homes, possibly indicating the population of children in nursing homes was small and difficult to track at the state level.

In our survey, 35 states indicated that the high cost of providing IDEArelated services and equipment was a challenge, with nearly half of states reporting this as extremely or very challenging.<sup>47</sup> Further, transporting the children to school presented challenges, according to our survey. Specifically, 35 states reported it was challenging to have appropriate medical care when getting the children to and from school and 30 states reported having appropriate vehicles to transport the children as challenging. For example, one school district superintendent told us the district must obtain buses adapted to transport children in wheel chairs.

<sup>&</sup>lt;sup>47</sup> IDEA-related equipment could include, for example, audiovisual instructional materials and technological aids and devices.
According to some school officials, school districts in which pediatric nursing homes are located may also be responsible for a particularly large share of high-cost services because of the large concentrations of children with high need in those districts.<sup>48</sup> Further, the high costs related to serving this population were exacerbated by limited IDEA funding (35) states) and state or other recent budget cuts to special education (33 states), according to state special education directors responding to our survey.<sup>49</sup> Limited funding may compound challenges related to the availability of special education teachers and related-service providers. which was reported by the majority of special education directors in our survey.<sup>50</sup> As one school district official told us, it is very difficult to find gualified nurses because schools must compete with hospitals and other medical facilities yet cannot provide comparable pay. In our survey, 31 states reported having sufficient numbers of special education teachers as a challenge to providing educational services to children living in nursing homes, although Education and the states have efforts to address teacher shortages.<sup>51</sup> In addition, staffing shortages caused by limited resources, one teacher said, have resulted in fewer teaching aides to help serve high-need children in the classrooms. Furthermore, provider shortages may be exacerbated in rural areas—a challenge indicated by the majority of state special education directors in our survey. To address these challenges, some school districts in the states we visited partnered to maximize resources for special education services, particularly for children with high needs. For example, in Texas, several school districts

<sup>50</sup> Related-service providers include occupational and physical therapists, for example.

<sup>&</sup>lt;sup>48</sup> In some states, such as in California and Texas, school districts with pediatric nursing homes are responsible for providing educational services for any children living in the nursing home regardless of whether the child's family lives in the district.

<sup>&</sup>lt;sup>49</sup> States may be able to use Medicaid and IDEA high-cost funds to help cover the high costs of these services. To qualify for reimbursement under Medicaid, the service must be listed in the child's IEP, the child must be enrolled in Medicaid, the service received must be covered in the state Medicaid plan, and the school district must be authorized by the state as a qualified Medicaid provider. Under IDEA, states may reserve 10 percent of the IDEA funds reserved for other state activities to establish and maintain a high-cost fund— or risk pool—to assist school districts serving high-need children. 20 U.S.C. § 1411(e)(3). According to Education, 15 states set aside money for high cost funds in fiscal year 2012.

<sup>&</sup>lt;sup>51</sup> Special education is considered a high-need teaching field and is on the 2014-2015 teacher area shortage list for most states, according to Education's nationwide Teacher Shortage Area lists for the 2014-2015 school years. Education and states use the Teacher Shortage Area list to highlight teaching fields where there is inadequate supply of teachers and to promote these fields to prospective teachers through student loan deferment programs and student grants. http://www2.ed.gov/about/offices/list/ope/pol/tsa.doc.

shared physical and occupational therapists across the districts. One large school district in California maintains several pediatricians, nurses, and health care assistants on staff, according to school officials, and small nearby school districts pay the larger district to access these service providers.

The Relatively Small, Dispersed Population of Children in Nursing Homes Complicates State and Federal Monitoring under IDEA Education's monitoring activities can miss children in nursing homes because such children are a relatively small, dispersed population and, as a result, special education officials may have limited awareness of them. Education monitors state compliance with IDEA, such as reviewing states' special education data, policies, and monitoring practices. States conduct more in-depth monitoring of school districts' compliance with IDEA. However, in our survey, 12 states did not know if their monitoring efforts included children educated in nursing homes in the last year, including three states that had relatively larger populations of children in nursing homes. Furthermore, officials from 11 states commented in our survey that they either did not have or were unaware that they had children in nursing homes, even though all of these states had children living in nursing homes at some point during 2012, according to our analysis of CMS data.<sup>52</sup> (See app. II.)

