

October 2010

CHILDREN WITH DOWN SYNDROME

Families Are More
Likely to Receive
Resources at Time of
Diagnosis Than in
Early Childhood



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Why GAO Did This Study

On October 8, 2008, the Prenatally and Postnatally Diagnosed Conditions Awareness Act was signed into law, requiring GAO to submit a report concerning the effectiveness of current health care and family support programs for the families of children with disabilities. In this report, GAO focused on Down syndrome because it is a medical condition that is associated with disabilities and occurs frequently enough to yield a sufficient population size for an analysis.

GAO examined (1) what is known about the extent to which children with Down syndrome receive medical care during early childhood and (2) what resources families of children with Down syndrome receive through their health care providers and what barriers families face to using these resources.

GAO analyzed fee-for-service claims data from a very large private health insurance company, for the claims representing its experience with one of the largest national employers, and Medicaid claims data from seven states with high Medicaid enrollment and low percentages of enrollees in Medicaid managed care. GAO also interviewed specialists at six prominent Down syndrome clinics and 12 advocacy groups to examine what resources families receive and to identify barriers they face. GAO also analyzed data from the Health Resources and Services Administration–sponsored 2005-2006 National Survey of Children with Special Health Care Needs on barriers to accessing needed services.

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CHILDREN WITH DOWN SYNDROME

Families Are More Likely to Receive Resources at Time of Diagnosis Than in Early Childhood

What GAO Found

GAO's analysis of data from a very large private health insurance company showed that from birth through early childhood, children with Down syndrome received medical care to address their special health care needs. Specifically, children with Down syndrome received, on average, five times more outpatient care (such as care in an urgent care facility) and over two times more office-based care (such as care in a physician's office) than children without Down syndrome. Overall, both groups received more office-based care than outpatient care. A key difference in the amount of care received by children with Down syndrome was the difference in the amount of therapy services, with a greater percentage of children with Down syndrome receiving physical, occupational, and speech therapy. In addition, children with Down syndrome have an increased risk of certain medical conditions and were hospitalized, on average, nearly twice as often and stayed twice as long as other children. Not surprisingly, differences were also found in medical care expenditures. The total average medical expenditures for children with Down syndrome were an average of five times higher than those for other children. However, both total expenditures and the difference in expenditures decreased substantially as the two groups of children reached 3 years of age. GAO's analysis of Medicaid claims data found similar differences between the two groups.

Down syndrome advocacy groups in selected communities told GAO that families of children with Down syndrome in those communities were more likely to receive the resources recommended for the time of diagnosis than those recommended for early childhood and may face barriers to using available resources. Specifically, advocacy groups reported that families were likely to receive about two-thirds (20 of 32) of the resources that specialists at the six Down syndrome clinics recommended they receive through their health care providers at the time of diagnosis. However, families were likely to receive only about one-quarter (6 of 23) of the resources that specialists recommended they receive through their health care providers after diagnosis and throughout early childhood. In addition, advocacy groups and results from the National Survey of Children with Special Health Care Needs indicate that families may face barriers that can prevent them from using available resources. For example, barriers such as outdated or inaccurate information could lead parents to underestimate their child's potential. Some advocacy groups reported that they and their communities have made efforts to address some of these barriers. For example, to address issues of inaccurate information, one advocacy group initiated an educational outreach program to health care professionals at area hospitals.

GAO provided a draft of this report to the Department of Health and Human Services for comment. It generally agreed with GAO's findings and noted that the report provides a thorough summary of the current practices and the successes and challenges faced by children with Down syndrome and their families.

Contents

Letter		1
	Background	6
	Children with Down Syndrome Received Medical Care to Address Special Health Care Needs	10
	Families Were More Likely to Receive the Resources Recommended for Time of Diagnosis Than Those Recommended for Early Childhood, and May Face Barriers to Using Available Resources	21
	Agency Comments	32
Appendix I	Medicaid Data	34
Appendix II	Comments from the Department of Health and Human Services	39
Appendix III	GAO Contact and Staff Acknowledgments	41
Tables		
	Table 1: Occurrence of Other Medical Conditions among Children with Down Syndrome	6
	Table 2: Resources That Specialists from Six Down Syndrome Clinics Recommended Families Receive Immediately upon Diagnosis, Likelihood of Receipt, and Consequences If Not Received	22
	Table 3: Resources Important to the Ongoing Health of the Child That Specialists from Six Down Syndrome Clinics Recommended Families Receive for Early Childhood, Likelihood of Receipt, and Consequences If Not Received	27
	Table 4: Barriers Commonly Cited by Advocacy Groups in Selected Communities	31
Figures		
	Figure 1: Average Number of Outpatient and Office-Based Services Received by Children in Our Review, by Age	11

Figure 2: Average Number of Outpatient and Office-Based Services Received by Children in Our Review from Birth through Age 4, by Service Type	13
Figure 3: Percentage of Children in Our Review Using Therapy Services, by Age and Therapy Type	15
Figure 4: Average Number of Hospitalizations of Children in Our Review, by Age	17
Figure 5: Average Length of Hospital Stay of Children in Our Review, by Age	18
Figure 6: Average Expenditures for Outpatient, Office-Based, and Inpatient Services for Children in Our Review, by Age	20
Figure 7: Average Number of Medicaid Outpatient and Office-Based Services for Children from Birth through Age 4, by State, 2007	35
Figure 8: Average Number of Medicaid Hospitalizations for Children from Birth through Age 4, by State, 2007	36
Figure 9: Average Length of Medicaid Hospital Stay for Children from Birth through Age 4, by State, 2007	37
Figure 10: Average Medicaid Expenditures for Office-Based, Outpatient, and Inpatient Services for Children from Birth through Age 4, by State, 2007	38

Abbreviations

AAP	American Academy of Pediatrics
ACMG	American College of Medical Genetics
ACOG	American Congress of Obstetricians and Gynecologists
DRG	diagnosis-related group
DSMIG	Down Syndrome Medical Interest Group
HHS	Department of Health and Human Services
HRSA	Health Resources and Services Administration
NDSC	National Down Syndrome Congress
NDSS	National Down Syndrome Society
NS-CSHCN	National Survey of Children with Special Health Care Needs
NSGC	National Society of Genetic Counselors

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United States Government Accountability Office
Washington, DC 20548

October 8, 2010

The Honorable Tom Harkin
Chairman
The Honorable Michael B. Enzi
Ranking Member
Committee on Health, Education, Labor, and Pensions
United States Senate

The Honorable Henry A. Waxman
Chairman
The Honorable Joe Barton
Ranking Member
Committee on Energy and Commerce
House of Representatives

Families of children who have disabilities, such as children with Down syndrome, may not always receive the resources necessary to address their children's special health care needs. Down syndrome is a chromosomal condition that is associated with a set of cognitive and physical symptoms, and each year an estimated 1 in 733 babies is born with the condition in the United States.¹ Because of an increased risk of certain medical conditions, such as congenital heart defects, gastrointestinal problems, and thyroid disease, children with Down syndrome need timely medical care. According to advocates and Down syndrome specialists, early identification and treatment of health issues result in better health and increased capabilities for these children. In addition, families of children who have disabilities, such as children with Down syndrome, need certain resources—including information, programs, and referrals for specialty medical care—at the time of diagnosis and as their child ages so they can effectively work with their child's health care provider to identify and treat medical conditions early. However, research indicates that not all families get the help they need. For example, researchers have consistently found that families reported

¹Centers for Disease Control and Prevention, "Improved National Prevalence Estimates for 18 Selected Major Birth Defects – United States, 1999 to 2001," *Morbidity and Mortality Weekly Report* (Jan. 6, 2006).

both a lack of support and a lack of accurate information from their physicians at the time of diagnosis and as the child ages.²

On October 8, 2008, the Prenatally and Postnatally Diagnosed Conditions Awareness Act was signed into law to increase the provision of scientifically sound information and support services to patients receiving a positive test diagnosis for Down syndrome or other prenatally and postnatally diagnosed conditions.³ This act required GAO to submit a report concerning the effectiveness of current health care and family support programs for the families of children with disabilities. In this report, we focused on Down syndrome because it is the most commonly occurring chromosomal condition at birth and, therefore, occurs frequently enough to yield a sufficient population size for an analysis. Moreover, physicians with experience treating children with Down syndrome and children who have other disabilities reported that many of the health care issues and experiences faced by families of children with Down syndrome are similar to those faced by families of children who have other disabilities. In this report, we examined (1) what is known about the extent to which children diagnosed with Down syndrome receive medical care during early childhood and (2) what resources families of children with Down syndrome receive through their health care providers and what barriers families face to using these resources.

To determine what is known about the extent to which children diagnosed with Down syndrome receive medical care during early childhood,⁴ we analyzed fee-for-service claims data from a very large private health insurance company for the claims representing its experience with one of the largest national employers. We also analyzed Medicaid fee-for-service claims data from seven states.⁵ We obtained the most recent full years of claims data available from each source. From the private health insurance company, we received nationwide claims data from 2001 through 2008,

²J. Ferguson et al., "Resident Physicians' Competencies and Attitudes in Delivering a Postnatal Diagnosis of Down Syndrome," *Obstetrics and Gynecology*, vol. 108, no. 4 (2006).

³Pub. L. No. 110-374, § 2, 122 Stat. 4051, 4051 (2008).

⁴It was beyond the scope of our work to evaluate the extent to which the medical care that the children received was appropriate.

⁵Medicaid is a joint federal-state program that finances health care for certain low-income children, families, and individuals who are aged or disabled. The Centers for Medicare & Medicaid Services is responsible for the Medicaid program and related data.

and from Medicaid, we received claims data from seven states for 2007.⁶ To select the seven states, we chose states with high Medicaid enrollment and low percentages of enrollees in Medicaid managed care; in 2006, the seven states accounted for over 40 percent of all Medicaid enrollees nationwide. For each 1-year period from birth through age 4, we analyzed claims data for children with Down syndrome⁷ who were enrolled in the private health insurance company or Medicaid for at least 11 months of that period.⁸ Specifically, we analyzed data on claims for outpatient, inpatient, and office-based care⁹ to describe the medical care received by children with Down syndrome during early childhood and corresponding health care expenditures. To provide a point of reference, we analyzed similar data for children without Down syndrome.¹⁰ The results of these analyses are not generalizable to all children with or without Down syndrome. We discussed the reliability of these data sources with knowledgeable officials and performed data reliability checks, such as examining the data for missing values and obvious errors, to test the internal consistency and reliability of the data. After taking these steps, we determined that the data were sufficiently reliable for our purposes.

⁶The seven states were California, Illinois, Louisiana, New York, North Carolina, Texas, and Wisconsin.

⁷To identify children with Down syndrome, we examined the diagnosis codes associated with services provided. In the private health insurance population, we identified the following cohorts of children with Down syndrome: children with Down syndrome under 1 year of age (N=318), 1 year of age (N=358), 2 years of age (N=418), 3 years of age (N=463), and 4 years of age (N=477). In the seven states where we analyzed Medicaid data, the population of children with Down syndrome from birth through age 4 ranged from a low of 261 children in one state to a high of 1,020 in another.

