



Report to the Chairman, Subcommittee
on Social Security, Committee on Ways
and Means, House of Representatives

August 2017

SSA'S COMPASSIONATE ALLOWANCE INITIATIVE

Improvements
Needed to Make
Expedited Processing
of Disability Claims
More Consistent and
Accurate

GAO Highlights

Highlights of [GAO-17-625](#), a report to the Chairman, Subcommittee on Social Security, Committee on Ways and Means, House of Representatives

Why GAO Did This Study

SSA in October 2008 implemented CAL to fast track individuals with certain conditions through the disability determination process by prioritizing their disability benefit claims. Since then, SSA has expanded its list of CAL conditions from 50 to 225. GAO was asked to review SSA's implementation of CAL.

This report examines the extent to which SSA has procedures for (1) designating CAL conditions, (2) identifying claims for CAL processing, and (3) ensuring the accuracy and consistency of CAL decisions. GAO reviewed relevant federal laws, regulations, and guidance; analyzed SSA data on disability decisions for CAL claims from fiscal years 2009 through 2016 and on CAL claims with manual actions in fiscal year 2016; reviewed a nongeneralizable sample of 74 claim files with fiscal year 2016 initial determinations; and interviewed medical experts, patient advocates, and SSA officials in headquarters and six DDS offices selected for geographic dispersion and varied CAL caseloads.

What GAO Recommends

GAO is making eight recommendations including that SSA develop a process to systematically gather information on potential CAL conditions, communicate criteria for designating CAL conditions, clarify guidance for manual corrections on CAL claims, update CAL impairment summaries, and use available data to ensure accurate, consistent decision-making. SSA agreed with GAO's recommendations.

View [GAO-17-625](#). For more information, contact Kathryn A. Larin at (202) 512-7215 or larink@gao.gov.

August 2017

SSA'S COMPASSIONATE ALLOWANCE INITIATIVE

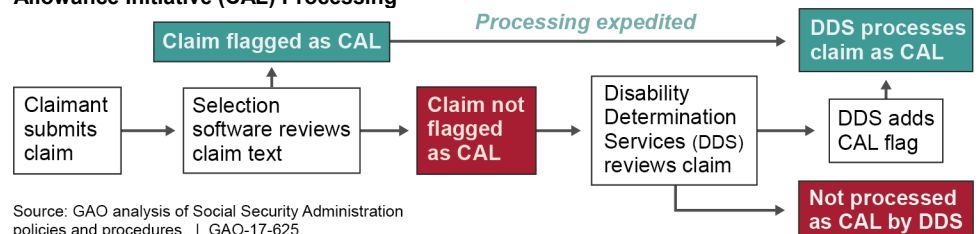
Improvements Needed to Make Expedited Processing of Disability Claims More Consistent and Accurate

What GAO Found

The Social Security Administration (SSA) does not have a formal or systematic approach for designating certain medical conditions for the Compassionate Allowance initiative (CAL). CAL was established in 2008 to fast track claimants through the disability determination process who are likely to be approved because they have certain eligible medical conditions. In lieu of a formal process for identifying conditions for the list of CAL conditions, SSA has in recent years relied on advocates for individuals with certain diseases and disorders to bring conditions to its attention. However, by relying on advocates, SSA may overlook disabling conditions for individuals who have no advocates, potentially resulting in individuals with these conditions not receiving expedited processing. Further, SSA does not have clear, consistent criteria for designating conditions for potential CAL inclusion, which is inconsistent with federal internal control standards. As a result, external stakeholders lack key information about how to recommend conditions for inclusion on the CAL list.

To identify disability claims for expedited CAL processing, SSA primarily relies on software that searches for key words in claims. However, if claimants include incorrect or misspelled information in their claims the software is hindered in its ability to flag all claimants with CAL conditions or may flag claimants for CAL processing that should not be flagged. SSA has guidance for disability determination services (DDS) staff on how to manually correct errors made by the software, but the guidance does not address when such corrections should occur (see figure). Without clear guidance on when to make manual changes, DDS examiners may continue to take actions that are not timely and may hinder expedited processing for appropriate claims, and this can also impact the accurate tracking of CAL claims.

Social Security Administration Process to Identify Disability Claims for Compassionate Allowance Initiative (CAL) Processing



Source: GAO analysis of Social Security Administration policies and procedures. | GAO-17-625

SSA has taken some steps to ensure the accuracy and consistency of decisions on CAL claims, including developing detailed descriptions of CAL conditions, known as impairment summaries. These summaries help examiners make decisions about whether to allow or deny a claim. However, nearly one-third of the summaries are 5 or more years old. Experts and advocates that GAO spoke to suggested that summaries should be updated every 1 to 3 years. This leaves SSA at risk of making disability determinations using medically outdated information. In addition, GAO found that SSA does not leverage data it collects to assess the accuracy and consistency of CAL adjudication decisions. Without regular analyses of available data SSA is missing an opportunity to ensure the accuracy and consistency of CAL decision-making.