The relatively small size of this population also makes it difficult for Education and the states to gather information on this population in order to monitor their education. State special education officials may have limited awareness of children in nursing homes in part because IDEA monitoring data are not set up to specifically track this or other small populations of children receiving special education services. Specifically, the IDEA data categories on educational environment do not include a separate category for children receiving their education in nursing homes.<sup>53</sup> Furthermore, according to our survey, these children are

<sup>&</sup>lt;sup>52</sup> States commenting that they did not have children in nursing homes were Maryland, Minnesota, North Dakota, Oklahoma, Rhode Island, and Vermont. States commenting that they were not aware of or did not track such children were Arizona, Georgia, Missouri, New Mexico, and South Dakota. Six of these states had fewer than 20 school-age children living in nursing homes in 2012, but 2 states had more than 60 such children. CMS data do not indicate where these children were receiving education services.

<sup>&</sup>lt;sup>53</sup> See table 2 for a full listing of the IDEA educational environment categories and definitions.

reported across several categories for educational environment. <sup>54</sup> As a result, this population of school-age children—less than 5,000 overall, with some states having 10 children or fewer—is essentially indistinguishable in the monitoring data from other children with disabilities educated in settings outside of regular schools.<sup>55</sup> Similarly, children in nursing homes are likely to be missed during the more indepth reviews that states conduct of school districts. According to officials in states we visited, state officials review individualized education programs (IEP) for selected students within school districts, in one case using random sampling to select these students.<sup>56</sup> Because this population is relatively small, such a sampling method is likely to miss these children.

While it is difficult for Education and the states to gather information on children in nursing homes under current monitoring efforts, nursing home monitoring conducted for HHS's Centers for Medicare & Medicaid Services (CMS) provides more regular and direct access to this group of children. As part of its oversight of nursing homes participating in Medicare and Medicaid, CMS contracts with state health agencies to ensure that the nursing homes comply with federal requirements.<sup>57</sup> To do this, these state agencies send surveyors to inspect each nursing home—including those that serve children—about once a year. During these inspections, surveyors review the care provided to a sample of nursing

<sup>56</sup> In three other states, state special education officials also said that they review a random sample of student IEPs within the school districts they select for in-depth monitoring. We interviewed these state officials in the process of developing our survey.

<sup>57</sup> Nursing homes must comply with these requirements in order to be eligible to participate in Medicare and Medicaid.

<sup>&</sup>lt;sup>54</sup> In our survey, states reported that their school districts may report students educated in nursing homes under the categories Homebound/ Hospital (37 states), Residential Facility (23 states), or Separate School (7 states)—or they could report them under one of the other categories listed in table 2 (3 states). Nine states also indicated that, within their state, different school districts may report these children under different categories. A senior Education official told us that states and school districts have the discretion to decide which reporting category is most appropriate for reporting these children.

<sup>&</sup>lt;sup>55</sup> Because some children living in nursing homes attend classes in regular schools, the population of children who are educated in nursing homes is smaller than the total number reported in figure 2. Children living in nursing homes, but receiving education at a regular public school would likely be reported under the IDEA educational environment categories "Inside the regular classroom 80 percent or more of the day, 40 to 79 percent of the day, or less than 40 percent of the day," as appropriate.

home residents. As part of this process, surveyors review residents' care plans, which are required to specify—among other things—objectives for meeting residents' cognitive needs (see table 5). Surveyors also verify that nursing homes comply with CMS's quality of life requirements, which include providing activities that promote residents' cognitive health. Although children's education is not specifically mentioned in CMS guidance to state surveyors, care plans for children in nursing homes should generally include educational goals, and the required activities for these children should include education, according to CMS officials we interviewed. CMS officials also said that special education and related services would be reasonable goals to include in a child's care plan.

 Table 5: Centers for Medicare & Medicaid Services Select Nursing Home

 Regulations and Guidance on Quality of Life and Activities

Centers for Medicare & Medicaid Services (CMS) requirements

Nursing homes must develop a comprehensive care plan for each resident with measurable objectives for meeting the resident's medical, nursing and mental and psychosocial needs that are identified through a comprehensive assessment<sup>a</sup>

Nursing homes must care for residents in a manner that promotes maintenance or enhancement of each resident's quality of life, including providing for an ongoing program of activities designed to meet the physical, mental, and psychosocial well-being of each resident.<sup>b</sup>

Activities should promote each resident's cognitive health and mental status<sup>c</sup>

Source: GAO analysis of CMS regulations and guidance documents. | GAO-14-585

<sup>b</sup> 42 C.F.R. § 483.15.