⁸In our analysis of the 2007 Medicaid data, the required minimum period of enrollment for children under 1 year of age was the child's age minus 1 month.

⁹Outpatient care includes services received in facilities such as urgent care facilities, ambulatory surgical centers, and hospital emergency rooms. Inpatient care includes services received in residential health care facilities such as hospitals. Office-based care includes services received in facilities such as physician offices, community health clinics, and school-based health clinics. For our analysis, we classified each service based on the type of facility in which it was provided. For example, in our analysis of the private health insurance claims data, we considered therapy services provided in an outpatient hospital setting to be outpatient care, while the same type of therapy services provided in a physician's office was classified as office-based care.

¹⁰The reference group of children includes all children from birth through age 4 who did not have a Down syndrome diagnosis.

To determine what resources families of children with Down syndrome receive through their health care providers and what barriers families face to using these resources, we conducted a series of interviews with national Down syndrome organizations and national disability organizations, specialists at Down syndrome clinics,¹¹ and Down syndrome advocacy groups.¹² Specifically, we interviewed 10 national Down syndrome organizations and national disability organizations and asked them to identify prominent Down syndrome clinics known for their expertise in treating children with Down syndrome. From these 10 interviews, we selected the six most commonly cited Down syndrome clinics¹³ and asked specialists at each of these clinics to recommend the resources families should receive through their health care providers both at diagnosis and through early childhood.¹⁴ We then selected 12 Down syndrome advocacy groups, representing six communities across the country, each of which was located in the same state as one of the six Down syndrome clinics. We asked the Down syndrome advocacy groups to review the list of resources that the specialists recommended and comment on whether families in their communities were likely to have received those resources through their health care providers. We also asked the Down syndrome advocacy groups to identify barriers families face to using the resources in their communities. The results of these interviews cannot be generalized to all Down syndrome clinics, all Down syndrome advocacy groups, or all families of children with Down syndrome.

To supplement our work, we obtained information from the National Survey of Children with Special Health Care Needs (NS-CSHCN), 2005-2006, which is sponsored by the Health Resources and Services

¹¹The specialists varied among the Down syndrome clinics we contacted and included health care professionals such as developmental pediatricians, nurse practitioners, and genetic counselors.

¹²For the purposes of our study, we define Down syndrome advocacy groups as local organizations that have been established to help children with Down syndrome and their families.

¹³For Down syndrome clinics identified an equal number of times, we considered the overall geographic diversity within our group of clinics to make our final selection.

¹⁴For the purposes of our study, health care providers include primary care professionals, such as family practitioners and pediatricians, and other providers at a hospital, such as genetic counselors and social workers, who interact with the family upon a postnatal diagnosis.

Administration (HRSA).¹⁵ Specifically, we obtained the most recent data available on issues such as access to health care, impact of special health care needs on the family, and barriers to accessing needed services. We analyzed survey data for families of children with Down syndrome from birth through age 17.¹⁶ The survey was designed to be representative of the entire U.S. population.¹⁷ We reviewed relevant data reliability materials and performed data reliability checks, such as examining the data for missing values and obvious errors, to test the internal consistency and reliability of the data. After taking these steps, we determined that the data were sufficiently reliable for our purposes.

We conducted this performance audit from November 2009 to October 2010 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.

¹⁵Maternal and Child Health Bureau of the Health Resources and Services Administration, National Survey of Children with Special Health Care Needs, 2005-2006. The NS-CSHCN, a large-scale telephone survey sponsored by HRSA and conducted by the Centers for Disease Control and Prevention, defines children with special needs as those who have or are at risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required for children generally. The NS-CSHCN provides information on the prevalence of children with special health care needs in the nation and in each state, the demographic characteristics of these children, the types of health and support services they and their families need, and their access to and satisfaction with the care they receive.

¹⁶We included survey data for families with children through age 17 to ensure a sufficient number of survey respondents.

¹⁷Based on the sampling error, the NS-CSHCN-reported percentages are within plus or minus 11 points using a 90 percent confidence interval.

Background

Overview of Down Syndrome

Down syndrome is most frequently caused by a chromosomal error that produces an extra copy of chromosome 21.¹⁸ The extra chromosomal material causes children with Down syndrome to have mental¹⁹ and physical differences and a greater risk of developing certain medical problems, such as hearing loss, eye disease, and congenital heart defects. (See table 1.) Because of this heightened risk, the American Academy of Pediatrics recommends that children with Down syndrome be closely screened throughout childhood for certain medical conditions.

Table 1: Occurrence of Other Medical Conditions among Children with Down Syndrome

Medical condition	Percentage of children with Down syndrome who have condition
Hearing loss	75
Eye disease	60
Congenital heart defects	50
Otitis media ^a	50-70
Obstructive sleep apnea	50-75
Thyroid disease	15
Gastrointestinal atresias ^b	12
Acquired hip dislocation	6
Leukemia	<1
Hirschsprung disease ^c	<1

Source: GAO analysis of American Academy of Pediatrics data in *Health Supervision for Children with Down Syndrome* (February 2001).

Note: Children with Down syndrome have a higher risk for developing these medical conditions than children without Down syndrome.

^aOtitis media is an infection or inflammation of the middle ear.

^bA gastrointestinal atresia is a complete blockage or obstruction in the gastrointestinal tract.

^cHirschsprung disease is a blockage of the large intestine caused by improper muscle movement in the bowel.

¹⁸According to the Centers for Disease Control and Prevention, chromosomes are small “packages” of genes in the body. They determine how a baby’s body forms during gestation and how, as the baby grows in the womb and after birth, the baby’s body functions. Typically, a baby is born with 46 chromosomes. Babies born with Down syndrome have an extra copy of all or part of chromosome 21.

¹⁹Down syndrome is typically associated with a degree of intellectual disability, usually ranging from mild to moderate.

Families of Children with Down Syndrome

The overall well-being of some families of children with Down syndrome can be affected by the special needs that their children may have. Research shows that these families experience more stress than families of typically developing children.²⁰ In addition, according to the NS-CSHCN, 21 percent of families of children from birth through age 17 with Down syndrome in the United States needed mental health care or family counseling in the previous year, and 26 percent experienced financial problems as a result of their child's health care issues.²¹ Research shows that families can benefit from family support resources, such as parent support groups where information and stories can be informally exchanged. In fact, connecting a new parent to other parents, such as through a parent support group, has been shown to be among the most helpful resources a physician can provide during the first conversation.²²

Research has shown that families of children with Down syndrome do not receive enough accurate information and emotional support at the time of diagnosis and as the child ages.²³ A 2005 study that surveyed 985 mothers who received a postnatal diagnosis of Down syndrome for their children indicated that when they learned of their child's diagnosis their physicians had not provided them with a satisfactory amount of up-to-date printed materials or telephone numbers of parents who already had a child with Down syndrome.²⁴ Another study found that families received some information from health care providers that they perceived as vague, inaccurate, or outdated.²⁵ Although there are studies such as these and

²⁰S. Rasmussen et al., "Setting a Public Health Research Agenda for Down Syndrome: Summary of a Meeting Sponsored by the Centers for Disease Control and Prevention and the National Down Syndrome Society," *American Journal of Medical Genetics Part A*, vol. 146A, issue 23 (2008), 2998-3010.

²¹Maternal and Child Health Bureau of the Health Resources and Services Administration, *National Survey of Children with Special Health Care Needs, 2005-2006*.

²²B. Skotko et al. for the Down Syndrome Diagnosis Study Group, "Postnatal Diagnosis of Down Syndrome: Synthesis of the Evidence on How Best to Deliver the News," *Pediatrics*, vol. 124, no. 4 (2009).

²³J. Ferguson et al., "Resident Physicians' Competencies and Attitudes in Delivering a Postnatal Diagnosis of Down Syndrome," *Obstetrics and Gynecology*, vol. 108, no. 4 (2006).

²⁴B. Skotko, "Mothers of Children with Down Syndrome Reflect on Their Postnatal Support," *Pediatrics*, vol. 115, no. 1 (2005).

²⁵Skotko et al., "Postnatal Diagnosis of Down Syndrome."

other initiatives²⁶ that focus on the first conversation between the health care provider and the family, there is very little research addressing subsequent conversations between the health care provider and the family as the child ages.

Down Syndrome Clinics, Programs, and Advocacy Groups

Down syndrome clinics, which are usually located in larger cities across the United States, are a source of specialty medical care for children with Down syndrome.²⁷ Pediatricians and family physicians vary widely in terms of their experience treating children with Down syndrome and refer patients to Down syndrome clinics as needed. The Down syndrome clinics are typically associated with medical schools or large hospitals and may include geneticists, developmental pediatricians, therapists, nutritionists, nurse practitioners, and genetic counselors. Families may visit these clinics on an annual basis to assess their child's development and to ensure that any health conditions have been properly diagnosed.²⁸ Families of children with multiple medical problems may visit these clinics more frequently to ensure that their child is receiving appropriate specialty care. In addition to caring for children, these clinics also support families by, for example, providing information about Down syndrome and referring families to community resources.

Pediatricians may also recommend that children with Down syndrome be referred to early intervention programs in their area. Children with Down syndrome qualify for early intervention services—which are generally

²⁶In November 2008, representatives from the following five organizations reached consensus that resources provided to parents of children with Down syndrome at the time of diagnosis should be complete, consistent, accurate, and up-to-date: the National Down Syndrome Society (NDSS), the National Down Syndrome Congress (NDSC), the American College of Medical Genetics (ACMG), the National Society of Genetic Counselors (NSGC), and the American College of Obstetricians and Gynecologists (ACOG). Since the consensus conversation, two of the representatives—from NDSS and NDSC—have collaborated with NSGC, ACMG, and ACOG representatives to develop “gold standard” packets of information for health care providers on how to deliver a prenatal and postnatal diagnosis, and a corresponding packet to be given to parents at the time of diagnosis. The prenatal packets were recently published, and the postnatal packet is currently under development.

²⁷The exact number of Down syndrome clinics in the United States is difficult to ascertain. However, NDSS lists contact information for 52 Down syndrome clinics for children and adults across the country.

²⁸According to a physician at a Down syndrome clinic, it is recommended that children with Down syndrome visit a Down syndrome clinic three to four times in the first year of life, two times in the second year of life, and annually every year after that, if needed.

administered by state-level agencies—beginning at birth and continuing until the age of 3.²⁹ The Individuals with Disabilities Education Act Part C program was created to provide infants and toddlers who have disabilities (or are at risk of developing a disability) and their families with early intervention services, such as speech therapy, occupational therapy, and family counseling.³⁰ We previously reported on research that found that the earlier a child with disabilities receives early intervention services, the more effective these services may be in enhancing the child's development.³¹ Parents may be referred to early intervention programs by their child's doctor, or they may seek out these services themselves.

There is also a widespread network of advocacy groups to support children with Down syndrome and their families. In addition to numerous national disability organizations, there are two national Down syndrome-specific organizations with over 300 local advocacy groups located across the country. They range in size from small parent support groups to larger organizations that provide services to families and their children. Advocacy groups support children with Down syndrome and their families by, for example, organizing activities for children, serving as information resources, and offering parent support groups.

²⁹At the age of 3, children with disabilities transition to special education programs.

