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SUPPLEMENTAL
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Preliminary Observations
on Children with Mental
Impairments

Statement of Daniel Bertoni, Director
Education, Workforce, and Income Security

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Highlights of [GAO-12-196T](#), testimony before the Subcommittee on Human Resources, Committee on Ways and Means, House of Representatives

Why GAO Prepared this Testimony

The Social Security Administration's (SSA) Supplemental Security Income (SSI) program provides cash benefits to eligible low-income disabled individuals, including children, as well as certain others. Children may generally qualify for SSI benefits if they meet certain financial requirements and are deemed to have a qualifying medically determinable physical or mental impairment of a specified duration or severity that results in a functional limitation. In 2010, SSA paid more than \$9 billion to about 1.2 million disabled children. Over the past decade, the overall number of children receiving SSI benefits has continued to rise.

In this statement, GAO discusses initial observations from its ongoing review and examines (1) the trends in the rate of children receiving SSI benefits due to mental impairments over the past decade; (2) the role that medical and nonmedical information, such as medication and school records, play in the initial determination of a child's medical eligibility; and (3) the steps SSA has taken to monitor the continued medical eligibility of these children. To examine these issues, GAO analyzed program data, interviewed SSA officials, conducted site visits to SSA field offices and state disability determination services (DDS) offices, and interviewed external experts. This work is ongoing and GAO has no recommendations at this time. GAO plans to issue its final report in April 2012.

View [GAO-12-196T](#). For more information, contact Daniel Bertoni at (202) 512-7215 or bertonid@gao.gov.

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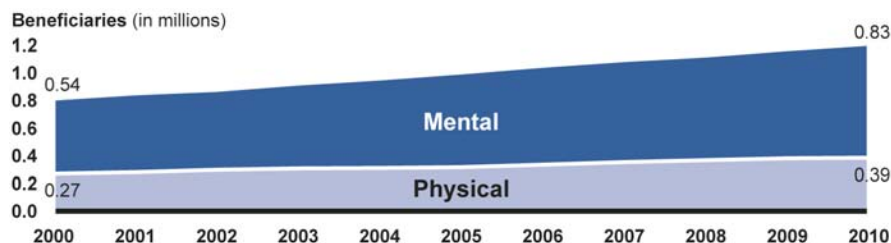
SUPPLEMENTAL SECURITY INCOME

Preliminary Observations on Children with Mental Impairments

What GAO Found

The numbers of children applying for and receiving SSI benefits due to a mental impairment has increased over the past decade and now comprise a growing majority of all child beneficiaries. While more than half of child applicants are denied each year, children with mental impairments, such as autism, have represented a growing share of those medically allowed for benefits—increasing from 60 to 67 percent between fiscal years 2000 and 2010. Factors including but not limited to the rising number of children living in poverty and increased diagnosis of certain mental impairments may have contributed to such growth. However, the relative effects of these and other factors on program growth are not fully known at this time.

Number of Children under Age 18 Receiving Federally Administered SSI Payments, by Mental and Physical Impairment Group, December 2000–December 2010



Source: GAO analysis of SSA data from the Supplemental Security Record.

Generally, DDS officials reported that they rely on a combination of key medical and nonmedical information—such as medical records and teacher and parent assessments—in determining a child's medical eligibility and that they consider the totality of information related to the child's impairments, rather than one piece of information in isolation. For example, SSA and DDS officials said that they consider a child's use of prescribed medications in the context of other information including school records and teacher assessments, which are critical in evaluating the child's functioning over time. Yet, despite the importance of such nonmedical evidence, GAO's work shows that examiners sometimes face challenges in obtaining this information partly due to teachers' reluctance to complete the assessments.

SSA is required to periodically review the medical eligibility of certain children receiving SSI benefits, but GAO's work shows that SSA has conducted significantly fewer childhood continuing disability reviews (CDR) in recent years. Between fiscal years 2000 and 2010, the number of childhood CDRs and age 18 reviews overall fell from more than 200,000 to about 126,000 (a 38 percent decrease), while childhood CDRs for those with mental impairments dropped from more than 84,000 to about 13,000 (an 84 percent decrease). SSA officials have acknowledged that the agency is not conducting childhood CDRs in a timely manner mostly due to resource constraints. However, SSA recognizes the importance of conducting CDRs and has recently estimated that the CDR process yields a savings-to-cost ratio of \$12.50 to \$1.

Mr. Chairman and Members of the Subcommittee:

I am pleased to be here today to discuss our preliminary observations on children with mental impairments in the Supplemental Security Income (SSI) program. Administered by the Social Security Administration (SSA), SSI is a nationwide federal assistance program that provides cash benefits to eligible low-income disabled individuals, including children, as well as certain individuals who are aged or blind. In 2010, SSA paid almost 8 million recipients about \$50 billion in SSI benefits, of which more than \$9 billion was paid to about 1.2 million disabled children. During the early and mid 1990s, the SSI program experienced a period of unprecedented growth for children due, in part, to legal developments that expanded program eligibility for children with mental impairments. For example, from the end of 1989 through 1996, the number of children receiving SSI benefits more than tripled from 265,000 to about 955,000. Since that time, the number of children receiving SSI benefits has continued to rise, especially for those with mental impairments. Our prior work has shown that accurately diagnosing some types of mental impairments is a complex and often subjective process for SSA, which can sometimes be vulnerable to fraud and abuse.

My statement today focuses on initial observations from our ongoing review and examines (1) the trends in the rate of children receiving SSI benefits due to mental impairments over the past decade; (2) the role that medical and nonmedical information, such as medication and school records, play in the initial determination of a child's medical eligibility; and (3) the steps SSA has taken to monitor the continued medical eligibility of these children. To examine these issues, we collected agency data on the overall number of initial disability determinations and allowances, the number and types of mental impairments, and the number of continuing disability reviews of children conducted by SSA. We assessed the reliability of the data presented in this statement and found potential limitations with the extent to which primary and secondary impairment codes within SSA's 831 disability files—the file that contains data on disability determinations—may be complete. However, because the 831 disability files are used by SSA to reflect the decisions made regarding medical determinations, we determined that these data were sufficiently reliable to describe certain trends among children in the SSI program. In our ongoing work, we will conduct a case file review of a random, generalizable sample of select SSI child mental impairments cases decided in fiscal year 2010, which will potentially assist us in better understanding the extent of this limitation. We also conducted in-depth interviews with SSA management and line staff at SSA headquarters and

six SSA regions—Philadelphia, Pennsylvania; Boston, Massachusetts; Atlanta, Georgia; Dallas, Texas; Chicago, Illinois; and San Francisco, California. Our work included site visits to 9 field offices within these regions, as well as 11 state disability determination services (DDS) offices (state agencies under the direction of SSA that perform medical eligibility determinations and continuing disability reviews of SSI applicants). We selected these sites on the basis of their geographic location, as well as the volume of SSI applications and benefit allowances for children with mental impairments. In addition, we interviewed numerous external experts from the medical and disability advocacy communities and reviewed relevant federal laws and regulations. We plan to issue our final report in April 2012 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 will provide a reasonable basis for our findings and conclusions based on our audit objectives.

Background

Since 1974, the SSI program, under Title XVI of the Social Security Act, as amended,¹ has provided benefits to low-income blind and disabled persons, including adults and children² as well as certain aged individuals who meet financial eligibility requirements and SSA's definition of disability. For children, a disability is a medically determinable physical or mental impairment that results in certain functional limitations, and is expected to result in death or which has lasted or can be expected to last for a continuous period of at least 12 months.³ Families of children receiving SSI payments are generally required to use the benefit to meet

¹Pub. L. No. 92-603, § 301, 86 Stat. 1329, 1465.

²For purposes of the SSI program, the term "child" means an individual who is neither married nor (as determined by the Commissioner of Social Security) the head of a household, and who is (1) under the age of 18, or (2) under the age of 22 and (as determined by the Commissioner of Social Security) a student regularly attending a school, college, or university, or a course of vocational or technical training designed to prepare him for gainful employment. 42 U.S.C. § 1382c(c).