<sup>c</sup>CMS Guidance to Surveyors for Long Term Care Facilities

Although CMS's purpose in monitoring nursing homes is to ensure their compliance with Medicare and Medicaid requirements, the requirements for care plans and residents' quality of life allow for opportunities to enhance Education's oversight of the education of children in nursing homes. However, the extent to which state surveyors look at the education of children included in their sample of a nursing home's residents varied among the states we reviewed because their interpretations of CMS guidance also varied. For instance, in New York health agency officials said that surveyors verify that children in nursing homes had IEPs in place as part of their inspections for CMS. However, in California, health agency officials said surveyors would look to see that children were receiving education services only if those services were outlined in the child's care plan, raising the possibility that they would not look for such services if education were left out of the care plan. The

<sup>&</sup>lt;sup>a</sup> 42 C.F.R. § 483.20(k).

differing interpretations and practices in these two states indicate the potential that in some other states monitoring of children in nursing homes may not include verifying that children have IEPs.<sup>58</sup>

While Education and CMS have different, yet complementary, responsibilities with respect to children living in nursing homes, officials from both agencies told us they have not collaborated in their monitoring efforts. For example, the agencies have not coordinated to ensure that children in nursing homes have IEPs in place or that state health agencies have protocols for contacting education agencies if surveyors find that children are not receiving educational services, according to Education and CMS officials. In addition, officials in both agencies had limited awareness of the other agency's requirements related to the education of this population. For example, while CMS officials told us that care plans for children in nursing homes should generally include educational goals, they also said they would not necessarily expect this to be the case for children who were not alert enough to participate in education. IDEA, however, requires that all eligible children with disabilities receive special education services.<sup>59</sup> Conversely, a senior Education official told us that CMS requirements for promoting residents' cognitive well-being pertained only to geriatric nursing home residents, not to children. However, as previously noted, CMS officials told us these requirements also pertain to child residents.

GAO has previously identified key practices that can help enhance collaboration among federal agencies with common interests. <sup>60</sup> One such key practice is to look for opportunities to address resource needs by leveraging each others' resources to obtain additional benefits that would not be available if agencies worked separately. Education is responsible

<sup>&</sup>lt;sup>58</sup> New York and California have relatively high numbers of children in nursing homes. In other states with only a few children in nursing homes, agencies that conduct nursing home inspections may be less likely to consider education or other issues particular to child residents.

<sup>&</sup>lt;sup>59</sup> In practice, on our site visits, some school and nursing home officials reported serving children who were in vegetative states or minimally responsive. Examples of educational services provided to these children included sensory stimulation and reading or talking to them.

<sup>&</sup>lt;sup>60</sup> GAO, Results-Oriented Government: Practices That Can Help Enhance and Sustain Collaboration among Federal Agencies, GAO-06-15 (Washington, D.C.: October 21, 2005), 16.

	for monitoring compliance with the IDEA requirement that states provide all children with disabilities with a free appropriate public education in the least restrictive environment and has developed a number of mechanisms for doing so. In practice, however, it is difficult for these monitoring mechanisms to gather information on the low-incidence population of children in nursing homes, which is particularly vulnerable and may be at risk of not being identified at all for education services. Given CMS's oversight role with respect to nursing homes and their residents, CMS is uniquely positioned to help ensure that these children receive education services that promote their quality of life. Improved collaboration between Education and CMS could help provide additional assurance that children in nursing homes receive the educational services to which they are entitled under IDEA.
Conclusions	Teachers who serve children with disabilities educated in nursing homes face difficult challenges. They typically operate outside of traditional school settings and are relatively isolated from other special education teachers. In addition, they serve children for whom teaching methods and curricula often need significant and individualized modifications to meet the children's unique needs. Education, working with state educational agencies, could take the lead in developing mechanisms for sharing information, including best practices. Such information sharing could help teachers who serve this relatively small population of children with disabilities be better equipped to effectively manage the varied, complex nature of children's education needs. In addition, the relatively small and dispersed nature of the population of children living in nursing homes complicates efforts by the states and Education to oversee their education. However, CMS' oversight of state nursing home inspections provides an additional opportunity to help Education bridge potential gaps in its monitoring of the education of children in nursing homes under IDEA.
Recommendations	<ol> <li>To enhance the education that children in nursing homes receive and to better support the professional development of special education teachers who serve these severely disabled children, the Secretary of Education should:</li> </ol>
	develop mechanisms to facilitate information sharing among teachers of students in nursing homes. For example, Education could facilitate the establishment of a medium, such as a list serve, for teachers of these children to share information, including best practices, on how to best serve these students.