³⁰20 U.S.C. § 1433.

³¹GAO, *Individuals with Disabilities Education Act: Education Should Provide Additional Guidance to Help States Smoothly Transition Children to Preschool*, [GAO-06-26](#) (Washington, D.C.: Dec. 14, 2005).

Children with Down Syndrome Received Medical Care to Address Special Health Care Needs

Children with Down Syndrome Received More Outpatient and Office-Based Care Than Other Children, with Number of Therapy Services a Key Difference

From birth through early childhood, children with Down syndrome received, on average, five times more outpatient care and over two times more office-based care than children without Down syndrome,³² according to our analysis of data from a private health insurance company.³³ For children under 1 year of age,³⁴ the average number of outpatient services was 10.4 for children with Down syndrome and 1.9 for children without. Similarly, the average number of office-based services for children under 1 year of age was 20.0 for children with Down syndrome and 10.7 for children without. As children with and without Down syndrome moved through early childhood, both groups received more office-based services than outpatient services.³⁵ However, while the amounts of outpatient and office-based services decreased over time, the differences in the amounts of outpatient and office-based services between the two groups remained. (See fig. 1.)

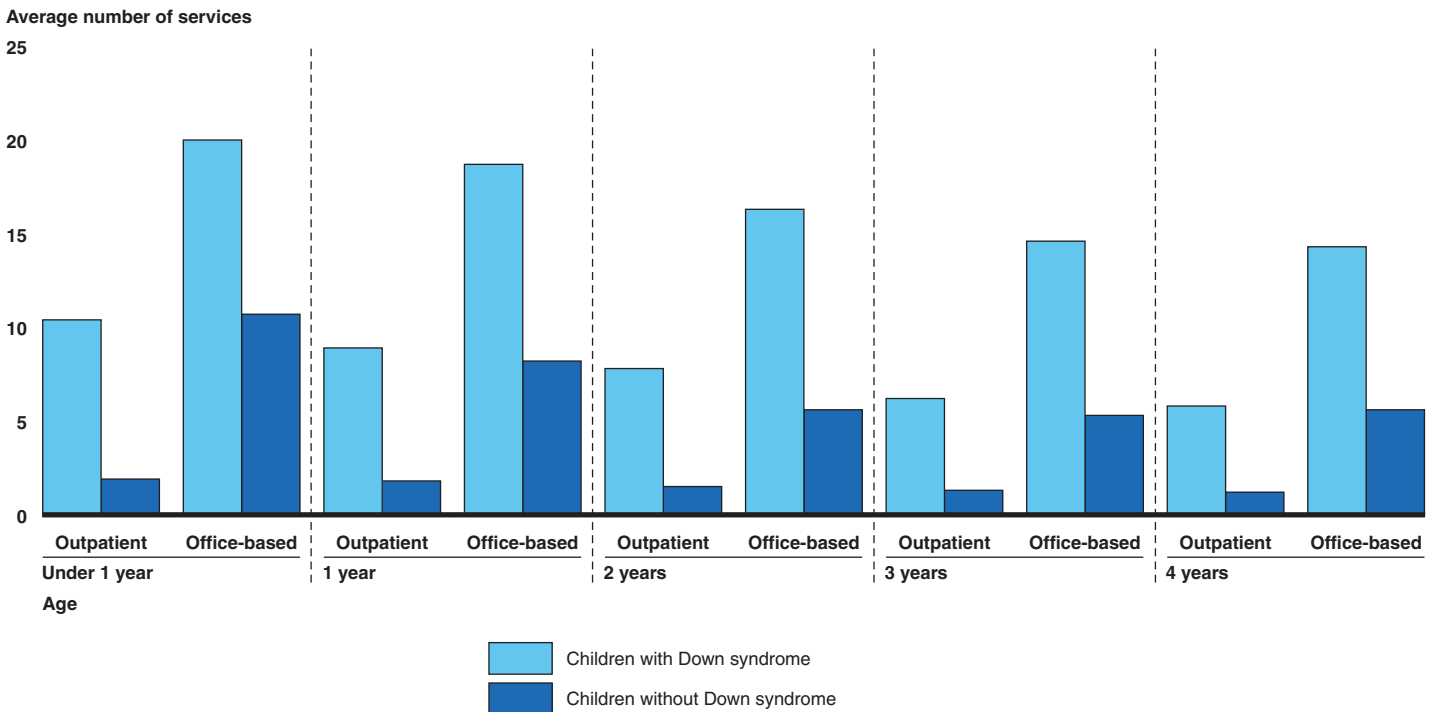
³²To obtain each of these averages, we calculated the ratios of services for children with Down syndrome compared to children without Down syndrome for each of the 5 years and averaged the ratios.

³³Outpatient care includes services received in facilities such as urgent care facilities, ambulatory surgical centers, and hospital emergency rooms. Office-based care includes services received in facilities such as physician offices, community health clinics, and school-based health clinics. Some services, such as therapy, can be provided in different types of facilities. For this analysis, we classified each service as outpatient care, office-based care, or inpatient care based on the type of facility in which it was provided.

³⁴The age ranges in our analysis are constructed so that, for example, “children under 1 year of age” includes all children from birth up to but not including their first birthday, and so on, with each range consisting of 1 full year.

³⁵It is likely that both groups of children received more office-based care than outpatient care because, in general, office-based care includes more routine services, such as office visits and vaccinations, while outpatient care includes less routine services, such as laboratory tests, surgical procedures, and emergency room visits.

Figure 1: Average Number of Outpatient and Office-Based Services Received by Children in Our Review, by Age



Source: GAO analysis of 2001 through 2008 data from a private health insurance company for the claims representing its experience with one of the largest national employers.

Notes: Outpatient care includes services received in facilities such as urgent care facilities, ambulatory surgical centers, and hospital emergency rooms. Office-based care includes services received in facilities such as physician offices, community health clinics, and school-based health clinics. Some services, such as therapy, can be provided in different types of facilities. For this analysis, we classified each service as outpatient care or office-based care based on the type of facility in which it was provided. The age ranges in our analysis are constructed so that, for example, “under 1 year” includes all children from birth up to but not including their first birthday, and so on, with each range consisting of 1 full year.

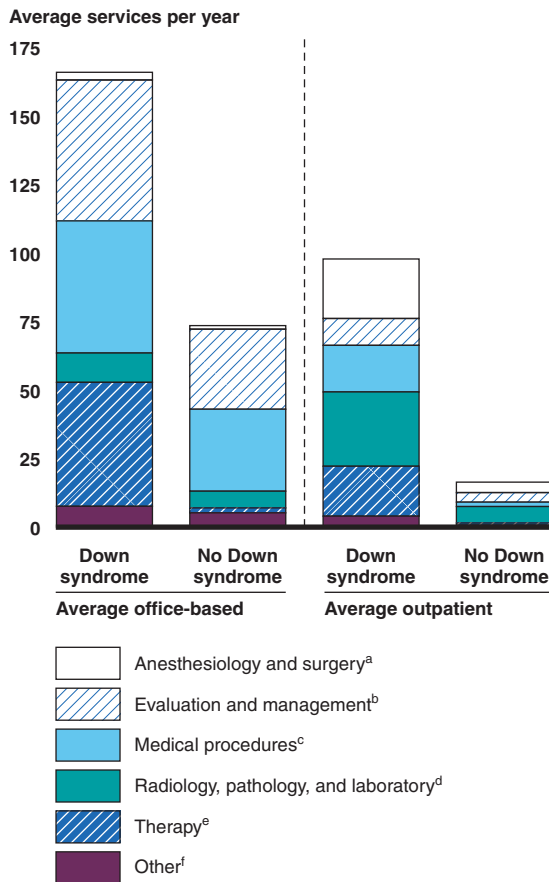
Across all types of services, children with Down syndrome from birth through age 4 received more outpatient and office-based services than children without. (See fig. 2.) For example, for both outpatient and office-based services, children with Down syndrome had more evaluation and management services,³⁶ more medical procedure services, and more therapy services. Specifically, for outpatient services, children with Down

³⁶Evaluation and management services refer to visits and consultations provided by physicians or other qualified health care professionals. Evaluation and management visits range from straightforward medical evaluations to highly complex patient evaluations and medical decision making.

syndrome had 3 times more evaluation and management services, 10 times more medical procedure services, and 22 times more therapy services than children without. For office-based services, children with Down syndrome had 2 times more evaluation and management services, 2 times more medical procedure services, and 25 times more office-based therapy services than children without. In addition, children with Down syndrome had 6 times more outpatient anesthesiology and surgery services than children without.³⁷

³⁷Children with Down syndrome are more likely to have outpatient surgeries, such as surgeries to insert ear tubes, than children without.

Figure 2: Average Number of Outpatient and Office-Based Services Received by Children in Our Review from Birth through Age 4, by Service Type



Source: GAO analysis of 2001 through 2008 data from a private health insurance company for the claims representing its experience with one of the largest national employers.

Notes: Outpatient care includes services received in facilities such as urgent care facilities, ambulatory surgical centers, and hospital emergency rooms. Office-based care includes services received in facilities such as physician offices, community health clinics, and school-based health clinics. Some services, such as therapy, can be provided in different types of facilities. For this analysis, we classified each service as outpatient care or office-based care based on the type of facility in which it was provided.

^aAnesthesiology and surgery includes services such as ear drum openings and wound repairs.

^bEvaluation and management includes services such as office, outpatient, and emergency department visits.

^cMedical procedures includes services such as vaccinations, hearing tests, and cardiac tests.

^dRadiology, pathology, and laboratory includes services such as thyroid tests and chest X-rays.

^eTherapy includes services such as physical, occupational, and speech therapy.

^fOther includes services such as dental services that are not captured in the other categories.