³42 U.S.C. § 1382c(a)(3)(C)(i) and 20 C.F.R. § 416.906.

a child's current and future needs, including food, clothing, and shelter.⁴ The maximum payment for a child receiving SSI benefits is \$674 per month regardless of the severity of the child's impairment.⁵ As of December 2010, the average monthly child benefit was \$597.

To apply for benefits, the child's parent or guardian usually submits an application to SSA either in person at a local SSA field office, by telephone, or by mail. SSA's field offices are responsible for processing these applications and for verifying the child's and legal guardian's nonmedical eligibility requirements, including income, resources, and living arrangement information. After initial verification, the field office transmits the case file to their state disability determination services office for a medical evaluation.⁶ To aid in evaluating whether a child is medically eligible, DDS offices review various medical and nonmedical information about the child, such as physician notes, psychological tests, school records, and teacher assessments.⁷ In certain situations, such as when

⁴Typically, a disabled child's SSI benefit is paid on behalf of the child to a "representative payee," such as a parent or guardian. The "representative payee" is responsible for using benefits received only for the child's use and benefit in a manner and for the purposes he or she determines, consistent with SSA guidelines, to be in the child's best interests. 20 C.F.R. § 416.635(a).

⁵All but five states and the Commonwealth of the Northern Mariana Islands supplement federal SSI benefits with additional payments. Fourteen states and the District of Columbia have state supplements that are either partially or wholly administered by SSA, and 31 states self administer their supplements.

⁶The medical evaluation is conducted under applicable legal requirements and SSA policy and assesses whether the child has a physical or mental impairment that is severe and that meets or medically or functionally equals impairments that are included in SSA's listing of impairments, and that meets the duration requirement. If these requirements are met, the child is found to be disabled for purposes of SSI. 20 C.F.R. § 416.924(a). The listing of impairments for children describes the impairments that cause marked and severe functional limitations. (See app. I for additional information about the listing of mental disorders for children.) If a child has a severe impairment that does not meet or medically equal any listing, DDS will decide whether the impairment results in limitations that "functionally equal" the listings. Under functional equivalence, a child can be found medically eligible for benefits if the child's impairment limits his or her functional ability to the same degree as described in the listed impairment. Functional equivalence is based on the principle that it is the functional limitations resulting from an impairment that make the child disabled, regardless of the particular medical cause. It was added as a basis for eligibility for children in response to the U.S. Supreme Court's decision in *Sullivan v. Zebley*, 493 U.S. 521, that SSA's use of medical listings of impairments for children—without conducting a functional analysis—was incomplete.

⁷20 C.F.R. § 416.913.

the evidence is not sufficient to support a decision as to whether a child is disabled, the DDS may purchase a consultative examination to assist in making the decision.⁸ If there is evidence that indicates the existence of a mental impairment, DDS makes every reasonable effort to ensure that a qualified psychiatrist or psychologist has completed the medical portion of the case review.⁹

After it makes its initial determination, the DDS returns the case file to the field office, where SSA completes any outstanding non-disability case development, computes the benefit amount, and begins paying benefits if the claimant was determined disabled. If the claim is denied, a claimant has 60 days to request that SSA reconsider its decision. If the claimant is dissatisfied with the reconsideration, he or she may request a hearing before an administrative law judge, whose decision may then be reviewed by SSA's Appeals Council. When these administrative review options have been exhausted, the claimant may request judicial review by filing an action in a federal district court.¹⁰

After SSA determines that a child is disabled, the agency is required by law, in certain circumstances, to conduct periodic reviews, known as a continuing disability review (CDR), to verify a child's continued medical eligibility for receiving SSI benefits.¹¹ SSA is generally required to perform CDRs (1) during the first year after birth for babies whose low birth weight is a contributing factor to the determination of disability¹² and (2) at least once every 3 years for all other children under age 18 whose conditions are considered likely to improve.¹³ DDS offices determine when

⁸20 C.F.R. § 416.919a(b). A consultative examination is a physical or mental examination or test purchased from a treating source or another medical source, including a pediatrician, for an individual at SSA's request and expense. 20 C.F.R. § 416.919.

⁹20 C.F.R. § 416.903(e).

¹⁰For more information about the administrative review process for disability determinations, see 20 C.F.R. § 416.1400 et seq.

¹¹SSA conducts two types of reviews to ensure that participants are eligible for benefits—CDRs and redeterminations. CDRs verify claimant's medical eligibility, while SSI redeterminations verify their financial eligibility and ensure that the beneficiary is receiving the right amount of SSI benefits. 20 C.F.R. §§ 416.989 and 416.204.

¹²42 U.S.C. § 1382c(a)(3)(H)(iv).

¹³42 U.S.C. § 1382c(a)(3)(H)(ii)(I).

beneficiaries will be due for CDRs on the basis of their potential for medical improvement, and select and schedule a review date—otherwise known as a “diary date”—for each beneficiary’s CDR. At the time of these reviews, the child’s representative payee generally must present evidence that the child is and has been receiving medically necessary and available treatment for his or her impairment. SSA is also required to redetermine the eligibility of children against the adult criteria¹⁴ for disability after they reach age 18.¹⁵

Number of Children Applying for and Receiving SSI Benefits Due to Mental Impairments Has Increased

The numbers of children applying for and receiving SSI benefits due to a mental impairment has increased over the past decade and now comprise a growing majority of all child beneficiaries. While not all such children who are deemed medically eligible ultimately meet SSI’s financial eligibility requirements,¹⁶ our preliminary analysis of medical allowances suggests that the growth in the number of child beneficiaries is roughly proportionate to the growth in the number of applicants. Furthermore, SSA data showed that the agency has denied a majority of child applicants each year.¹⁷ Between fiscal years 2000 and 2010, the average medical allowance rates for children with physical and mental impairments were about 37 and 46 percent, respectively (see fig.1).

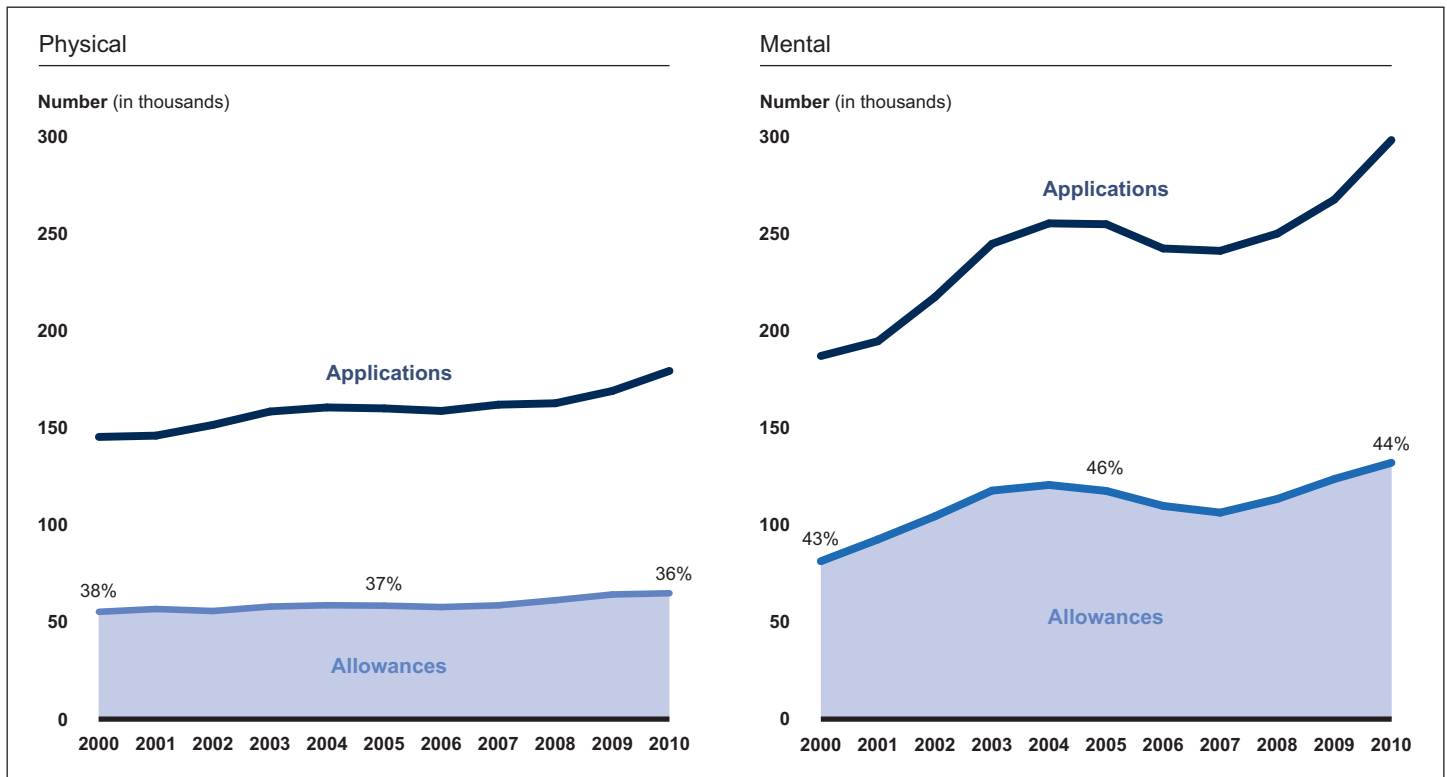
¹⁴Adults are considered disabled if they are unable to engage in substantial gainful activity by reason of a medically determinable physical or mental impairment expected to result in death or last at least 12 months. 42 U.S.C. § 1382c(a)(3)(A).