	2. To provide additional oversight of this vulnerable, low-incident, and largely hidden population of children with disabilities living in nursing homes, and to minimize potential monitoring gaps, the Secretaries of Education and of HHS should: jointly explore opportunities to use CMS's existing oversight mechanisms of nursing homes to help Education better ensure the education of such children. For example, Education and CMS could work together to encourage state nursing home surveyors—as part of their on-site reviews of medical and quality of life standards—to confirm that school-age children in nursing homes are receiving education services, and, if not, take appropriate follow-up steps with the nursing home and school district as needed. In another example, Education, CMS could encourage state health agencies to share information with state educational agencies when surveyors learn of school-age children in nursing homes.
Agency Comments and Our Evaluation	We provided a draft copy of this report to the Departments of Education, Health and Human Services, and Justice for review and comment. Education's comments are reproduced in appendix IV and HHS' comments are reproduced in appendix V. Justice provided only technical comments, which we incorporated as appropriate with the technical comments we received from Education.
	In its comments, Education agreed with our recommendation on information sharing among teachers of children in nursing homes. Education also stated that, under IDEA, states and school districts are primarily responsible for ensuring that personnel have the necessary skills and knowledge. According to the department, Education intends to issue guidance for states about providing special education and related services to children with disabilities in nursing homes, including information on requirements, best practices, and existing resources and avenues for information sharing for teachers of these children.
	With regard to our recommendation for Education and HHS to jointly explore opportunities to use CMS's existing oversight of nursing homes, Education and HHS agreed that it was important to collaborate, with Education noting that working together can produce benefits that may not be achieved working separately. Education also stated that Education and CMS do coordinate their efforts to better assure the education of

children in nursing homes, citing in particular Education's collaboration with CMS to help CMS and state and local educational agencies understand the requirements for accessing Medicaid to pay for special education and related services under IDEA. While such collaboration is important, the specific focus of our recommendation pertains to monitoring the education of children in nursing homes. Education also stated that it does not believe that it is CMS's responsibility to help verify the education of children with disabilities, but rather that of state and local educational agencies. We agree that oversight of IDEA compliance is the responsibility of Education and the states and have further clarified this fact in our report. However, as noted in our draft report, CMS' oversight of nursing homes and its requirements to ensure residents' quality of life uniquely positions it to provide important information to Education and the states about the education of children in nursing homes. Such information is important because, as we noted in our draft report, Education and states' oversight potentially misses children in nursing homes. In its comments, Education further stated that it can best serve children with disabilities in nursing homes by helping state and local agencies carry out their IDEA responsibilities rather than by creating additional federal oversight mechanisms. In recommending that Education leverage CMS's existing, regular nursing home inspections to aid Education in its oversight of this relatively small, dispersed population of children, we specifically sought to ensure that an additional oversight mechanism would not be created. In its comments, HHS said that it conditionally concurs with our joint recommendation and will continue to collaborate with Education. HHS also stated that monitoring of IDEA compliance should not be added to state surveyors' responsibilities, noting-and we agree-that Education has the primary responsibility for monitoring compliance with IDEA. Our report points out, however, that looking at children's education is well within nursing home surveyors' current responsibilities, since agency requirements for ensuring child residents' quality of life should include children's education, according to CMS officials responsible for the survey.

If you or your staff have any questions about this report, please contact me at 617-788-0534 or emreyarrasm@gao.gov. Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this report. Other key contributors to this report are listed in appendix VI.