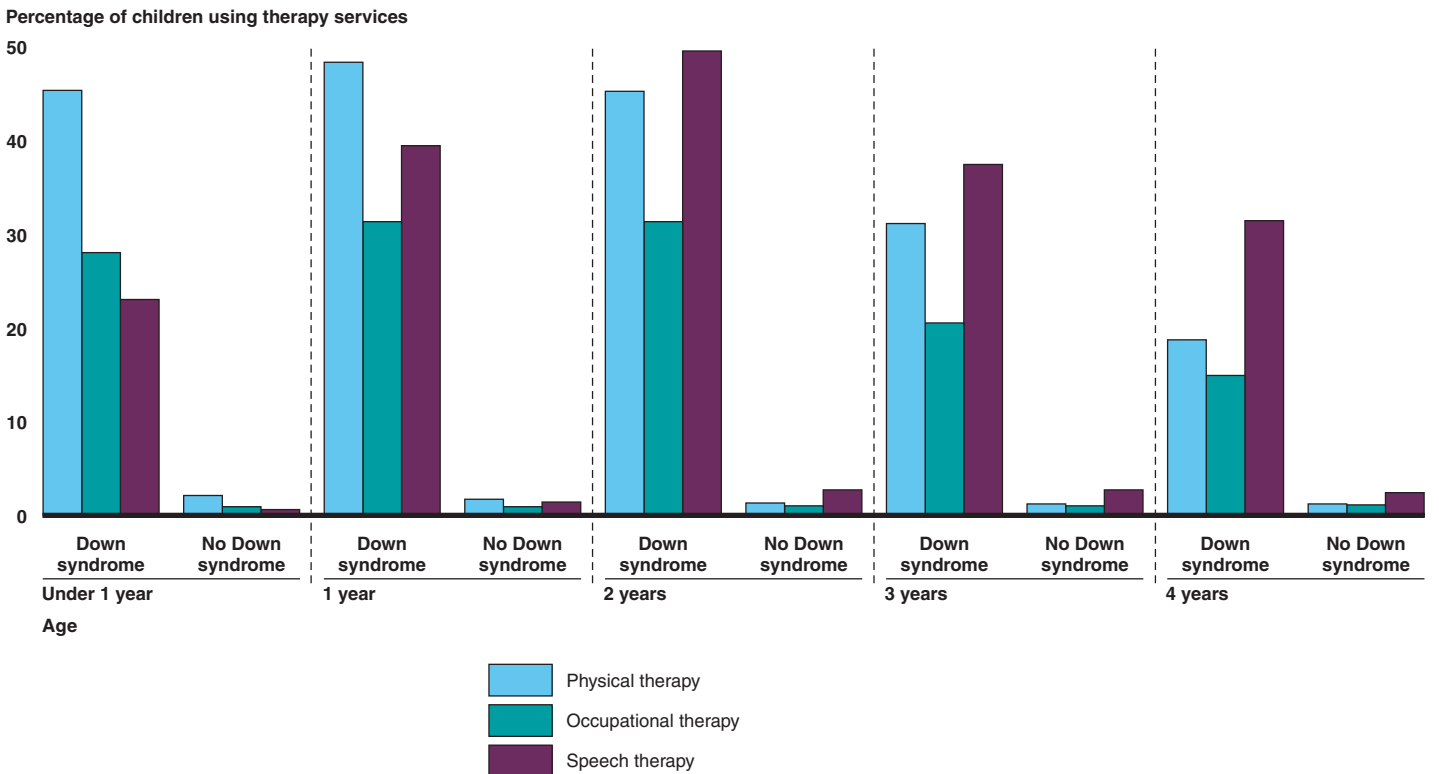
We found other differences within the types of services received, such as greater percentages of children with Down syndrome receiving services such as thyroid, cardiac, and hearing tests than other children. For example, our review of the outpatient services found that 21 percent of children with Down syndrome under 1 year of age had a specific thyroid function test, compared to 1 percent of other children of the same age.³⁸ In addition, children with Down syndrome were more likely than other children to receive an influenza vaccination; for example, 30 percent of 4-year-olds with Down syndrome received the influenza vaccine, compared to 15 percent of other children of the same age.

A key difference in the amount of outpatient and office-based care received by children with Down syndrome and other children was the difference in the amount of therapy services received. Our analysis of therapy usage showed that the percentage of children with Down syndrome who received physical, occupational, and speech therapy—therapies that Down syndrome specialists say are important for children with Down syndrome to receive to maximize their development—was much higher than it was for other children.³⁹ For example, 50 percent of children with Down syndrome, birth through age 4, received physical therapy services, compared to 3 percent of other children. This represented an average of 30 physical therapy claims per child with Down syndrome, compared to an average of less than 1 physical therapy claim per child without. This difference in the amount of children who received therapy services was evident in each age group and for each therapy type. (See fig. 3.)

³⁸This difference also appears in all other age groups. In addition to this specific thyroid-stimulating hormone blood test, children may have received other types of thyroid tests.

³⁹The majority of physical, occupational, and speech therapy services—which accounted for nearly 100 percent of therapy services received—occurred in outpatient and office-based settings. Less than 15 percent occurred in other settings, such as the child’s home.

Figure 3: Percentage of Children in Our Review Using Therapy Services, by Age and Therapy Type



Source: GAO analysis of 2001 through 2008 data from a private health insurance company for the claims representing its experience with one of the largest national employers.

Note: The age ranges in our analysis are constructed so that, for example, “under 1 year” includes all children from birth up to but not including their first birthday, and so on, with each range consisting of 1 full year.

The Medicaid data that we reviewed from seven states also show that children from birth through age 4 with Down syndrome who were enrolled in Medicaid in 2007 received more outpatient and office-based care to address their special health care needs than other children of the same age.⁴⁰ For example, among the seven states, children with Down syndrome received 2.7 to 5.3 times more outpatient services and 1.6 to 4.5 times

⁴⁰While overall patterns of utilization are consistent between the private health insurance company and Medicaid, more detailed comparisons of the data, such as a more detailed comparison of therapy services, cannot be made because of differences in insurance coverage as well as differences in how services are recorded and accounted for.

more office-based services than children without Down syndrome. (See app. I for more Medicaid data.)

Children with Down Syndrome Were Hospitalized More Frequently and Had Longer Hospital Stays Than Other Children

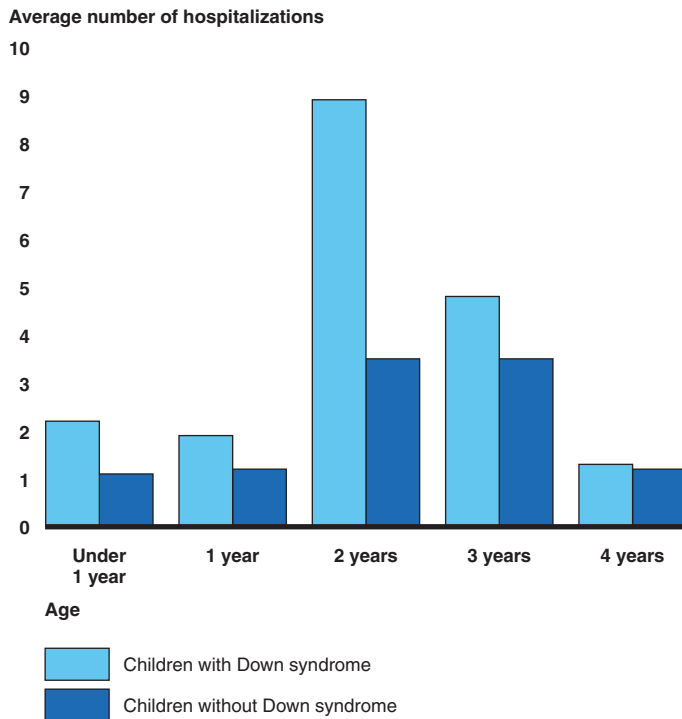
According to our analysis of inpatient care⁴¹ data from a large private health insurance company, from birth through early childhood, children with Down syndrome were hospitalized, on average, nearly twice as often and stayed twice as long as children without Down syndrome.⁴² The differences in the average number of hospitalizations and the average length of stay were most pronounced in the first years of life and diminished by age 4. (See figs. 4 and 5.) For example, for children with Down syndrome under 1 year of age, the average number of hospitalizations was 2.2, and the average length of stay was 7.6 days. In contrast, for children of the same age without Down syndrome, the average number of hospitalizations was 1.1, and the average length of stay was 2.1 days.⁴³ In an older group—children 4 years of age—children with and without Down syndrome were hospitalized about the same number of times, an average of 1.3 times for children with Down syndrome and an average of 1.2 times for children without, and for about the same length of time, an average of 2.0 days for children with Down syndrome and 1.7 days for children without.

⁴¹Inpatient care includes services received in residential health care facilities, such as hospitals.

⁴²To obtain each of these averages, we calculated the ratios of services for children with Down syndrome compared to children without Down syndrome for each of the 5 years and averaged the ratios.

⁴³Children with Down syndrome may be hospitalized for longer periods in their first year of life for reasons such as additional screening tests or complex surgeries (such as heart surgery).

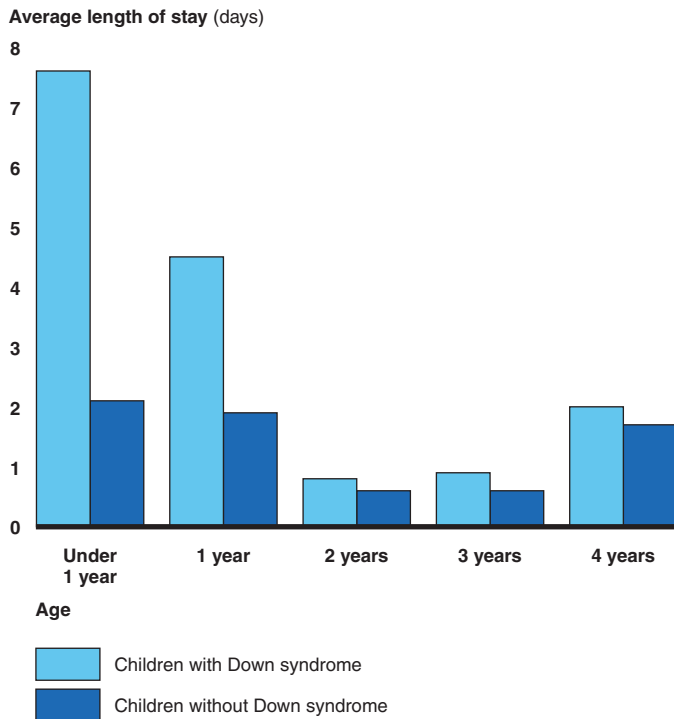
Figure 4: Average Number of Hospitalizations of Children in Our Review, by Age



Source: GAO analysis of 2001 through 2008 data from a private health insurance company for the claims representing its experience with one of the largest national employers.

Notes: The increase in hospitalizations for children 2 years of age with Down syndrome may be a result of physicians waiting to address certain health issues—such as some ear, nose, and throat issues—until children are older. The age ranges in our analysis are constructed so that, for example, “under 1 year” includes all children from birth up to but not including their first birthday, and so on, with each range consisting of 1 full year.

Figure 5: Average Length of Hospital Stay of Children in Our Review, by Age



Source: GAO analysis of 2001 through 2008 data from a private health insurance company for the claims representing its experience with one of the largest national employers.

Note: The age ranges in our analysis are constructed so that, for example, “under 1 year” includes all children from birth up to but not including their first birthday, and so on, with each range consisting of 1 full year.

Our review of inpatient claims data showed some differences in the types of hospitalizations for children with Down syndrome compared to other children.⁴⁴ For example, the most common type of hospitalization for children with Down syndrome under 1 year of age was cardiothoracic-related surgery; 6 percent of children under 1 year of age with Down syndrome had this hospitalization type, compared to 0.03 percent of other children.⁴⁵ Furthermore, while other hospitalization types—such as

⁴⁴We determined the types of hospitalizations based on the diagnosis-related group (DRG) associated with each hospitalization. DRGs are a system for classifying hospital stays based on diagnosis and procedures. Because of a change in DRG coding for 2008, our analysis included DRG data from 2001 through 2007.

⁴⁵The percentage of children hospitalized under this hospitalization type does not represent all the cardiac-related hospitalizations that could have occurred.

bronchitis and asthma, pneumonia, and ear issues—appeared as common types of hospitalizations in both groups, the percentage of children with Down syndrome hospitalized for these reasons was higher.