¹⁵42 U.S.C. § 1382c(a)(3)(H)(iii).

¹⁶Although a child may be found medically eligible for benefits due to a physical or mental impairment, SSA must verify the child’s financial and other non-medical eligibility. If these other criteria are not met, the child will not receive SSI benefits.

¹⁷Data and references to “applications” or “applicants” throughout this statement reflect SSI benefit claims where an initial disability determination was made each year. Some claims may have more than one determination if selected for a quality review or if the disability claim is updated during the same year.

Figure 1: SSI Applications and Allowances for Children under Age 18, by Mental and Physical Impairment Group, Fiscal Years 2000-2010



Source: GAO analysis of SSA data from the 831 Disability Files.

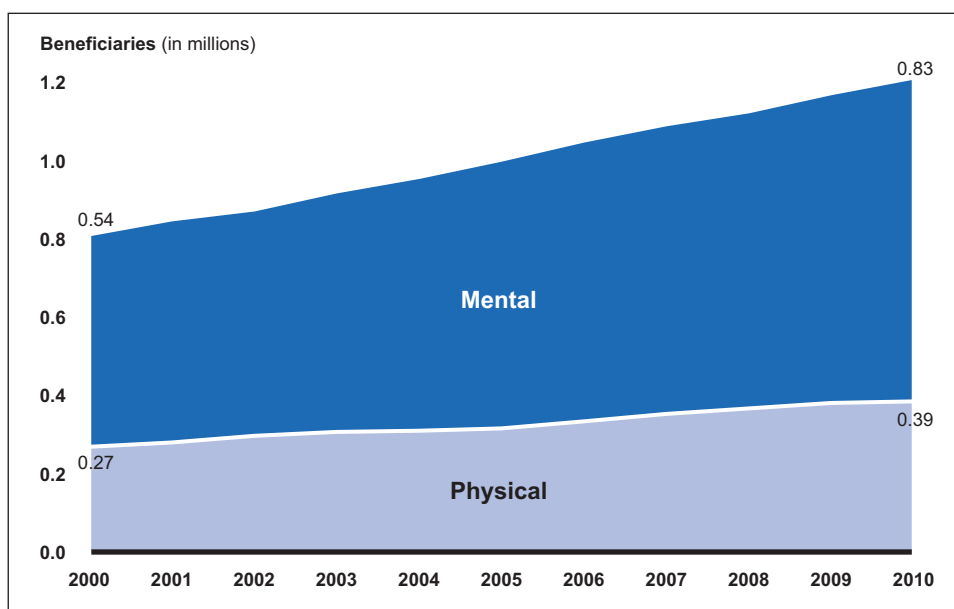
Note: The information highlighted in this figure is based on the primary impairment code recorded in the disability determination. Data represented as “applications” reflect SSI benefit claims were an initial disability determination was made each year. Some claims may have more than one determination if selected for a quality review or if the disability claim is updated during the same year. Such determinations are reflected in the data presented above.

SSA data show the number of child applicants with mental impairments increased 60 percent between fiscal year 2000 and fiscal year 2010, from 187,052 to 298,264, while the total number of SSI child beneficiaries with mental impairments on the rolls grew 52 percent from 543,000 to 827,000 (see fig. 2).¹⁸ Our preliminary research suggests that several factors may

¹⁸The number of adults receiving SSI benefits has also steadily increased over the past decade. As of December 2010, 6.7 million adults were receiving SSI disability benefits up from 5.8 million as of December 2000.

have contributed to the increased number of child applicants and beneficiaries, including but not limited to SSA's and child advocates' outreach efforts, improved access to health insurance for children, the rising number of children living in poverty, and increased diagnosis of certain mental impairments. However, the relative effects of these and other factors on program growth are not fully known at this time.

Figure 2: Number of Children under age 18 Receiving Federally Administered SSI Payments, by Mental and Physical Impairment Group, Dec. 2000–Dec. 2010



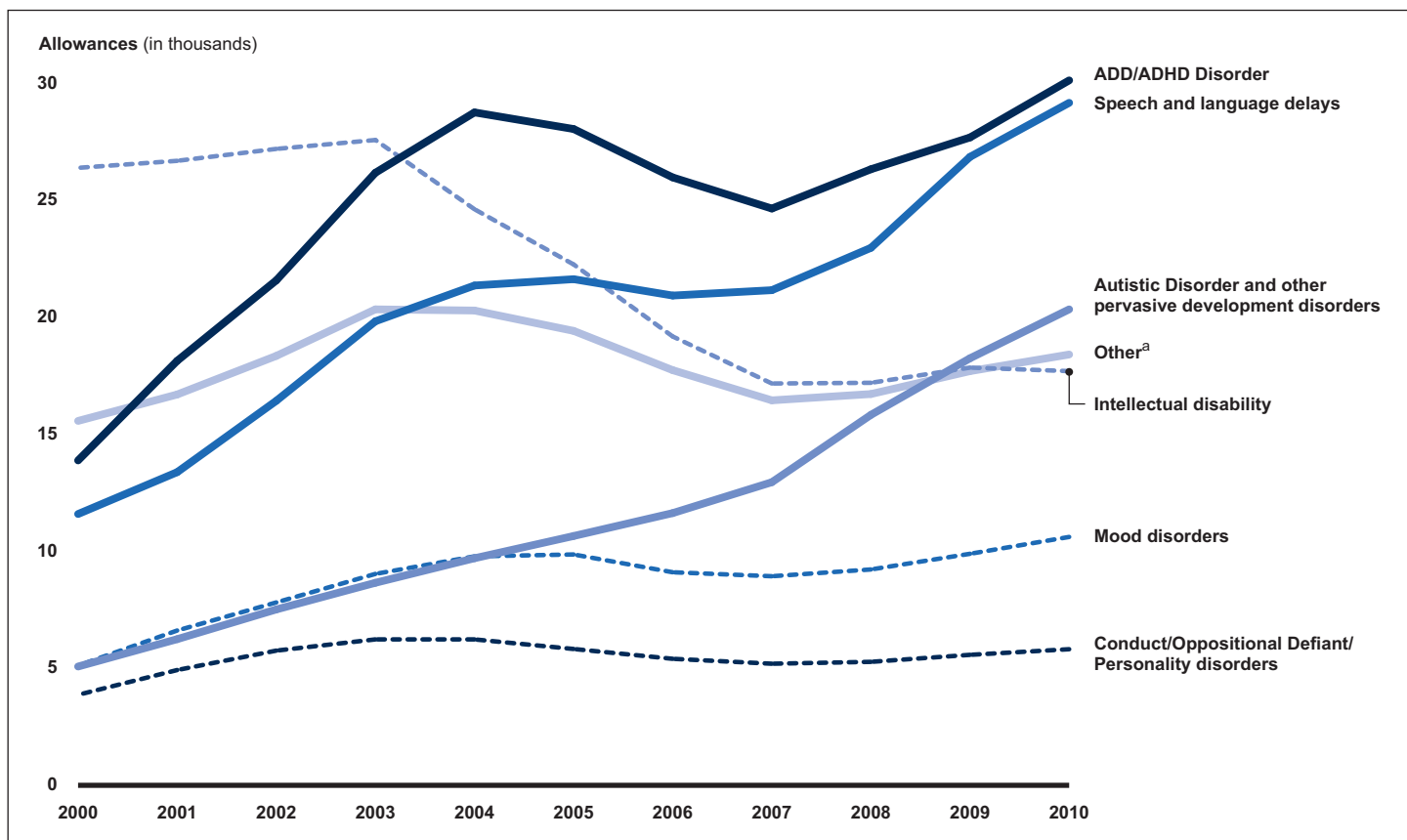
Source: GAO analysis of SSA data from the Supplemental Security Record.