Sincerely yours,

Melina Emez. anas

Melissa Emrey-Arras Director, Education, Workforce, and Income Security

# Appendix I: Objectives, Scope, and Methodology

	Our study of the education of children with disabilities in nursing homes was framed around four objectives: (1) What are the characteristics of school-children who live in nursing homes? (2) How are such children referred for special education services and how are services delivered? (3) What challenges do states and localities face in delivering special education services to these children in the least restrictive environment? and (4) How do agencies monitor the education of school-age children in nursing homes. To address these objectives, we used a variety of methods, including analysis of administrative data on nursing home residents; a web-based survey of state special education directors; a review of federal laws, regulations, and guidance; interviews with federal and other officials; site visits to three states; and investigative telephone calls.
Analysis of Nursing Home Data	To determine the characteristics of school-age children living in nursing homes, we obtained and analyzed administrative data from the Centers for Medicare & Medicaid Services' (CMS) Minimum Data Set 3.0 (MDS) for calendar year 2012 (January 1, 2012 through December 31, 2012), which was the most recent year for which data were available for our purposes. These data included information on all children who were in a Medicare- and Medicaid-certified nursing home in the United States at any point, and for any duration, in calendar year 2012. Medicare- and Medicaid-certified nursing homes, including skilled nursing homes, provide information annually to CMS on residents' demographics and overall health and functionality through the MDS. We focused our analysis on the population of children ages 6 through 21, which is consistent with the Individuals with Disabilities Education Act (IDEA) reporting requirements for school-age children. We analyzed key demographic information as well as information on children's overall health and functionality, such as active medical diagnoses, special medical treatments (e.g., tracheostomy care and suctioning), activities of daily living (e.g., bed mobility and toileting), speech clarity, and length of stay in a nursing home. For measures that reflected the children's health and functionality, we reviewed all assessment records available—not just the most recent assessment—for individual children starting from their date of admission to a nursing home. <sup>1</sup>

<sup>&</sup>lt;sup>1</sup> For example, we reviewed all assessment records for each child to determine whether the child had been diagnosed with a disease at any point in time from their date of admission to a cut-off date of December 31, 2012.

For special medical treatments, we limited our analysis to treatments that the children had received after their entry into the nursing home. These refer to special treatments and procedures the resident performed themselves independently or that were performed for them by nursing home staff within 14 days of the assessment, according to CMS definitions. For activities of daily living, we analyzed the measures in which the resident needed extensive help or were totally dependent on staff to perform. For speech clarity, we analyzed if the resident had unclear speech with slurred or mumbled words or no speech with absence of spoken word. To determine the length of time a child was in the nursing home, we calculated the total cumulative time, starting from the child's date of admission into a nursing home to the discharge date from the current nursing home. If there was no discharge date in the child's record or last assessment as of December 31, 2012, we assumed that the child was still in a nursing home.<sup>2</sup> Because discharge dates were sometimes missing, some children appeared to be current residents even though they had been discharged. To address this limitation, we checked whether any assessment had been recorded within the last 120 days for residents with no discharge dates. This number of days was selected because nursing homes conduct assessments every 90 days, and we allowed a few additional days for data to be entered into the MDS system. If an assessment had been recorded within the 120 days, then we assumed the child still resided in a nursing home. We also consulted with an outside expert with extensive experience with using MDS data about our approach to calculating length of stays in nursing homes and other matters.

To assess the reliability of MDS data, we reviewed relevant CMS documentation, including guidance to nursing home staff on data collection and reporting, and conducted electronic data testing. We also interviewed CMS agency officials about the processes they use to ensure the completeness and accuracy of the MDS data that are submitted from nursing homes. Many states have established additional MDS requirements for Medicare and Medicaid payment and quality monitoring purposes. Because of these state reviews, as well as the steps taken by CMS officials to ensure the completeness and accuracy of these data, we

<sup>&</sup>lt;sup>2</sup> Discharge assessments capture a resident's clinical condition at discharge. When discharge assessments are not completed or submitted as required, the true length of time in a nursing home is difficult to calculate and may result in children appearing to stay in the nursing homes when they have been discharged.