The Medicaid data that we reviewed from seven states also show that children from birth through age 4 with Down syndrome who were enrolled in Medicaid in 2007 generally had more inpatient care. Children with Down syndrome had more hospitalizations (in six of the seven states) and longer hospital stays to address their special health care needs than other children of the same age.⁴⁶ For example, among the seven states, children with Down syndrome had 1.0 to 7.4 times more hospitalizations and 1.5 to 10.2 times longer stays than children without Down syndrome. (See app. I for more Medicaid data.)

Children with Down Syndrome Had Higher Average Medical Care Expenditures Than Other Children, with Differences Decreasing as Children Aged

In our review, the total average medical expenditures⁴⁷ for children with Down syndrome, from birth through early childhood, were an average of five times higher than the expenditures for children without Down syndrome;⁴⁸ however, both total expenditures and the difference in expenditures decreased substantially by the time children with Down syndrome were 3 years of age. (See fig. 6.) The expenditures were also higher for children with Down syndrome for each type of medical care—outpatient, office-based, and inpatient care. Inpatient care for children under 1 year of age had the greatest difference, with average expenditures of almost \$43,000 for children with Down syndrome and \$2,000 for children without. The difference in expenditures reflects the fact that children with Down syndrome had a higher utilization of medical care or more expensive medical services than children without Down syndrome.

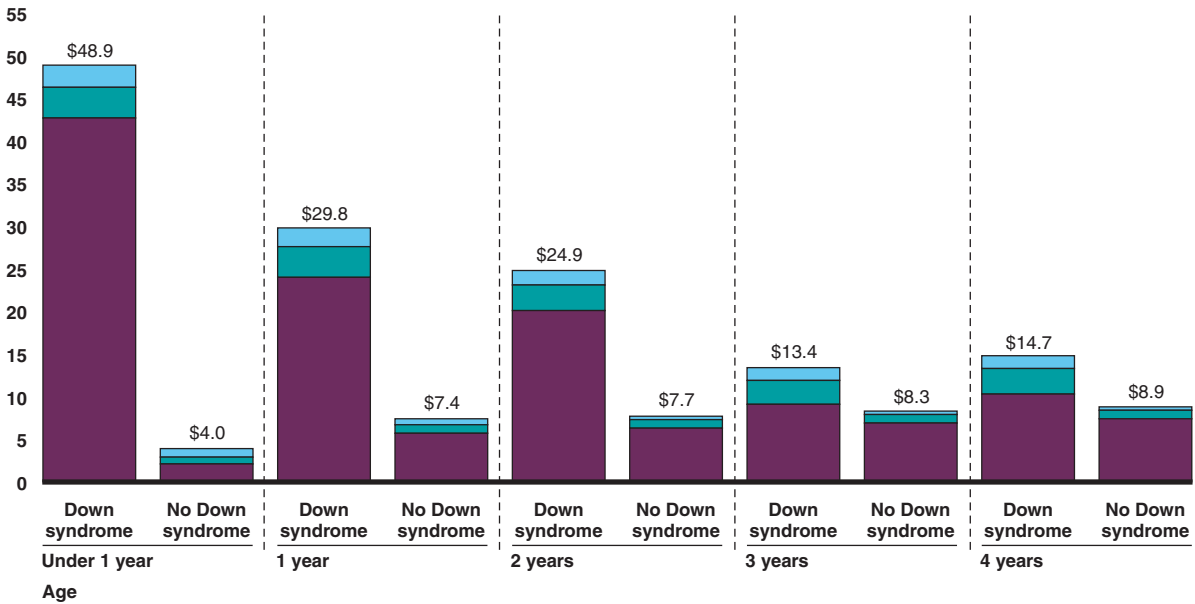
⁴⁶While overall patterns of utilization are consistent between the private health insurance company and Medicaid, more detailed comparisons of the data cannot be made because of differences in insurance coverage as well as differences in how services are recorded and accounted for.

⁴⁷Expenditure data were adjusted to 2008 dollars and include the amount paid by the primary insurance company, the deductible, coinsurance, and the amount paid by secondary insurance.

⁴⁸To obtain this average, we calculated the ratios of services for children with Down syndrome compared to children without Down syndrome for each of the 5 years and averaged the ratios.

Figure 6: Average Expenditures for Outpatient, Office-Based, and Inpatient Services for Children in Our Review, by Age

Average expenditures (dollars in thousands)



Office-based
Outpatient
Inpatient

Source: GAO analysis of 2001 through 2008 data from a private health insurance company for the claims representing its experience with one of the largest national employers.

Notes: Office-based care includes services received in facilities such as physician offices, community health clinics, and school-based health clinics. Outpatient care includes services received in facilities such as urgent care facilities, ambulatory surgical centers, and hospital emergency rooms. Inpatient care includes services received in residential health care facilities such as hospitals. Some services, such as therapy, can be provided in different types of facilities. For this analysis, we classified each service as outpatient care, office-based care, or inpatient care based on the type of facility in which it was provided. Expenditure data were adjusted to 2008 dollars and include the amount paid by the primary insurance company, the deductible, coinsurance, and the amount paid by secondary insurance. The age ranges in our analysis are constructed so that, for example, “under 1 year” includes all children from birth up to but not including their first birthday, and so on, with each range consisting of 1 full year.

Families Were More Likely to Receive the Resources Recommended for Time of Diagnosis Than Those Recommended for Early Childhood, and May Face Barriers to Using Available Resources

Families Were Likely to Receive Many, but Not All, of the Resources That Down Syndrome Clinic Specialists Recommended They Receive at Diagnosis

Down syndrome advocacy groups in selected communities told us that families in those communities were likely to receive many, but not all, of the resources that Down syndrome clinic specialists recommended they receive at the time of diagnosis. The specialists from six Down syndrome clinics we interviewed recommended 32 resources. (See table 2.) Advocacy groups reported that families were likely to receive about two-thirds (20 of 32) of the recommended resources; these resources were generally directly related to the health of children with Down syndrome, such as information about the risk of cardiac problems and the need for thyroid screening. Families were less likely to receive about one-third (10 of 32) of the recommended resources; these resources were generally related to the family's understanding of Down syndrome and overall family well-being, such as a copy of the Down syndrome-specific health care

guidelines⁴⁹ and information about the causes of Down syndrome and the effect of Down syndrome on the family and caregivers.⁵⁰

Table 2: Resources That Specialists from Six Down Syndrome Clinics Recommended Families Receive Immediately upon Diagnosis, Likelihood of Receipt, and Consequences If Not Received

Recommended resources	Twelve advocacy groups' assessment of likelihood of receipt by families	Consequences Down syndrome clinic specialists reported if resource not received
Information about:		
Need to screen for cardiac problems	●	If the child is not screened, serious complications or death in the first days or weeks of life may occur.
Need to perform echocardiogram ^a	●	If not performed, a congenital heart problem could go undiagnosed, and serious complications or death may occur.
Need for thyroid screening ^b	●	If the child is not screened, hypothyroidism may not be detected, and permanent cognitive impairment, along with growth and metabolic issues, may occur.
Need for complete blood count screening	●	If the child is not screened, early signs of leukemia may go undetected.
Need for hearing screening ^c	●	If the child is not screened, problems such as impaired language development or permanent hearing loss may occur.
Need for vaccines (following standard schedule)	●	If the child is not vaccinated, severe illness due to delayed immune system maturity may occur.
Impact of low muscle tone (e.g., for feeding, walking)	●	If not received, families may not understand the need for interventions such as therapy services, which can help improve feeding and gross and fine motor skills, such as learning how to sit, crawl, stand, and walk.

⁴⁹There are two sets of health care guidelines available to help primary care physicians manage the medical care of children with Down syndrome—the American Academy of Pediatrics guidelines and the Down Syndrome Medical Interest Group guidelines. These serve as a resource for primary care physicians by outlining screenings that should occur and resources that should be shared with families at key points in a child's life. In addition, the guidelines indicate when primary care physicians should refer patients to specialists, if needed.

⁵⁰For the remaining 2 of the 32 recommended resources, half of the 12 advocacy groups reported that the resource was likely to be received, and the other half reported that the resource was less likely to be received.

Recommended resources	Twelve advocacy groups' assessment of likelihood of receipt by families	Consequences Down syndrome clinic specialists reported if resource not received
Potential for gastrointestinal problems	●	If not informed, families may be unaware that the child can experience complications such as an intestinal obstruction, which may be life-threatening.
Potential need for referrals to pediatric specialists	●	If families do not access a specialist when care is needed, conditions may go undiagnosed or untreated.
Potential developmental delays	●	If families are not prepared for potential developmental delays, such as delayed speech, they may have unrealistic expectations of their child and experience additional stress and confusion.
Most medical issues for children with Down syndrome being treatable	●	If not received, families may experience unnecessary stress and anxiety about their child's health and well-being.
Need for therapy services (e.g., occupational and speech therapy)	●	If not received, the child may not have appropriate therapies and may develop maladaptive behaviors.
Likelihood for Down syndrome recurrence (e.g., check karyotype ^d)	●	If not received, parents may be unaware that their child has a rare, inherited form of Down syndrome.
Breast feeding support resources	●	If not received, child may have difficulty feeding—especially sucking and swallowing—which can affect growth.
Overview of health issues that are likely to occur in the first year or two of life	●	If families do not receive this information, they may be unaware of what conditions their child is at risk for developing and what symptoms they should look for.
Referral to early intervention program in their area	●	If this referral is not received, developmental delays cannot be addressed and monitored and the child may develop maladaptive behaviors.
Referral to meet with a genetic counselor	●	If not received, family may not benefit from the expertise of a genetic counselor, who can discuss the cause of Down syndrome and any related health concerns.
Contact information for local Down syndrome support groups	●	If not received, families may not benefit from learning about the experiences of other families and may face difficulties, such as feeling isolated, which may affect their ability to care for their child with Down syndrome or their other children.
Contact information for a Down syndrome clinic (if available in their area)	●	If not received, child or family may not benefit from the specialized resources of a Down syndrome clinic, if needed.

Recommended resources	Twelve advocacy groups' assessment of likelihood of receipt by families	Consequences Down syndrome clinic specialists reported if resource not received
Additional support (e.g., social workers) to families whose babies have long hospital stays	●	If not received, families may experience higher stress levels, which could affect their ability to care for their child with Down syndrome or their other children.
Information about:		
When child's first early intervention ^e visit should occur	○	If families are not informed that the first visit should occur within the first few weeks or months of birth, they may delay accessing this important resource.
Importance of mother and infant bonding	○	If families are not informed of the importance of this bonding and the mother is struggling to bond with her infant, she may experience depression and anxiety, which can have repercussions for the health of the child if it continues over a long period of time.
Causes of Down syndrome	○	If not received, families without information or with inaccurate information may struggle to cope with the diagnosis and understand their child.
Effect of Down syndrome on family and caregivers	○	If not received, family members may experience stress and develop feelings of isolation.
Sibling support resources	○	If not received, siblings may experience stress and develop feelings of isolation that could affect long-term family well-being.
Sources for accurate, up-to-date Down syndrome information	○	If families do not receive accurate, up-to-date Down syndrome information, they may not be informed advocates for their child and family as they negotiate the health care system.
Importance of enjoying time with baby	○	If families are not informed of the importance of enjoying their baby, they may focus more on the Down syndrome diagnosis than on their new baby.
Financial assistance resources (e.g., advisor, public insurance)	○	If families do not receive this information, they may be unaware of the long-term financial planning needs of their child with Down syndrome or the insurance coverage that their child can access.
Contact information for national Down syndrome groups	○	If not received, families may not access important resources that can help with stress and feelings of isolation.
Copy of health care guidelines for children with Down syndrome (e.g., those from AAP and/or DSMIG)	○	If not received, families may not be fully aware of the health risks their child may face and, as a result, may be less effective advocates.