Note: The above figure does not include those diagnostic groups that SSA reported as “unknown.” SSA data showed that as of December 2000, “unknowns” totaled 33,042 children (0.04 percent), and as of December 2010, 26,417 children (0.02 percent).

While it is unclear how various factors are contributing to growth at this time, SSA data show that since fiscal year 2000, children with mental impairments have represented the majority of all child applications and medical allowances for SSI benefits. For example, in fiscal year 2010, about 62 percent of all SSI child applicants had a mental impairment as a primary diagnosis, and about 67 percent of those applicants were medically approved for benefits. For those applicant children with mental impairments, SSA data also suggests that the number of children found medically eligible for benefits has increased for almost every mental impairment category—such as speech and language delay and mood

disorders—between fiscal years 2000 and 2010, with the exception of intellectual disability as most notable (see fig. 3).¹⁹

Figure 3: Medical Allowances for SSI Children with Mental Impairments, by Primary Impairment, Fiscal Year 2000-2010



Source: GAO analysis of SSA data from the 831 Disability Files.

Note: The information highlighted in this figure is based on the primary impairment code recorded in the disability determination.

^aThe “other” category includes borderline intellectual functioning; learning disorders; developmental and emotional disorders in newborns and younger infants; psychoactive substance dependence disorder; somatoform disorders/eating and tic disorders; anxiety disorders; schizophrenic, delusional, schizoaffective and other psychotic disorders; and organic mental disorders.

¹⁹In accordance with Rosa’s Law, “intellectual disability” has generally replaced the term “mental retardation.” Pub. L. No. 111-256, 124 Stat. 2643.

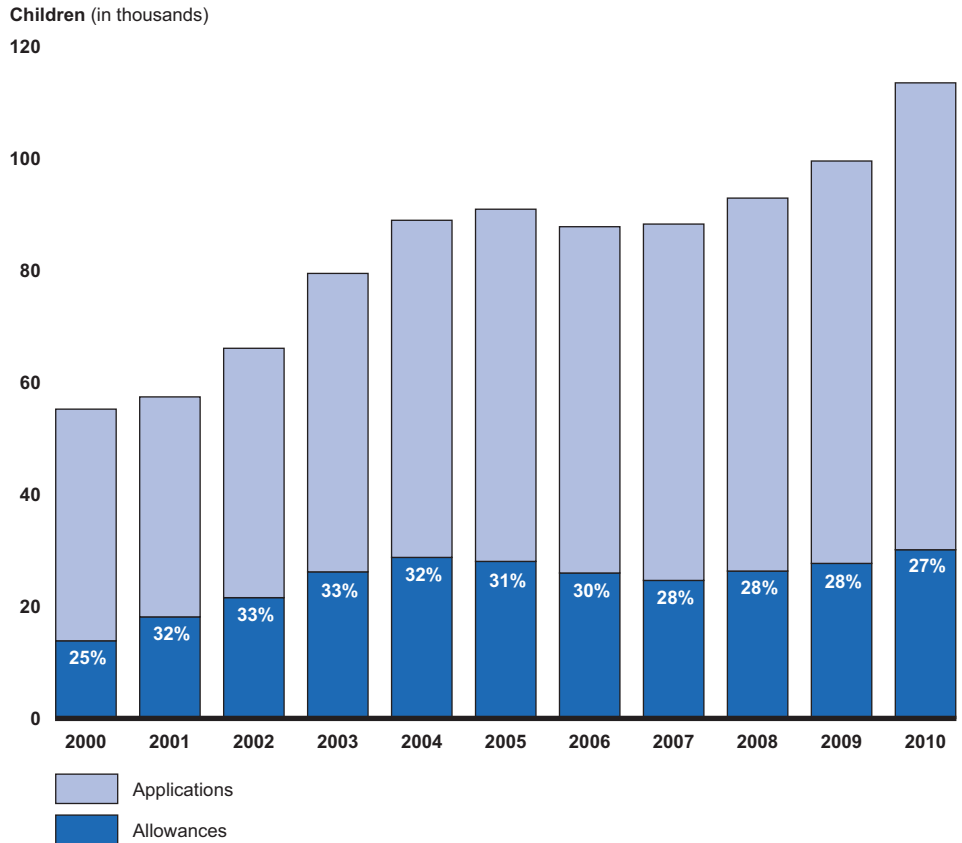
As part of our preliminary work, we examined individual mental impairments to determine which impairments had the highest number of applications and medical allowances. SSA's data on disability determinations is based on the primary impairment as designated by the DDS.²⁰ SSA's policy operations manual directs DDS examiners to code the primary impairment as the most severe condition that rendered the child disabled. In instances where multiple impairments are present, the secondary impairment is generally the next most severe following the primary. However, SSA officials have acknowledged that primary impairment codes are sometimes missing or inaccurately coded.²¹ In addition, the primary impairment code listed may be only one of several impairments that led DDS examiners to find the child medically eligible for benefits. In our ongoing review, we plan to conduct an in-depth case file review to determine the extent to which a secondary impairment was present for the most prevalent impairments and the extent to which the secondary impairment, or combination of impairments, influenced the eligibility decision. SSA data show that for fiscal year 2010, the three most prevalent primary mental impairments among medical allowances were for (1) attention deficit disorder/attention deficit hyperactivity disorder (ADD/ADHD), (2) speech and language delay, and (3) autistic disorder and other pervasive development disorders (autism). The following information provides a brief summary of each of these three impairments as they compare to the incidence of all mental impairments, as well as in terms of the proportion of applications and medical allowances:

ADD/ADHD. Between fiscal years 2000 to 2010, applications for this condition as a primary impairment more than doubled, from about 55,000 to 113,000. Also, the number of children found to be medically eligible increased by more than 100 percent, from 13,857 to 30,108 (see fig. 4). By December 2010, about 212,000 such children were receiving SSI benefits, and they comprised 26 percent of child recipients with mental impairments.

²⁰The recorded primary impairment code identifies the primary impairment used in the medical determination for an individual's eligibility for Title XVI disability benefits. It appears in the Social Security Administration's 831 and 832/833 Disability files.

²¹According to SSA officials, the error rate for impairment coding is estimated between 5 to 6 percent.

Figure 4: Applications and Medical Allowances for Children with Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder as a Primary Impairment, Fiscal Year 2000–2010



Source: GAO analysis of SSA data from the 831 Disability Files.

Note: The information highlighted in this figure is based on the primary impairment code recorded in the disability determination. Data represented as “applications” reflect SSI benefit claims where an initial disability determination was made within each year.