	determined that they were sufficiently reliable for the purposes of this report.
Survey of State Special Education Directors	To obtain information on state monitoring and challenges, we conducted a web-based survey of special education directors in all 50 states and the District of Columbia. This survey was in the field from September to December 2013. In the survey, we asked states to provide information on how they provide educational and related services to children living in nursing homes, how they monitor the provision of services to those children, the challenges they face in doing so, and guidance states have provided to school districts and received from the Department of Education related to serving this population. The survey included an introductory statement specifying that the survey questions pertained to school-age children (ages 6 through 21), that "nursing homes" referred to nursing homes and similar medical facilities providing long-term nursing care to children with complex medical conditions, and that we were interested in children with stays of at least 100 days in these facilities— not short-term stays for rehabilitation. We received responses from all 50 states and the District of Columbia, for a 100 percent response rate. We reviewed state responses and followed up by telephone and e-mail with selected states for additional clarification and context.
	The quality of survey data can be affected by nonsampling error, which includes variations in how respondents interpret questions, respondents' willingness to offer accurate responses, and data collection and processing errors. To minimize such error, we included the following steps in developing the survey and in collecting and analyzing survey data: In developing the web-based survey, we pretested draft versions of the instrument with special education officials in five states to check the clarity of the questions and the flow and layout of the survey. On the basis of the pretests, we made revisions to the survey. Further, using a web-based survey and allowing state special education staff to enter their responses directly into an electronic instrument created an automatic record for each state in a data file and eliminated the errors associated with a manual data entry process. In addition, the program used to analyze the survey data was independently verified to ensure the accuracy of this work. While these steps helped minimize nonsampling error, this survey may have been subject to additional error related to the low-incidence of children in nursing homes and state officials' limited awareness of these children. As noted in our findings, several state officials commented in their survey responses that there are no children in nursing homes in their states, or that they are not aware of such children.

	survey questions based on how they serve children in other out-of-school settings, such as hospitals or intermediate care facilities for children with intellectual disabilities.
Review of Laws, Regulations, and Guidance and Interviews with Federal Officials	For all four objectives, we reviewed relevant federal laws, regulations, and guidance and interviewed federal and state officials and other experts regarding children living in nursing homes and educational services for these children. We interviewed federal officials from the Office of Special Education Programs, the Office of Special Education and Rehabilitative Services, and the Office for Civil Rights at the Department of Education. We also interviewed officials at CMS and Administration on Aging's Long- Term Care Ombudsman Program at the Department of Health and Human Services (HHS), as well as officials from the Disability Rights Section, Educational Opportunities Section, and Special Litigation Section at the Department of Justice. We interviewed state special education officials in California, New York, and Texas and held more limited interviews with officials in several other states during our design work and survey pretests. In addition, we interviewed researchers, experts, and advocates in the fields of special education, disability, and Medicaid affiliated with the following organizations: Abt Associates; the Arc National Office; Advocates for Justice and Education, Inc. (The Parent Training and Information Center for the District of Columbia); Children's National Medical Center in Washington, D.C.; Family Voices; the National Alliance for Medicaid in Education, Inc.; the National Association of State Directors of Special Education, Inc.; and the National Disability Rights Network.
Site Visits	To learn how school-age children are referred for special education services and how such services are delivered, as well as to gather additional information about their characteristics and challenges in providing services, we conducted site visits to three states—California, New York, and Texas—to visit nursing homes and school districts. We selected these states on the basis of their comparatively large numbers of children residing in nursing homes. Together, these states accounted for 42 percent of all children living in nursing homes in 2011. <sup>3</sup> We also considered the number of students in IDEA in the state as a share of national IDEA enrollment and geographic dispersion. Within the three selected states, we used state licensing information to identify nursing

<sup>&</sup>lt;sup>3</sup> GAO analysis of 2011 data from the CMS *Nursing Home Data Compendium*, 2012, the latest compendium data available during our design phase.

	homes with pediatric beds. <sup>4</sup> We then selected a mix of nursing homes that serve only pediatric patients and those that serve both pediatric and geriatric patients. In total, we visited seven nursing homes in the three states. During these visits, we interviewed nursing home administrators and social workers, school district officials, special education teachers and, wherever possible, parents of children living in nursing homes. We also observed the instruction of children living in the nursing homes both in nursing homes and in schools. In order to illustrate the types of goals and services outlined in individualized education programs (IEP), we obtained a select number of IEPs of children living in the nursing homes we visited. All together, we obtained eight IEPs across the three states. We did not evaluate the IEPs to determine whether the goals and services described in the IEP were actually delivered. At the state level, we interviewed by telephone state special education directors as well as state health officials responsible for carrying out Medicare and Medicaid surveys to learn about state oversight of special education and nursing homes respectively. We also reviewed state policies to obtain information on state requirements or guidance related to identification, service delivery, and monitoring.
	Information we gathered on our site visits represents only the conditions present in the states and local areas at the time of our site visits. Furthermore, our fieldwork focused on in-depth analysis of only a few selected states. On the basis of our site visit information, we cannot generalize our findings beyond the states we visited.
Investigative Phone Calls	In the states we visited, we also investigated how school districts and nursing homes portrayed to a parent or guardian the educational setting and types of educational services a child might receive when admitted into a nursing home. Posing as a guardian of a child with complex medical needs who was considering placing the child in the nursing home, our undercover investigative staff contacted by telephone 11 schools, 7 school districts, and 10 nursing homes. During these calls, our investigator asked questions about the setting and types of educational services the child might receive if admitted to a nursing home. Our calls
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<sup>&</sup>lt;sup>4</sup> In some locations, we visited sub-acute care facilities and specialty hospitals that provide long-term care to school-age children with complex medical conditions. For the purposes of this report, we use the term "nursing home" throughout to include such skilled nursing facilities.