Recommended resources	Twelve advocacy groups' assessment of likelihood of receipt by families	Consequences Down syndrome clinic specialists reported if resource not received
Information about what Down syndrome is	⊙	If not received, families may have inaccurate information, which may affect how they understand and cope with the diagnosis and advocate for their child.
Additional support to families who ask for help talking about Down syndrome diagnosis	⊙	If not received, families may experience confusion, anxiety, and isolation because they do not know how to cope with the diagnosis and convey their child's diagnosis to people in their social networks.

Source: GAO.

- The majority of the 12 advocacy groups we interviewed reported that these resources were likely to be received.
- The majority of the 12 advocacy groups we interviewed reported that these resources were less likely to be received.
- ⊙ Half of the 12 advocacy groups we interviewed reported that these resources were likely to be received, and half reported that these were less likely to be received.

Note: According to the Down syndrome clinic specialists, some of the resources in this table should be received by families at the time of diagnosis and again throughout the child's life.

^aAn echocardiogram is a test that uses sound waves to create a moving picture of the heart.

^bNewborns across the United States are universally screened for thyroid problems at birth.

^cNewborns in most states are universally screened for hearing problems at birth.

^dA karyotype is a test to examine the chromosomes in a sample of cells.

^eEarly intervention programs, which are generally administered by state-level agencies, provide infants and toddlers (ages 0 to 3) who have a disability, or who are at risk of developing a disability, and their families with appropriate services, such as speech therapy, occupational therapy, and family counseling.

^fBoth the American Academy of Pediatrics (AAP) and the Down Syndrome Medical Interest Group (DSMIG) have published Down syndrome-specific health care guidelines for physicians. These guidelines for physicians contain many of the same health items that are on this list.

The time of diagnosis is a key time for children with Down syndrome and their families. According to the Down syndrome clinic specialists, if newborns are not tested for certain medical conditions immediately after diagnosis, serious and even life-threatening consequences can occur. In addition, specialists from one Down syndrome clinic noted that this is a key time for families to be given information to help them understand how their child's diagnosis may affect their family. However, according to the Down syndrome clinic specialists, families can be overwhelmed if too much information is presented at the time of diagnosis, especially if they are already overwhelmed emotionally and psychologically from receiving the diagnosis.

All of the specialists we interviewed at the six Down syndrome clinics agreed that if families do not receive resources recommended for the time of diagnosis, the health consequences for the child could be severe. For example, if a newborn’s heart defect is not detected early, he or she may experience serious complications and even death in the first days or weeks of life. If a newborn’s hypothyroidism⁵¹—which can be easily treated—is not detected early, he or she may experience additional cognitive impairment or other complications. If a family is not provided with a copy of the Down syndrome-specific health care guidelines, they may not be fully aware of the health risks their child may face, and they may be less effective advocates. (See table 2 for these and other health consequences that may occur if these resources are not received by families.)

Advocacy groups told us that if there were gaps in the resources that families received from their health care providers upon diagnosis, advocacy groups and other community organizations sometimes provided the missing material. For example, advocacy groups sometimes drop off “New Parent Packets” at area hospitals that include the Down syndrome-specific health care guidelines and information about what Down syndrome is and how it can affect the family. Advocacy groups also offer family support groups, including groups geared specifically toward grandparents and fathers, and host seminars on financial planning.

Families Were Less Likely to Receive Most of the Resources That Down Syndrome Clinic Specialists Recommended for Early Childhood

In contrast to the time of diagnosis, Down syndrome advocacy groups in selected communities told us that families of children with Down syndrome in those communities were less likely to receive most of the recommended resources from their health care providers for early childhood. These resources are important to their children’s ongoing health and the well-being of their families. The specialists from six Down syndrome clinics we interviewed recommended 23 resources that families should receive through their health care providers after diagnosis and throughout early childhood. (See table 3.) Advocacy groups reported that families were likely to receive only about one-quarter (6 of 23) of these resources. For example, resources that families were likely to receive included information about the need to screen for celiac disease, the need for vision screening, and the risk for upper respiratory infections. But

⁵¹Hypothyroidism is a condition in which the thyroid gland does not produce enough thyroid hormone.

families were less likely to receive about three-quarters (17 of 23) of the resources recommended for early childhood. For example, families were less likely to receive information about the need to see a pediatric dentist, how to prevent obesity, and the importance of communicating with their child. In addition, families were less likely to receive a copy of a Down syndrome-specific growth chart.

Table 3: Resources Important to the Ongoing Health of the Child That Specialists from Six Down Syndrome Clinics Recommended Families Receive for Early Childhood, Likelihood of Receipt, and Consequences If Not Received

Recommended resources	Twelve advocacy groups' assessment of likelihood of receipt by families	Consequences Down syndrome clinic specialists reported if resource not received
Information about:		
Need for vision screening	●	If the child is not screened, an undiagnosed impairment may delay vision development and may cause permanent blindness.
Need for celiac disease screening ^a	●	If the child is not screened, undiagnosed celiac disease may affect the child's growth and cause problems such as diarrhea, constipation, and behavioral changes.
Need for cervical spine screening ^b	●	If the child is not screened, undiagnosed movement of the cervical spine may lead to serious or permanent damage to the spinal cord.
Need to perform neck X-ray	●	If the child is not screened, undiagnosed movement of the cervical spine may lead to serious or permanent damage to the spinal cord.
Need to perform neurological examination ^c	●	If the child is not screened, undiagnosed movement of the cervical spine may lead to serious or permanent damage to the spinal cord.
Risk for upper respiratory infections	●	If not informed, families may not be aware that upper respiratory issues need to be treated quickly to prevent more serious illness.
Need for more doctor visits for child with Down syndrome	○	If not received, families may be surprised and unprepared for the frequent referrals to specialists and the need for follow-up appointments.
Need to see a pediatric dentist	○	If not received, families may be unaware that children with Down syndrome have a high risk for dental problems, such as missing or crowded teeth.
Potential for infantile spasms ^d	○	If not informed, the parents may not recognize the symptoms, which might lead to additional developmental delays.

Recommended resources	Twelve advocacy groups' assessment of likelihood of receipt by families	Consequences Down syndrome clinic specialists reported if resource not received
Potential sleeping issues	○	If not informed, families may be unaware that sleeping issues, particularly obstructive sleep apnea and sleep disturbances, can lead to chronic cardiopulmonary disease as well as problems with attention, behavior, and learning.
Potential use of Synagis vaccine ^g (e.g., for respiratory illness)	○	If not informed, at-risk children may not be vaccinated and can develop respiratory syncytial virus, which can cause illnesses ranging from the common cold to a very severe illness, and even death.
Potential sensory processing disorders ^f	○	If not informed, families may be unaware that children with Down syndrome can develop sensitivities such as those related to food texture, touch, and sound, which can lead to behavior that further complicates development.
Physical activity and proper nutrition to prevent obesity	○	If not informed, families may be unaware that the child can develop obesity and associated medical conditions, such as type II diabetes and blood pressure problems. Lack of physical activity affects other health issues, such as energy levels, sleep, and mental health.
Transition that occurs at age 3 from early intervention ^g to school system	○	If not informed, parents may not place their child in the most appropriate educational setting.
Importance of communicating with child (e.g., sign language)	○	If not informed, families may not use early communication techniques, which may lead to frustration and behavioral problems.
Learning styles for children with Down syndrome (e.g., visual learners)	○	If not informed, parents may not learn about educational techniques that work well for children with Down syndrome.
What it is like to grow up with Down syndrome	○	If not received, families may have inaccurate information, which may affect how they cope with the diagnosis, approach parenting, and understand what is possible for their child.
National conferences where families can network and get information	○	If not received, families may miss an opportunity to interact with other people with Down syndrome and their families and gather important information.
Support groups for comorbidities/dual diagnoses, if needed (e.g., autism)	○	If not received, families of children with dual diagnoses may feel excluded from Down syndrome-only support groups and experience feelings of isolation.
The Special Olympics ^h	○	If not received, children may not participate in the Special Olympics; programs such as this help physical development, which is important for mental health and weight management.

Recommended resources	Twelve advocacy groups' assessment of likelihood of receipt by families	Consequences Down syndrome clinic specialists reported if resource not received
Social development opportunities in the community (e.g., playgroups)	○	If not received, children with Down syndrome may miss the opportunity to practice speech and language, model behaviors, and develop social skills.
Non-Down syndrome community resources for children	○	If not received, children with Down syndrome may not feel integrated into their community and could miss out on these social development opportunities.
Copy of a Down syndrome-specific growth chart ^d	○	If not received, families may not have an understanding of the growth expectations for their child and how they differ from the typical growth chart.

Source: GAO.

- The majority of the 12 advocacy groups we interviewed reported that these resources were likely to be received.
- The majority of the 12 advocacy groups we interviewed reported that these resources were less likely to be received.

Note: Both the American Academy of Pediatrics (AAP) and the Down Syndrome Medical Interest Group (DSMIG) have published Down syndrome-specific health care guidelines for physicians. These guidelines for physicians contain many of the same items that are on this list.

^aCeliac disease causes a reaction to eating gluten, which damages the lining of the small intestine and prevents the intestine from absorbing food.

^bA cervical spine screening can detect increased mobility of the cervical spine, a condition also referred to as atlantoaxial instability.

^cA neurological examination uses a series of questions and tests to check the brain, spinal cord, and nerve function. The examination also checks mental status, coordination, and the functioning of muscles, senses, and reflexes.

^dInfantile spasms are a type of seizure seen in infancy and childhood that causes a sudden bending forward of the body with a stiffening of the arms and legs.

^eSynagis is a Food and Drug Administration-approved medication to help protect young babies from respiratory syncytial virus, a common virus that can be serious and, in some cases, can cause death.

^fSensory processing disorders are characterized by over- or undersensitivity to environmental stimuli.

^gEarly intervention programs, which are generally administered by state-level agencies, provide infants and toddlers (ages 0 to 3) who have disabilities, or who are at risk of developing a disability, and their families with appropriate services, such as speech therapy, occupational therapy, and family counseling.

^hThe Special Olympics is an organization and competition for people who have intellectual disabilities and guides local, national, and international programs. Children with intellectual disabilities between the ages of 2 through 7 can participate in the Youth Athletes program, and children with intellectual disabilities ages 8 and older can become Special Olympics athletes.

ⁱC. Cronk et al. "Growth Charts for Children with Down Syndrome: 1 Month to 18 Years of Age," *Pediatrics*, vol. 81, no. 1 (1988).