While children with ADD/ADHD represent the single largest primary diagnostic group, SSA data show that the majority of ADD/ADHD applications over the years have been medically denied. Some of the examiners we interviewed said that they rarely find a child medically eligible for benefits solely on the basis of an ADD/ADHD impairment alone, but more commonly in combination with another impairment, such as asthma or oppositional defiant disorder. Nevertheless, SSA officials suggested that the increase in both applications and medical allowances for children with ADD/ADHD might be attributable to an increase in

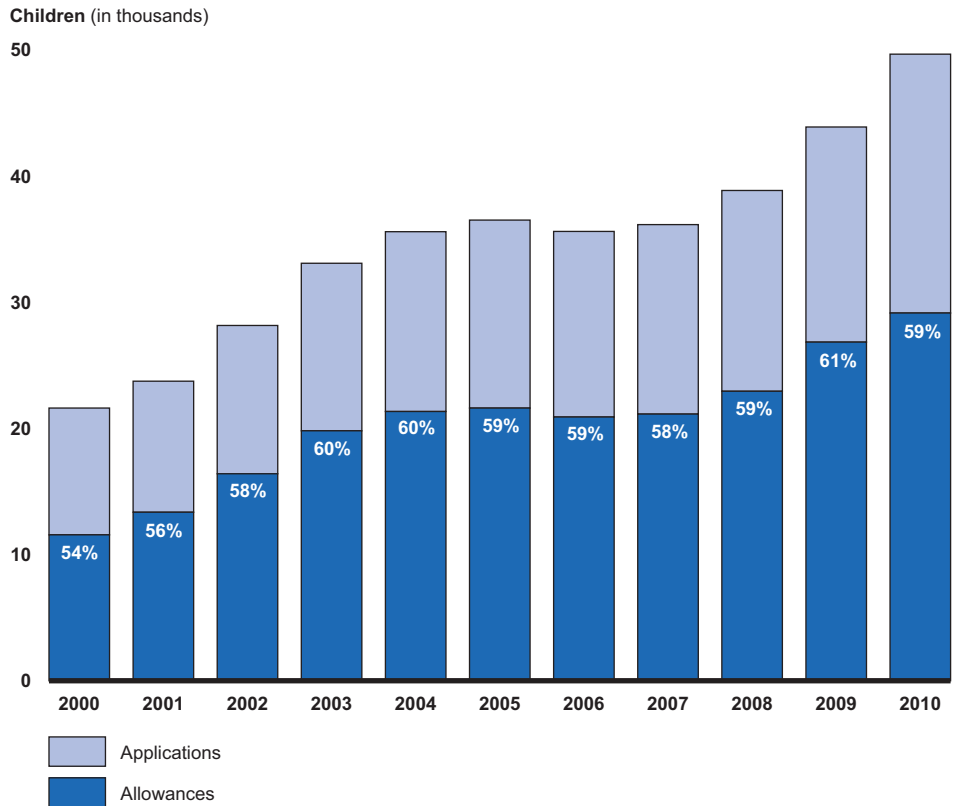
diagnosis over the last decade, and cited a National Institute of Health survey finding that ADHD diagnoses had increased, on average, by 3 percent from 1996 to 2006 and by 5.5 percent, on average, from 2003 to 2007.²² SSA officials also noted a 2008 medical study reporting that ADHD is one of the most commonly diagnosed childhood neurobehavioral disorders.²³

Speech and language delay. During the last decade, both applications and medical allowances for children with speech and language delay have increased overall, but the proportion of applicants found medically eligible has remained relatively stable over time. Between fiscal years 2000 to 2010, applications for this impairment more than doubled, from 21,615 to 49,664 while the number of children found to be medically eligible nearly tripled, from 11,565 to 29,147 (see fig. 5). As of December 2010, about 174,000 (21 percent) children with mental impairments were receiving benefits due to a speech and language delay. While some DDS officials expressed the view that increases could be attributed to increased school testing and screening programs, SSA officials said further study was needed to better understand these particular increases.

²²Centers for Disease Control and Prevention/National Survey of Children's Health, "National Health Interview Survey, 2004-2006."

²³Pastor, P.N., Reuben, C.A., "Diagnosed attention deficit hyperactivity disorder and learning disability: United States, 2004-2006" Vital Health Stat 2008; 10 (237).

Figure 5: Applications and Medical Allowances for Children with Speech and Language Delay as Primary Impairment, Fiscal Year 2000–2010



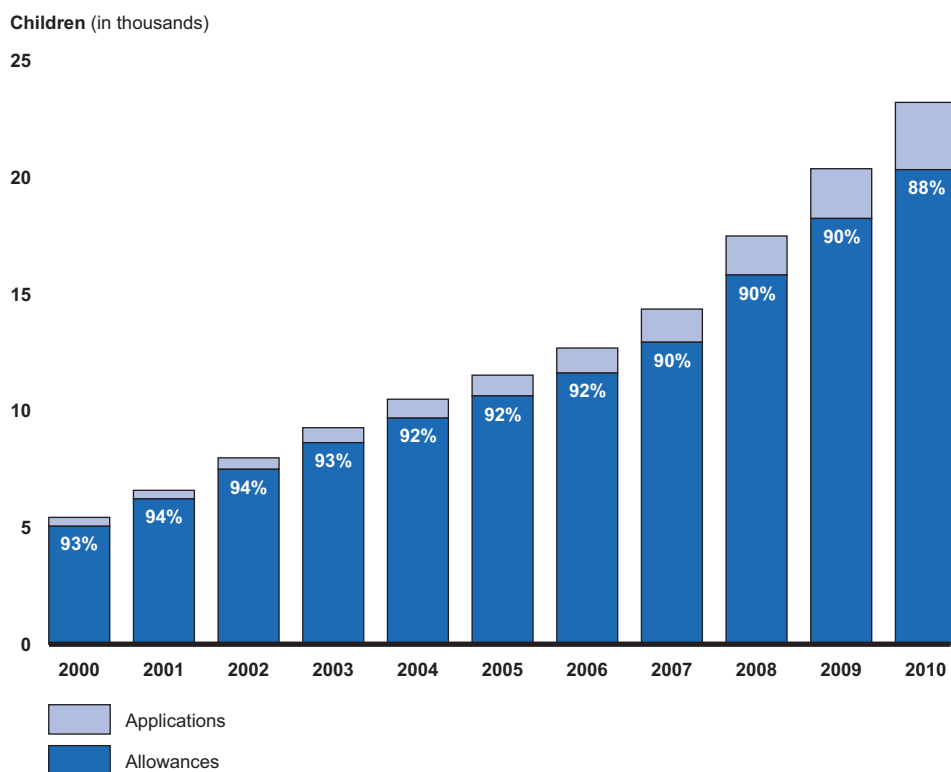
Source: GAO analysis of SSA data from the 831 Disability Files.

Note: The information highlighted in this figure is based on the primary impairment code recorded in the disability determination. Data represented as “applications” reflect SSI benefit claims where an initial disability determination was made within each year.

Autism. Between fiscal years 2000 and 2010, autism applications more than quadrupled from 5,430 to 23,203, and medical allowances increased similarly from 5,050 to 20,319 (see fig. 6). As of December 2010, about 95,000 (11 percent) children with mental impairments were receiving SSI benefits due to autism. DDS examiners have generally found the vast majority of those children applying for SSI on the basis of autism medically eligible for benefits. SSA officials attributed the increase in the number of autism applications and medical allowances over the years to greater incidence of autism among children and explained that some children who may have previously been diagnosed as intellectually disabled are instead being diagnosed as autistic. According to one study

SSA cited, the prevalence of autism in children has increased from 0.6 per 1,000 live births in 1994 to 3.1 per 1,000 live births in 2003, while the prevalence of intellectual disability decreased by 2.8 per 1,000 live births in 2003.²⁴

Figure 6: Applications and Medical Allowances for Children with Autism as a Primary Impairment, Fiscal Year 2000–2010



Source: GAO analysis of SSA data from the 831 Disability Files.