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Abbreviations

ALS	Amyotrophic Lateral Sclerosis
CAL	Compassionate Allowance initiative
DDS	disability determination services
DI	Disability Insurance
HIV	human immunodeficiency virus
National Academies	National Academies of Sciences, Engineering, and Medicine
NIH	National Institutes of Health
NORD	National Organization for Rare Disorders
POMS	Program Operations Manual System
SSA	Social Security Administration
SSI	Supplemental Security Income
TERI	Terminal Illness
QDD	Quick Disability Determination

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August 11, 2017

The Honorable Sam Johnson
Chairman
Subcommittee on Social Security
Committee on Ways and Means
House of Representatives

Dear Mr. Chairman:

The Social Security Administration (SSA) oversees two key federal programs for individuals with disabilities—Disability Insurance (DI) and Supplemental Security Income (SSI).¹ In December 2016, these programs provided about \$15.7 billion in disability benefits to nearly 17.4 million individuals. In order to be eligible for these programs on the basis of a disability, applicants must be determined to have a qualifying disability through a complex, multi-step process that can take months. In light of these lengthy time frames, SSA in October 2008 implemented the Compassionate Allowance initiative (CAL). CAL fast-tracks those applicants through the disability determination process who are likely to be approved because they have certain medical conditions, such as specific cancers, Amyotrophic Lateral Sclerosis (ALS), or early-onset Alzheimer’s disease. Since 2008, SSA has expanded its list of CAL conditions from 50 to 225, resulting in increasing numbers of individuals qualifying for disability benefits through CAL. From the initiative’s inception through the end of fiscal year 2016, SSA had approved more than 500,000 applications, or claims, for disability benefits through CAL.

In a 2010 audit, SSA’s Office of the Inspector General found that SSA had not identified all cases that qualified for CAL processing and processed some cases through CAL that did not qualify. More recently, concerns have been raised by representatives of disease and disorder patient advocacy organizations that SSA does not have a transparent process for identifying conditions for inclusion on the CAL list and its descriptions of certain CAL conditions may be medically out of date. You asked us to review several aspects of CAL.

¹SSI also serves individuals who are aged or blind.

This report examines the extent to which SSA has procedures for (1) identifying conditions for the CAL list; (2) identifying claims for CAL processing; and (3) ensuring the accuracy and consistency of CAL decisions.

To address these objectives, we reviewed relevant federal laws and regulations, as well as SSA policies, procedures, training materials, and other guidance for CAL. We analyzed SSA data on CAL, including the number of allowance (approval) and denial decisions on disability claims identified with CAL conditions from fiscal year 2009, when CAL was implemented, through fiscal year 2016.² We also analyzed the number of CAL claims processed, nationwide and by disability determination services (DDS) offices, for this period, and claims flagged by staff for manual addition or removal of the CAL designation in fiscal year 2016.³ We assessed the reliability of these data by interviewing knowledgeable SSA officials and reviewing related documentation and internal controls. We also conducted a nongeneralizable review of 74 claim files that received initial determinations in fiscal year 2016 to confirm our understanding of how claims are identified as CAL automatically by the selection software and manually by DDS officials, and to further assess the reliability of CAL management data.⁴ As a result of these steps, we determined these data were sufficiently reliable for our purposes.

To understand procedures related to CAL, we interviewed officials from SSA headquarters, as well as examiners, supervisors, and quality review staff in 6 state DDS offices, selected based on geographic dispersion and varied CAL caseloads. We assessed SSA's procedures and guidance against standards for internal control in the federal government.⁵ To

²SSA implemented CAL in October 2008, the beginning of fiscal year 2009.

³According to SSA officials in July 2017, there are 119 DDS offices that serve the 50 states, District of Columbia, and the U.S. territories. Some states have centralized DDS offices which serve the entire state, whereas other states have several decentralized locations.

⁴We sampled claims from four categories: (1) claims in which the CAL flag was manually added to the claim; (2) claims in which the CAL flag was manually removed from the claim; (3) claims that involved the 4 CAL conditions with the most claims among conditions with the highest denial rates in fiscal year 2016; and (4) claims with the specific CAL conditions that staff from the 6 selected DDS offices we interviewed said were challenging to adjudicate.

⁵GAO, *Standards for Internal Control in the Federal Government*, [GAO-14-704G](#) (Washington, D.C.: Sept. 2014).

gather additional information on implementation of CAL, we interviewed representatives from nine disease and disorder patient advocacy groups, selected based on their affiliation with CAL conditions with high allowance and high denial rates, as well as with conditions that SSA considered but did not add to the CAL list. We also interviewed relevant medical and disability experts from the National Institutes of Health (NIH) and the National Academies of Sciences, Engineering, and Medicine (National Academies).⁶ See appendix I for more details on our scope and methodology.