According to the Down syndrome clinic specialists, some information is most useful if provided in early childhood rather than at the time of diagnosis. For example, information about celiac disease is not necessary at diagnosis because it usually is not detectable until the child has begun eating solid foods.

According to the clinic specialists, if families do not receive the resources recommended for early childhood, there may be health consequences for the child. For example, if a child's poor vision is not detected, he or she may develop permanent vision loss. Similarly, if a child's celiac disease is not treated, the child's growth may be affected and he or she may develop diarrhea, constipation, and behavioral changes. (See table 3 for these and other health consequences that may occur if these resources are not received by families.)

Advocacy groups told us that if there were gaps in the resources that families received from their health care providers in early childhood, advocacy groups and other community organizations sometimes provided the missing material. For example, one advocacy group initiated a support group for families of children with Down syndrome who also have other medical conditions, such as autism. In addition, advocacy groups provide social development opportunities for children with Down syndrome by hosting playgroups, providing information about the Special Olympics to families, and sponsoring members to attend national and state conferences. Some community organizations also offer social opportunities for children, including children with Down syndrome, such as baseball leagues and swimming classes.

Advocacy Groups and National Survey Results Indicate Families May Face Barriers Such as Outdated or Inaccurate Information

According to Down syndrome advocacy groups, families in their communities may face barriers that can prevent them from using available resources, which can have a significant impact on the child and the family. (See table 4.) For example, barriers such as outdated or inaccurate information may lead parents to have a limited understanding of their child's Down syndrome diagnosis and, as a result, underestimate their child's potential. Important resources, such as early intervention therapy services and parent support groups, can be out of reach for some families who face barriers. For instance, advocacy groups identified barriers related to difficulty communicating in English, a lack of transportation, lengthy travel times to appointments (because of distance to resources or geographic location), or busy work schedules (which prevent them from accessing certain resources, such as early intervention therapy services and doctor appointments, that may only be available during the

workweek). Furthermore, advocacy groups mentioned that culture can be a barrier to accessing resources. For example, in some communities, parents of children with Down syndrome from other countries were reluctant to seek resources because of concerns about their community's social acceptance of people with Down syndrome.

Table 4: Barriers Commonly Cited by Advocacy Groups in Selected Communities

Barriers	Number of advocacy groups that cited barrier
Outdated or inaccurate information	7 of 12
Lack of insurance or barriers to access to care	7 of 12
Lack of transportation	7 of 12
Lack of adequate financial resources	6 of 12
Difficulty communicating in English	6 of 12
Negative attitudes about Down syndrome	6 of 12
Lack of technology access (e.g., computer, Internet, telephone)	5 of 12
Inability to recognize or connect with resources	5 of 12
Cultural differences	5 of 12
Distance to resources, geographic location	4 of 12
Limited time	4 of 12

Source: GAO analysis of information provided by 12 advocacy groups.

Note: Barriers cited by fewer than 4 of the advocacy groups were not included.

Results of the 2005-2006 NS-CSHCN also showed that families of children with Down syndrome may have trouble accessing needed services. The survey indicated that of the families of children with Down syndrome, birth through age 17, in the United States who needed a referral in the previous 12 months, an estimated 24 percent had problems obtaining referrals. Similarly, of the families whose children needed physical, occupational, or speech therapy in the previous 12 months, 18 percent of their children did not receive all needed therapies. In addition, 16 percent of families of children with Down syndrome reported that they faced barriers using needed resources in the previous 12 months. Some of the most commonly cited barriers were as follows:

- not getting services when their child needed them,
- not getting needed information,
- having problems finding service providers with needed skills,
- not having the types of services their child needed in their area, and
- having problems in communication between service providers.

Except for problems in communication between service providers, each of these barriers was also mentioned in our interviews with advocacy groups.

Some advocacy groups reported that they and their communities have made efforts to address some of the barriers faced by families related to inaccurate information, financial issues, language, and transportation. To address issues of inaccurate information, one advocacy group initiated an educational outreach program to health care professionals at area hospitals to share important information about Down syndrome, including contact information for local support groups and suggestions for giving a Down syndrome diagnosis to a family. Some advocacy groups made efforts to address financial issues; for example, some advocacy groups arranged for financial advisors to speak to parents at workshops. In addition, some advocacy groups made efforts to address language barriers by translating materials into Spanish and having a staff person available who spoke Spanish.⁵² Finally, several advocacy groups told us that they were taking steps to address barriers related to transportation. For example, an advocacy group located in an urban area established four satellite community groups in outlying areas so that families could access resources without driving into the city.

Agency Comments

We provided a draft of this report to the Secretary of Health and Human Services for comment. In response, the Department of Health and Human Services (HHS) provided us with general comments, which are reprinted in appendix II, and technical comments that we incorporated as appropriate. In its general comments, HHS indicated that our report “presents a thorough summary of the current practices and the successes and challenges faced by children with Down syndrome and their families.” HHS emphasized the importance of early intervention services in maximizing children’s long-term development. The agency also suggested that cost-benefit analyses, which were beyond the scope of this review, could inform decisions about providing health care services to children with Down syndrome. HHS also suggested that we compare the results of the data analyses from the private health insurance data, the Medicaid data, and the NS-CSHCN data. As we noted earlier in this report, detailed comparisons across the private health insurance and Medicaid data would not be appropriate because of differences in the underlying insurance

⁵²However, some of these groups noted that they did not have the resources to meet the needs of families who spoke languages other than Spanish.

coverage. Finally, HHS suggested that we provide population sizes for the data sets analyzed, which we have done.

We are sending a copy of this report to the Secretary of Health and Human Services. The report also is available at no charge on the GAO Web site at <http://www.gao.gov>.

If you or your staffs have any questions regarding this report, please contact me at (202) 512-7114 or bascettac@gao.gov. Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this report. GAO staff who made major contributions to this report are listed in appendix III.



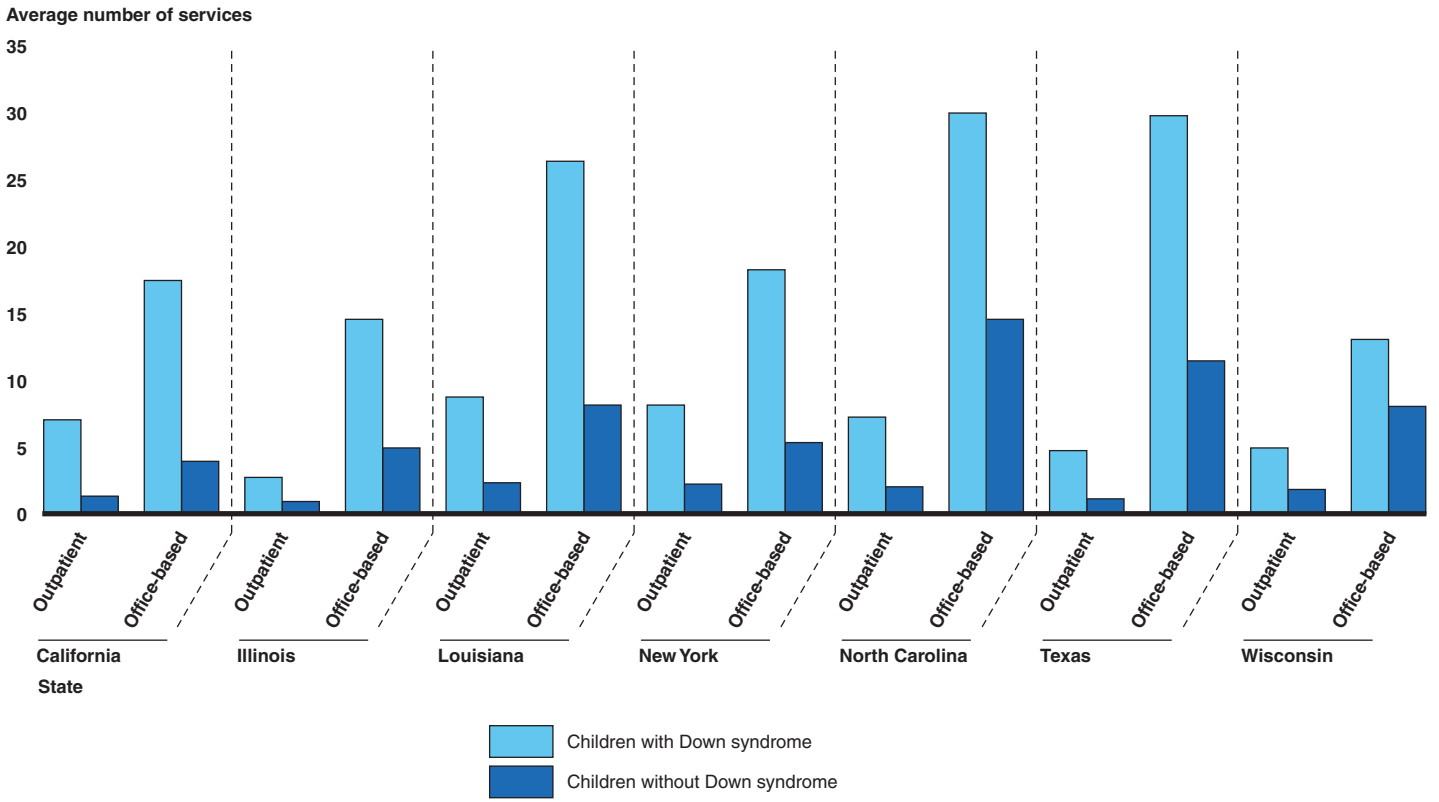
Cynthia A. Bascetta
Director, Health Care

Appendix I: Medicaid Data

Figures 7 through 10 show that of the children enrolled in Medicaid in 2007, children with Down syndrome from birth through age 4 received more medical care than children without Down syndrome in the seven states in our study.¹ Children with Down syndrome had more outpatient and office-based services than children without Down syndrome in each state we reviewed. (See fig. 7.) In addition, children with Down syndrome generally had more hospitalizations and a longer average length of stay than children without Down syndrome. (See figs. 8 and 9.) Medicaid expenditures were higher for children with Down syndrome than for children without Down syndrome for outpatient, office-based, and inpatient care. (See fig. 10.)