were primarily made to the entities we visited during our site visits, as well as an additional nursing home and school district or school in each of the three states in order to investigate these issues with entities we had not visited.

We conducted this performance audit from March 2013 through July 2014 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. We conducted our related investigative work in accordance with standards prescribed by the Council of Inspectors General on Integrity and Efficiency.

### Appendix II: Number of School-Age (6 through 21) Children Living in Nursing Homes by State, Calendar Year 2012

State	No. of children living in nursing homes in calendar year 2012 <sup>a</sup>
Alabama	130
Alaska	b
Arizona	117
Arkansas	17
California	908
Colorado	b
Connecticut	47
Delaware	16
District of Columbia	b
Florida	286
Georgia	38
Hawaii	29
Idaho	12
Illinois	155
Indiana	210
Iowa	89
Kansas	19
Kentucky	123
Louisiana	46
Maine	11
Maryland	70
Massachusetts	140
Michigan	56
Minnesota	37
Mississippi	20
Missouri	62
Montana	14
Nebraska	66
Nevada	42
New Hampshire	35
New Jersey	297
New Mexico	13
New York	595
North Carolina	24
North Dakota	b
Ohio	215

State	No. of children living in nursing homes in calendar year 2012 <sup>a</sup>
Oklahoma	40
Oregon	111
Pennsylvania	102
Rhode Island	b
South Carolina	b
South Dakota	b
Tennessee	36
Texas	236
Utah	60
Vermont	b
Virginia	112
Washington	59
West Virginia	17
Wisconsin	33
Wyoming	b
Total in the United States	4,794

Source: GAO analysis of Center for Medicare and Medicaid Services Minimum Data Set 3.0. | GAO-14-585

<sup>a</sup> The number of school-age children (6 through 21) who were in a nursing home in the United States at any point, and for any duration, in calendar year 2012 (January 1, 2012 through December 31, 2012).

<sup>b</sup> Eight states had 10 or fewer children living in nursing homes in calendar year 2012 including: Alaska, District of Columbia, North Dakota, Rhode Island, South Carolina, South Dakota, Vermont, and Wyoming.

### Appendix III: State Performance Report Indicators and Data Collection Topics Used by Education to Monitor Compliance with Part B of the Individuals with Disabilities Education Act

#### Table 6: Indicators and Definitions Used in State Performance Plans and Annual Performance Reports

Indicator	Definition
1	Percent of youth with individualized education programs (IEP) graduating from high school with a regular diploma.
2	Percent of youth with IEPs dropping out of high school.
-	Participation and performance of children with IEPs on statewide assessments:
	A. Percent of the districts with a disability subgroup that meets the state's minimum "n" size that meet the state's adequate yearly progress targets for the disability subgroup.
3	B. Participation rate for children with IEPs.
	C. Proficiency rate for children with IEPs against grade level, modified and alternate academic achievement standards.
	Rates of suspension and expulsion:
	A. Percent of districts that have a significant discrepancy in the rate of suspensions and expulsions of greater than 10 days in a school year for children with IEPs; and
4	B. Percent of districts that have: (a) a significant discrepancy, by race or ethnicity, in the rate of suspensions and expulsions of greater than 10 days in a school year for children with IEPs; and (b) policies, procedures or practices that contribute to the significant discrepancy and do not comply with requirements relating to the development and implementation of IEPs, the use of positive behavioral interventions and supports, and procedural safeguards.
	Percent of children ages 6 through 21 with IEPs served:
5	A. Inside the regular class 80 percent or more of the day;
5	B. Inside the regular class less than 40 percent of the day; and
	C. In separate schools, residential facilities, or homebound/hospital placements.
	Percent of children ages 3 through 5 with IEPs attending a:
6	A. Regular early childhood program and receiving the majority of special education and related services in the regular early childhood program; and
	A. Separate special education class, separate school or residential facility.
	Percent of preschool children aged 3 through 5 with IEPs who demonstrate improved:
	A. Positive social-emotional skills (including social relationships);
7	<ul> <li>B. Acquisition and use of knowledge and skills (including early language/ communication and early literacy); and</li> </ul>
	C. Use of appropriate behaviors to meet their needs.
8	Percent of parents with a child receiving special education services who report that schools facilitated parent involvement as a means of improving services and results for children with disabilities.
9	Percent of districts with disproportionate representation of racial and ethnic groups in special education and related services that is the result of inappropriate identification.
10	Percent of districts with disproportionate representation of racial and ethnic groups in specific disability categories that is the result of inappropriate identification.
11	Percent of children who were evaluated within 60 days of receiving parental consent for initial evaluation or, if the State establishes a timeframe within which the evaluation must be conducted, within that timeframe.