Note: The information highlighted in this figure is based on the primary impairment code recorded in the disability determination. Data represented as “applications” reflect SSI benefit claims where an initial disability determination was made within each year.

²⁴Shattuck, P.T., “The contribution of diagnostic substitution to the growing administration prevalence of autism in the U.S. Special Education data.” *Pediatrics*. 2006 117: 1028-1037.

Examiners Report Using a Combination of Key Information Sources in Determining Medical Eligibility

In our preliminary work, DDS officials reported that they rely on a combination of key medical and nonmedical information—such as medical records, prescribed medications, school records, and teacher and parent assessments—in determining a child’s medical eligibility.²⁵ Several DDS officials said that when making a determination, they consider the totality of information related to the child’s impairments, rather than one piece of information in isolation.²⁶ With regard to the medical information used by examiners, SSA generally requires DDS examiners to assist children and their parents or guardians in obtaining medical records in an effort to develop at least a 1-year-long medical history prior to applying for benefits.²⁷ According to many of the DDS officials we interviewed, examiners attempt to obtain medical evidence, such as psychological tests, physician’s notes, and mental health records, for children with alleged mental impairments. If such evidence is not available or existing evidence is inconclusive, some DDS officials we spoke with said that they will purchase a consultative examination for the child. This examination is intended to provide the additional medical evidence, such as results of a physical examination and laboratory findings, needed for a determination. However, many DDS officials told us that such examinations are only a “snap-shot” in time and do not provide a longitudinal view of the child’s functioning over time. For this reason, some DDS officials said that information from a treating source with a long-standing relationship with the child, such as a physician, is more useful.

In response to concerns among many about the role medication plays in the determination process, we asked SSA and DDS officials how information about a child’s use of prescribed medications is used, and they told us it is generally given no more weight than any other medical or

²⁵See 20 C.F.R. § 416.913.

²⁶See 20 C.F.R. § 416.924(a).

²⁷20 C.F.R. § 416.912(d).

nonmedical information in determining a child's medical eligibility.²⁸ Several DDS officials told us that when making determinations for children with mental impairments, medication is considered in the context of other sources of information as "just one piece of the puzzle." To the extent that medication improves functioning, some DDS officials told us they could potentially find that the child is not disabled under program rules. Despite this fact, certain field office and DDS officials acknowledged they believe some parents are under the impression that medicating their children will improve their likelihood of being found eligible for benefits. However, other DDS officials said they think a number of parents may avoid medicating their child prior to a consultative examination so that the child misbehaves and appears more disabled.

To better understand the role of prescribed medications, in March 2011, SSA conducted an analysis to determine the effect reported use of medications has on determinations for children with three different mental impairments and concluded that no effect existed. To conduct this review, SSA compiled reports of medication usage for all fiscal year 2010 initial determinations for children with ADD/ADHD, oppositional/defiant disorder, or conduct disorder impairments.²⁹ For each impairment, SSA calculated the share of allowance and denial decisions for those claims with and without related medications. SSA subsequently noted that for the children examined, those with reports of related medication were more likely to be denied than to be allowed. Although SSA's analysis indicates that allowance and denial rates were similar for children with ADD/ADHD who were and were not taking related medications, children with related medications were somewhat more likely to be allowed for oppositional/defiant disorder and conduct disorder than those without

²⁸SSA regulations require that, when evaluating the effect of a child's impairment on his or her functioning, examiners consider the effects of treatment, including medication, the child is receiving. Specifically, they are required to consider the effects of medication on the child's symptoms, signs, laboratory findings, and functioning. If it appears that the child's symptoms are reduced by medications, they are required to consider (1) any functional limitations that persist, despite the medication; (2) whether the medications create any side effects that cause or contribute to the child's limitations; (3) the frequency of the child's need for medication; (4) changes in the child's medication or the way it is prescribed; and (5) any evidence over time of how the medication helps or does not help the child to function compared to other children the same age who do not have impairments. 20 C.F.R. § 416.924a(b)(9)(i).

²⁹SSA excluded from its analysis any medications that were not related to the three impairments. For example, a claim for a child with ADD/ADHD who was only taking asthma medication would not be classified as having a related medication.

medications. Because only about one-third of those allowed for these three impairments had reports of related medication, SSA concluded that medication usage does not affect the allowance of child claims for these impairments. However, SSA's analysis did not control for other factors, such as DDS location or claimant age, which may also affect allowance rates. Without a more in-depth analysis, the effect of the underlying causes of such differences is unknown. Although we did not independently validate SSA's findings, as part of our ongoing review, we plan to conduct a case file review of a random, generalizable sample of initial determinations decided in fiscal year 2010 for the most prevalent mental impairments—ADD/ADHD, speech and language delay, and autism. As part of this effort, we will identify what sources DDSs reported using to determine the child's medical eligibility and how they reported weighing various sources if material inconsistencies could not be resolved. This case file review should allow us to verify testimonial evidence from interviews with field office and DDS officials.

In addition to medical evidence, SSA policy directs DDS offices to use available evidence from nonmedical sources to evaluate the severity of the child's impairment and functioning as part of the eligibility determination. These sources include parents, day care providers, teachers, and others knowledgeable about the child's day-to-day behavior and activities. SSA field office staff may also provide observations about the child, if the child is present when the parent submits the application, in person, and the field office may notify the DDS if multiple siblings apply for benefits at the same time. Several DDS officials told us school records and teacher assessments (standardized questionnaires)³⁰ are especially critical, because these assessments provide information on the child's functioning over time and are generally more objective than parent assessments. Because parents may be unable to accurately assess the extent of their child's impairment, nearly all the DDS officials we interviewed said that information from the school, including the teacher assessment, was critical for making accurate determinations. According to some DDS officials, parents may primarily observe their child in an unstructured home environment after the child's medications have worn off, and they may not know what behaviors are developmentally normal, whereas teachers are generally in a position to compare the child to other

³⁰The standardized SSA teacher questionnaire includes checkboxes and multiple choice questions and is organized into sections that cover broad domains of functioning, such as acquiring and using information and attending and completing tasks.

children and provide neutral observations on how the child relates to peers, responds to medication, and performs in school. Several DDS officials told us that they compare all the information they collect to identify inconsistencies and decide how much weight to assign the various sources. For example, some officials told us examiners assess the credibility of parents' assessments of children's functioning by comparing it to physicians' and teachers' statements.

Despite the importance of nonmedical information in determining a child's medical eligibility, our preliminary work shows that examiners sometimes face challenges obtaining complete information. For example, some DDS offices reported difficulty obtaining school records or teacher assessments, which they partly attributed to school and teacher concerns about the time involved to compile this information, potential liability issues, or confusion about how such information is used in the disability decision-making process. In addition, DDS examiners told us that they do not routinely receive information on multiple siblings receiving SSI benefits within the same household even though they are directed to be alert for such cases. SSA's policy operations manual states that disabilities may occur in more than one member of a family or household, but notes prior case experience has shown this type of situation is an indicator of potential fraud or abuse, particularly where certain mental impairments are involved. For example, SSA recently investigated a case in which parents applied for SSI benefits on behalf of their four children, alleging that they all suffered from ADHD and conduct issues.³¹ However, investigators found that the school guidance counselor had never observed the children exhibiting symptoms of ADHD despite seeing them daily and that a doctor had rescinded an order authorizing the school to administer ADHD medication to the children. In this instance, SSA subsequently denied the siblings' applications for SSI benefits. Based on our interviews, it appears that SSA field offices do not consistently notify DDS examiners when an applicant's siblings are already receiving SSI benefits, nor are they always made aware of concurrent sibling applications. Without such information, DDS examiners may be limited in their abilities to identify potential fraud or abuse in the program.