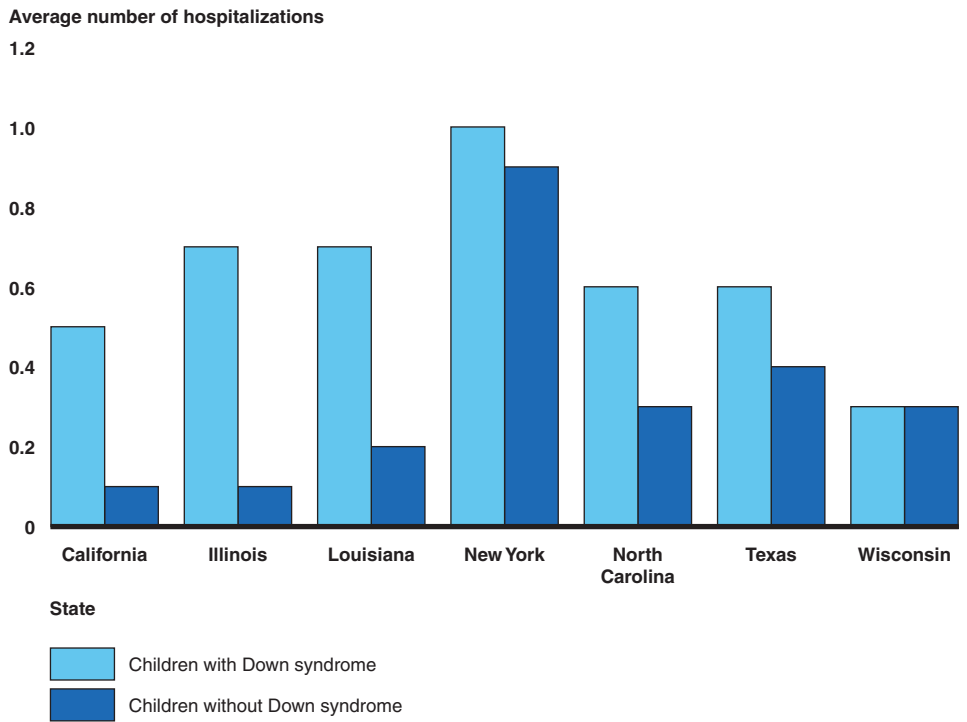
¹We analyzed fee-for-service claims for services provided in 2007; however, because of coverage variations within and across states, not all services may be covered by fee-for-service plans across all states.

Figure 7: Average Number of Medicaid Outpatient and Office-Based Services for Children from Birth through Age 4, by State, 2007



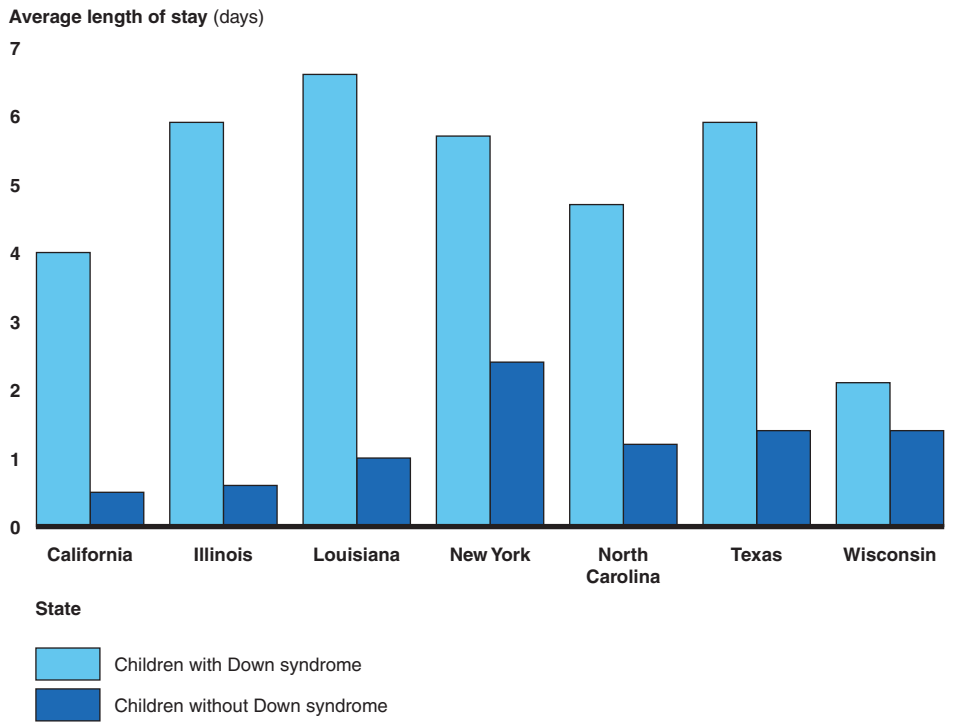
Source: GAO analysis of 2007 Medicaid MAX data.

Figure 8: Average Number of Medicaid Hospitalizations for Children from Birth through Age 4, by State, 2007



Source: GAO analysis of 2007 Medicaid MAX data.

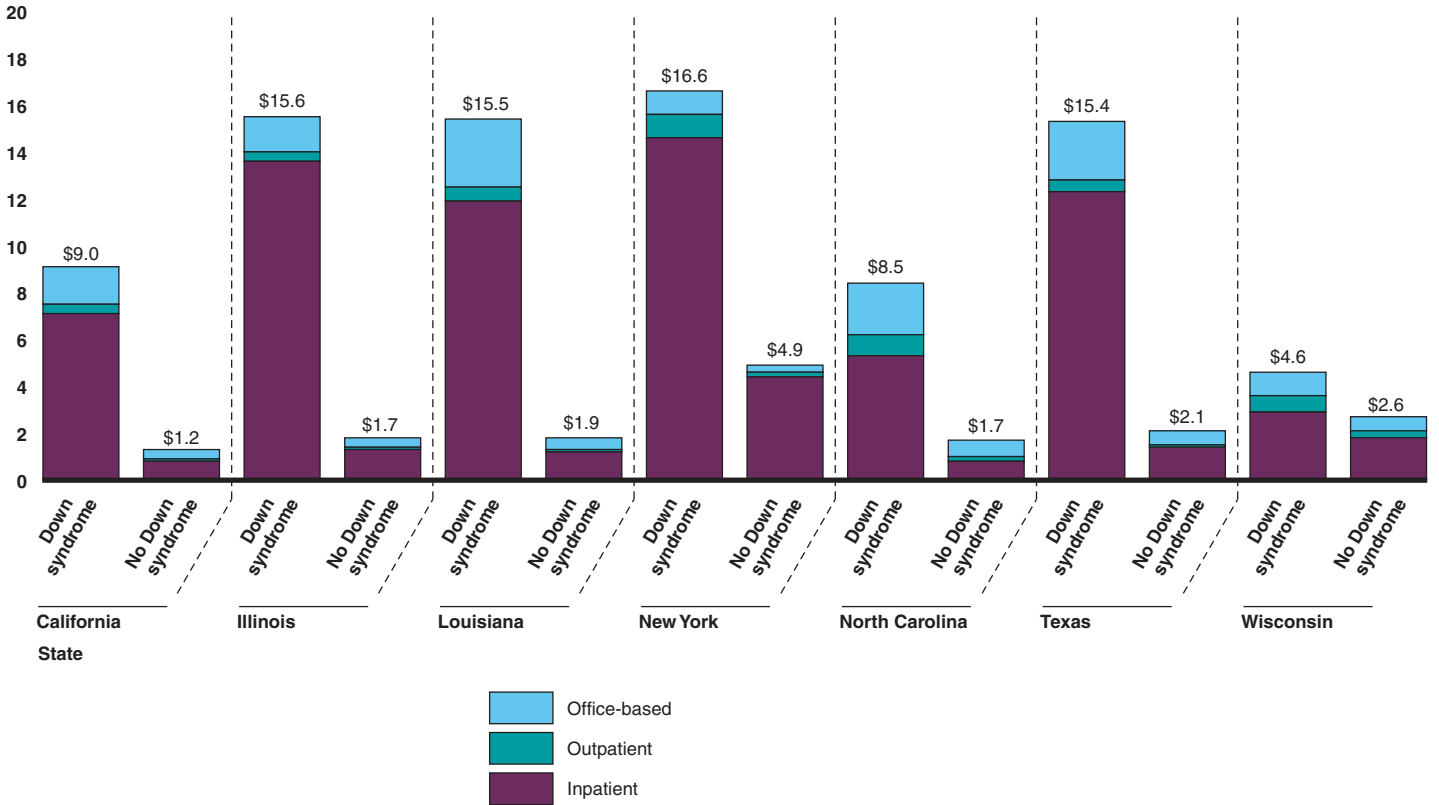
Figure 9: Average Length of Medicaid Hospital Stay for Children from Birth through Age 4, by State, 2007



Source: GAO analysis of 2007 Medicaid MAX data.

Figure 10: Average Medicaid Expenditures for Office-Based, Outpatient, and Inpatient Services for Children from Birth through Age 4, by State, 2007

Average expenditures (dollars in thousands)



Source: GAO analysis of 2007 Medicaid MAX data.

Note: Expenditures represent the average Medicaid payments for office-based, outpatient, and inpatient care made under fee-for-service arrangements.

Appendix II: Comments from the Department of Health and Human Services



DEPARTMENT OF HEALTH & HUMAN SERVICES

OFFICE OF THE SECRETARY

Assistant Secretary for Legislation
Washington, DC 20201

SEP 24 2010

Cynthia A. Bascetta
Director, Health Care
U.S. Government Accountability Office
441 G Street N.W.
Washington, DC 20548

Dear Ms. Bascetta:

Attached are comments on the U.S. Government Accountability Office's (GAO) report entitled: "Children with Down Syndrome: Families Are More Likely to Receive Resources at Time of Diagnosis Than in Early Childhood" (GAO-10-975).

The Department appreciates the opportunity to review this report before its publication.

Sincerely,

A handwritten signature in cursive script that reads "Jim R. Esquea".

Jim R. Esquea
Assistant Secretary for Legislation

Attachment

GENERAL COMMENTS OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS) ON THE GOVERNMENT ACCOUNTABILITY OFFICE'S (GAO) DRAFT CORRESPONDENCE ENTITLED, "CHILDREN WITH DOWNS SYNDROME: FAMILIES ARE MORE LIKELY TO RECEIVE RESOURCES AT TIME OF DIAGNOSIS THAN IN EARLY CHILDHOOD"(GAO-10-975)

The Department appreciates the opportunity to review and comment on this draft report. The report presents a thorough summary of the current practices and the successes and challenges faced by children with Down Syndrome and their families. Following are specific comments:

The report and report title suggest that Down Syndrome patients and families receive more treatment and services than those families without children with Down Syndrome. However, the report then proceeds to note these children are not getting all the services that specialists would recommend.

We are concerned that the report's emphasis on the number of services received will drown out the improved impact from early intervention and the long term benefits. We suggest more context be provided from the previous GAO evaluation cited in footnote 31. If possible cost-benefits should also be discussed. Given the concern about increased health care costs, quoting costs without context is not providing a fair review of the impact of the services and what benefits may be gained.

GAO may also want to provide a hypothesis or make a statement regarding the difference in findings between health insurance (private and Medicaid), health services utilization, and expenditure data for children with Down Syndrome and the survey findings from specialists at Down Syndrome Specialty Care Clinics, advocacy groups, and the National Survey of Children with Special Health Care Needs results.

Finally, we suggest that GAO may want to provide the population size for the data analyzed. For example, what are the total numbers for children with Down Syndrome compared to children without Down Syndrome in both the Medicaid study population and the large private health insurance company study population?

Appendix III: GAO Contact and Staff Acknowledgments

GAO Contact

Cynthia A. Bascetta, (202) 512-7114 or bascettac@gao.gov

Staff Acknowledgments

In addition to the contact named above, Jenny Grover, Assistant Director; Julianne Flowers; Rich Lipinski; Sarah-Lynn McGrath; Julie E. Pekowski; Roseanne Price; Laurie F. Thurber; Karin J. Wallestad; and Jennifer Whitworth made key contributions to this report.

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