Appendix III: State Performance Report Indicators and Data Collection Topics Used by Education to Monitor Compliance with Part B of the Individuals with Disabilities Education Act

Indicator	Definition
12	Percent of children referred by Part C prior to age 3, who are found eligible for Part B, and who have an IEP developed and implemented by their third birthdays.
13	Percent of youth ages 16 and above with IEPs that include appropriate measurable postsecondary goals that are annually updated and based upon an age appropriate transition assessment; transition services, including courses of study that will reasonably enable the student to meet those postsecondary goals; and annual IEP goals related to the student's transition service needs. There also must be evidence that the student was invited to the IEP Team meeting where transition services are to be discussed and evidence that, if appropriate, a representative of any participating agency was invited to the IEP Team meeting with the prior consent of the parent or student who has reached the age of majority.
	Percent of youth who are no longer in secondary school, had IEPs in effect at the time they left school, and were:
	A. Enrolled in higher education within 1 year of leaving high school.
14	B. Enrolled in higher education or competitively employed within 1 year of leaving high school.
	C. Enrolled in higher education or in some other postsecondary education or training program; or competitively employed or in some other employment within 1 year of leaving high school.
15	Percent of hearing requests that went to resolution sessions that were resolved through resolution session settlement agreements.
16	Percent of mediations held that resulted in mediation agreements.
17	The state's State Performance Plan/ Annual Performance Report includes a State Systemic Improvement Plan that meets Education's requirements.
Source: Information	provided by the Department of Education.   GAO-14-585
	Note: This list of indicators was finalized in May 2014. States will submit their first State Performance Plans and Annual Performance Reports using this indicator list in February 2015. These indicators are the same as those submitted by states in February 2014, with two exceptions: Education eliminated two indicators—on state identification and correction of noncompliance and on the timeliness and accuracy of state reported data—and replaced them with the indicator on State Systemic Improvement Plans.

Data Collection Topics for States' Direct Reporting of Special Education Monitoring Data	<ul> <li>Child Count</li> <li>Personnel</li> <li>Educational Environments</li> <li>Exiting Special Education</li> <li>Discipline</li> <li>Assessment</li> <li>Dispute Resolution</li> <li>Local Educational Agency Maintenance of Effort Reduction and Coordinated Early Intervening Services</li> </ul>
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## Appendix IV: Comments from the Department of Education







## Appendix V: Comments from the Department of Health and Human Services

	LTH & HUMAN SERVICES	OFFICE OF THE SECRETARY
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	JUL 1 2014	
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ear Ms. Emrey-Arras:		
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## Appendix VI: GAO Contact and Staff Acknowledgments

GAO Contact	Melissa Emrey-Arras (617) 788-0534 or emreyarrasm@gao.gov
Staff Acknowledgments	In addition to the contact named above, Sherri Doughty (Assistant Director), Deborah A. Signer (Analyst-In-Charge), George A. Scott, Sheranda Campbell, Lauren Gilbertson, Ethan Levy-Forsythe, Cady S. Panetta, and James Rebbe made key contributions to this report. Also contributing to this report were Lori Achman, Deborah Bland, Holly Dye, Jessica Farb, Jean McSween, Mimi Nguyen, Ramon Rodriguez, James Ungvarsky, and Helina Wong.

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