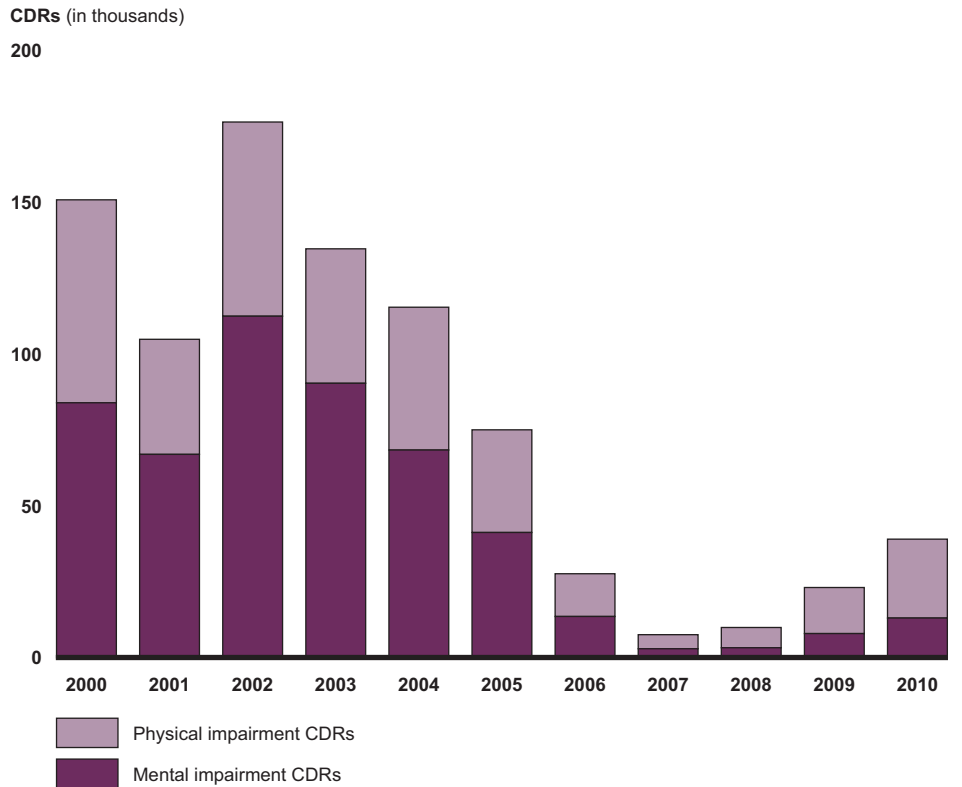
³¹SSA's Office of Operations and the Office of the Inspector's General Cooperative Disability Investigations Unit, which is responsible for investigating questions of fraud in SSA's disability programs, conducted this investigation.

SSA Has Conducted Significantly Fewer CDRs for SSI Children with Mental Impairments

SSA is required to periodically review the medical eligibility of certain individuals,³² though our preliminary work shows that SSA has conducted significantly fewer CDRs for children receiving SSI benefits in recent years, including those with mental impairments. Between fiscal years 2000 and 2010, childhood CDRs for those recipients under age 18 and age 18 redeterminations overall fell from more than 200,000 to about 126,000 (a 38 percent decrease), and more specifically, childhood CDRs for those with mental impairments declined from more than 84,000 to about 13,000 (an 84 percent decrease) (see fig. 7). SSA officials attribute the decrease in CDRs overall primarily to resource limitations and a greater emphasis on processing initial claims and reducing the backlog of requests for appeals hearings in recent years. While SSA did increase the number of CDRs it performed after receiving additional funding specifically targeted for CDRs between fiscal years 1996 and 2002, CDRs decreased once the funding expired.

³²Under Title XVI of the Social Security Act, SSA is required to (1) perform CDRs at least every 3 years on all children recipients under age 18 whose impairments are likely to improve (or, at the Commissioner's option, recipients whose impairments are unlikely to improve) (42 U.S.C. § 1382c(a)(3)(H)(ii)(I)) and (2) redetermine, within 1 year of the individual's 18th birthday, the eligibility of any individual who was eligible for SSI childhood payments in the month before attaining age 18, by applying the criteria used in determining initial eligibility for individuals who are age 18 (42 U.S.C. § 1382c(a)(3)(H)(iii)).

Figure 7: Number of Childhood CDRs Conducted for SSI Recipients under Age 18, by Primary Impairment, Fiscal Years 2000-2010



Source: GAO analysis of SSA data from the CDR Waterfall Files.

SSA has conducted fewer childhood CDRs in recent years. As of August 1, 2011, SSA had not yet conducted CDRs for about 434,000 SSI recipients under age 18 with mental impairments who had reached their scheduled CDR date (see fig. 8).³³ Of these recipients, about 343,000 (79 percent) had exceeded the scheduled date by at least a year, with about 205,000 (47percent) exceeding their date by 3 years and 24,400 (6 percent) exceeding by 6 years. SSA data also indicate that while age 18 redeterminations are conducted in a more timely manner, about 8 percent

³³About 845,000 child recipients with mental impairments were receiving SSI benefits as of Aug. 1, 2011.

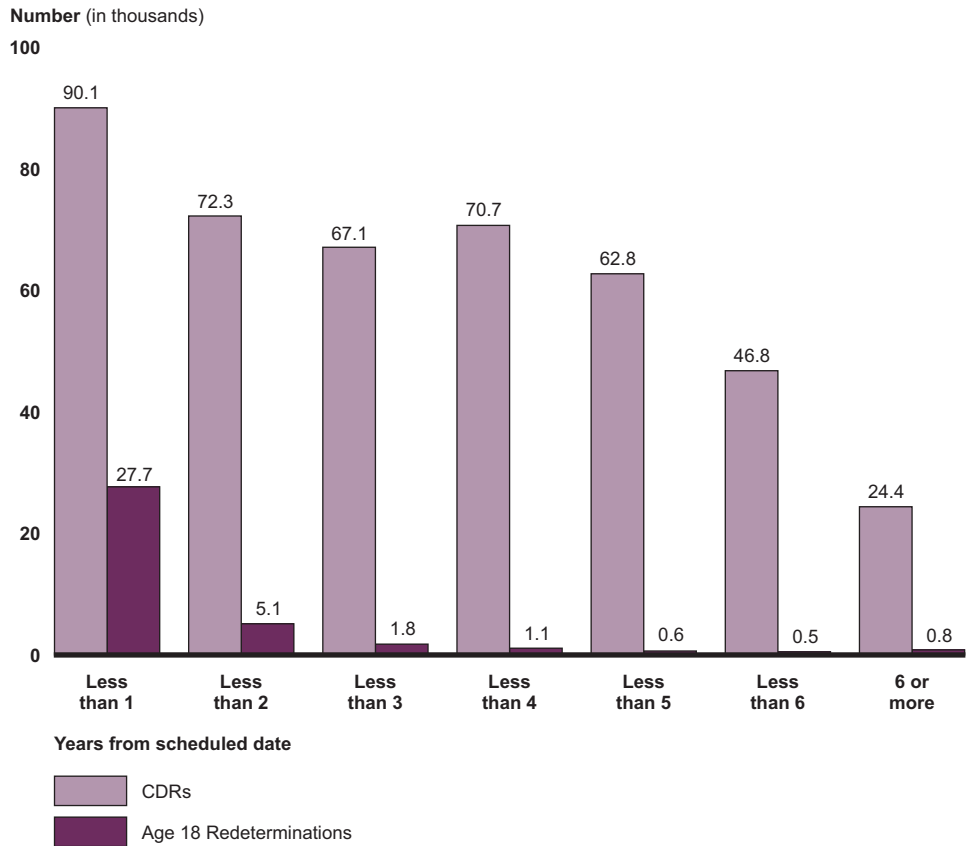
of these reviews are also overdue by 3 years or more.³⁴ In September 2011, SSA's Office of the Inspector General also reported that SSA had not completed all childhood CDRs and age 18 redeterminations in a timely manner. When reviews of benefits are delayed or not conducted, some beneficiaries may receive benefits for which they are no longer eligible. The Inspector General estimated that SSA had paid about \$1.4 billion in SSI benefits to approximately 513,000 recipients under age 18 who should not have received them.³⁵ SSA has recently estimated that the CDR process yielded a savings-to-cost ratio of roughly \$12.50 to \$1 in fiscal year 2009, and that those CDRs conducted for adults and children combined in fiscal year 2009 will save federal programs an estimated \$4.6 billion.³⁶

³⁴SSA informed us that 95.6 percent of the age 18 redeterminations are released to the field offices for processing by SSA headquarters within 2 months of the recipients' 18th birthday, and most all of them were released by no later than their 19th birthday.

³⁵The Inspector General estimated that SSA did not complete 79 percent of childhood CDRs and 10 percent of age 18 redeterminations on the basis of the results of 275 cases of physical and mental impairments they reviewed. (Social Security Administration Office of the Inspector General, "Follow-Up: Childhood Continuing Disability Reviews and Age 18 Redeterminations" (A-01-11-11118), Sept. 23, 2011.)

³⁶This estimate represents the combined savings to the SSI, Disability Insurance, Medicare, and Medicaid programs from CDRs conducted for the SSI and Disability Insurance programs, as in some cases eligibility for those programs confers eligibility for certain Medicare or Medicaid benefits, as well.

Figure 8: Pending Childhood CDRs and Age 18 SSI Redeterminations for Recipients with Mental Impairments, by Time Lapsed, as of August 1, 2011



Source: GAO analysis of SSA data from the CDR Waterfall Files.

Of those reviews conducted for child recipients in recent years, the vast majority were for age 18 redeterminations and low-birth weight babies. SSA is generally required by law to conduct age 18 redeterminations, within 1 year after a child turns 18, and within 12 months after the birth of a child who was allowed benefits because of low birth weight. In fiscal year 2010, 87 percent of CDRs conducted for child recipients were done in these two areas, and SSA subsequently terminated benefits for about 52 percent of age 18 recipients and 60 percent of low birth weight recipients. The remaining 13 percent of CDRs conducted were mostly reviews of children with mental impairments. Of those CDRs conducted for children under age 18 with mental impairments, SSA terminated benefits for about 24 percent of recipients in fiscal year 2010, and

personality disorders³⁷ and speech and language delay had the highest cessation rates (34 and 33 percent, respectively).

SSA and DDS officials have acknowledged that the agency is not conducting reviews for child recipients in a timely manner, and in some cases, they have not conducted required childhood CDRs prior to a child's age 18 redeterminations. SSA officials said that they would like to conduct additional childhood CDRs, but added that due mostly to funding constraints they are not able to do so. From 1996 to 2002, Congress provided funding to SSA to conduct additional CDRs for both Social Security disability and SSI beneficiaries. Since this funding expired, the number of CDRs SSA has conducted overall has dramatically declined.³⁸ The recently enacted Budget Control Act of 2011³⁹ authorized an increase in funding for CDRs and redeterminations under both the SSI and the Social Security Disability Insurance programs, starting with an additional \$623 million in fiscal year 2012 and reaching an additional \$1.3 billion in each of fiscal years 2017 to 2021. At the time of this statement, SSA was evaluating how to use this funding for CDRs, should it be appropriated, and it is not yet known to what extent the agency would (a) increase the number of childhood CDRs in the future or (b) target such CDRs toward those mental impairments with the highest cessation rates.

Mr. Chairman and Members of the Subcommittee, this concludes my prepared statement. I will be happy to respond to any questions.

³⁷Personality disorders are manifested by pervasive, inflexible, and maladaptive personality traits, which are typical of the child's long-term functioning and not limited to discrete episodes of illness. 20 C.F.R. pt. 404, subpt. P, app. 1

³⁸In part to reduce the CDR backlog, the Obama Administration proposed to increase the overall number of CDRs for adults and children in the SSI program in fiscal year 2012. The proposed fiscal year 2012 budget requests \$562 million for conducting, in part, SSI CDRs and SSI redeterminations (for child and adult recipients combined), an increase of \$298 million over FY 2011. SSA estimates that if granted, this level of funding would result in almost \$4.2 billion in savings to the SSI program alone over the next 10 years.

³⁹Pub. L. No. 112-25, sec. 101, § 251(b)(2)(B), 125 Stat. 240, 243-44.

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Appendix I: Listings for Mental Disorders for Children under Age 18

The structure of the mental disorders listings for children under age 18 parallels the structure for the mental disorders listings for adults but is modified to reflect the presentation of mental disorders in children. Under federal regulations, when a child is not performing substantial gainful activity and the impairment is severe, SSA is required to examine whether the child's impairment meets, medically equals, or functionally equals any of the impairments contained in the listings. The actual listings go into further detail about the level of severity necessary for this step of the determination, but the general listings for mental disorders in children are arranged in 11 diagnostic categories.¹ These categories include:

Organic mental disorders: Abnormalities in perception, cognition, affect, or behavior associated with dysfunction of the brain. The history and physical examination or laboratory tests, including psychological or neuropsychological tests, demonstrate or support the presence of an organic factor judged to be etiologically related to the abnormal mental state and associated deficit or loss of specific cognitive abilities, or affective changes, or loss of previously acquired functional abilities.

Schizophrenic, delusional (paranoid), schizoaffective, and other psychotic disorders: Onset of psychotic features, characterized by a marked disturbance of thinking, feeling, and behavior, with deterioration from a previous level of functioning or failure to achieve the expected level of social functioning.

Mood disorders: Characterized by a disturbance of mood (referring to a prolonged emotion that colors the whole psychic life, generally involving either depression or elation), accompanied by a full or partial manic or depressive syndrome.

Mental retardation: Characterized by significantly sub-average general intellectual functioning with deficits in adaptive functioning.²

¹For purposes of this appendix, we have provided basic information about the 11 mental disorders for children included in SSA's listings. For additional information about these listings, refer to 20 C.F.R. pt. 404, subpt. P, app. 1.

²Although for most purposes SSA refers to intellectual disabilities rather than mental retardation, its medical listings have not been updated to reflect this change.

Anxiety disorders: In these disorders, anxiety is either the predominant disturbance or is experienced if the individual attempts to master symptoms; e.g., confronting the dreaded object or situation in a phobic disorder, attempting to go to school in a separation anxiety disorder, resisting the obsessions or compulsions in an obsessive compulsive disorder, or confronting strangers or peers in avoidant disorders.

Somatoform, eating, and tic disorders: Manifested by physical symptoms for which there are no demonstrable organic findings or known physiologic mechanisms; or eating or tic disorders with physical manifestations.

Personality disorders: Manifested by pervasive, inflexible, and maladaptive personality traits, which are typical of the child's long-term functioning and not limited to discrete episodes of illness.

Psychoactive substance dependence disorders: Manifested by a cluster of cognitive, behavioral, and physiologic symptoms that indicate impaired control of psychoactive substance use with continued use of the substance despite adverse consequences.

Autistic disorder and other pervasive developmental disorders: Characterized by qualitative deficits in the development of reciprocal social interaction, in the development of verbal and nonverbal communication skills, and in imaginative activity. Often, there is a markedly restricted repertoire of activities and interests, which frequently are stereotyped and repetitive.

Attention deficit hyperactivity disorder: Manifested by developmentally inappropriate degrees of inattention, impulsiveness, and hyperactivity.

Developmental and emotional disorders of newborn and younger infants (birth to attainment of age 1): Developmental or emotional disorders of infancy are evidenced by a deficit or lag in the areas of motor, cognitive/communicative, or social functioning. These disorders may be related either to organic or to functional factors or to a combination of these factors.

According to SSA, these listings are examples of common mental disorders that are severe enough to find a child disabled. When a child has a medically determinable impairment that is not listed, an impairment that does not meet the requirements of a listing, or a combination of impairments none of which meets the requirements of a listing, SSA will

make a determination whether the child's impairment(s) medically or functionally equals the listings.³ This determination can be especially important in older infants and toddlers (age 1 to attainment of age 3), who may be too young for identification of a specific diagnosis, yet demonstrate serious functional limitations. Therefore, the determination of equivalency is necessary to the evaluation of any child's case when the child does not have an impairment that meets or medically equals a listing.

³See 20 C.F.R. §§ 416.926 and 416.926a.

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