We conducted this performance audit from June 2016 to August 2017 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

Background

Overview of SSA's Disability Programs

To apply for disability benefits through either of SSA's disability programs—DI or SSI—individuals submit a claim in-person, by telephone, mail, or online.⁷⁻⁸ The application and related forms ask for a description of the claimant's impairment (or impairments); sources of the claimant's treatment, such as doctors, hospitals, clinics, and other institutions; and other information related to the disability claim.

SSA assesses the claimant's non-medical eligibility for benefits and sends the claim to a state DDS office for a review of the claimant's

⁶Those we interviewed were involved in conducting research for SSA on aspects of CAL, as well as the disability determination process.

⁷DI provides benefits to eligible individuals who have qualifying disabilities or blindness, and their eligible family members. SSI provides benefits to individuals who are aged, blind, or have disabilities and have limited income and resources.

⁸As of April 2017, SSI applicants who meet certain criteria may apply for benefits through SSA's online disability application. An online application for DI benefits has been available since 2002.

medical eligibility.⁹ Although SSA is responsible for the programs, the law generally calls for initial determinations of disability to be made by state agencies.¹⁰ An individual meets the definition of disability for these programs if the individual has a medically determinable physical or mental impairment that (1) prevents the individual from engaging in any substantial gainful activity, and (2) has lasted or is expected to last at least 1 year or is expected to result in death.¹¹ As part of the medical determination process, DDS examiners assemble medical and vocational information for the claim, including medical evidence from the claimant's medical providers. If that evidence is unavailable or insufficient to make a determination regarding the claimant's eligibility for benefits, the DDS office will arrange for a consultative exam to obtain additional information.¹² DDS examiners assess the applicant's medical condition against SSA's Listings of Impairments (medical listings), which contains medical conditions that have been determined by the agency to be severe enough to qualify an applicant for disability benefits.¹³ Based on this assessment, a DDS examiner decides whether to medically allow or deny a claim for DI or SSI benefits.¹⁴

⁹Non-medical eligibility requirements may include age, employment history, and performance of substantial gainful activity.

¹⁰See 42 U.S.C. § 421(a)(1). The work performed at DDS offices is federally financed and carried out under SSA disability program regulations, policies, and guidelines.

¹¹42 U.S.C. §§ 423(d)(1)(A) and 1382c(a)(3)(A). Substantial gainful activity is generally work activity involving significant physical or mental activities that are done for pay or profit, whether or not a profit is realized. 20 C.F.R. §§ 404.1572 and 416.972. In 2017, the substantial gainful activity threshold is \$1,950 per month for blind recipients and \$1,170 per month for individuals with other disabilities.

¹²A consultative examination is a physical or mental examination or test purchased for an individual at SSA's request and expense. 20 C.F.R. §§ 404.1519 and 416.919. The type of examination or tests purchased depends upon the specific additional evidence needed for adjudication.

¹³However, an individual may still qualify as disabled even if his or her medical condition is not included in the medical listings. If the individual's impairment does not meet or equal the severity of at least one of those in the listings, DDS officials will assess the individual's physical and mental residual functional capacity. For adult disability claims, adjudicators follow a five-step sequential evaluation process. See 20 C.F.R. §§ 404.1520(a)(4), 416.920(a)(4). Under that process, if the adjudicator finds that the impairment does not meet or equal a listing, the adjudicator assesses the claimant's residual functional capacity and determines whether the claimant can perform his or her past relevant work or other jobs that exist in significant numbers in the national economy.

¹⁴A DDS examiner may consult with a medical professional, psychological professional, or both as part of this assessment.

CAL

SSA began CAL in October 2008 with the stated goal of providing expedited benefit processing to those with certain medical conditions whose claims are likely to be approved. According to SSA documents, expedited benefit processing through CAL helps to lessen the emotional and financial hardship that claimants might otherwise experience as a result of delays in SSA's disability process. At the time of its inception, the initiative was also considered a way to help reduce disability claim backlogs. SSA has expanded the number of conditions—and thus the number of claimants—which qualify for CAL over time. When the CAL list debuted, it contained 50 conditions—25 rare diseases and 25 cancers. In the years that followed, SSA added more conditions to the list in batches, eventually expanding it to 225 conditions as of April 2017. (See appendix II for the current list of CAL conditions.)

CAL claims may be processed more quickly than other claims, in part because they are given priority status and requests for medical evidence to substantiate these claims can be expedited. When a claimant submits a claim for disability benefits, it is flagged as CAL if the claimant's description of his or her impairment includes certain key words or phrases signifying the claimant has a CAL condition. Certain expedited processing rules apply to claims that are flagged for CAL. These claims are given priority in disability examiners' and medical consultants' queues of incoming claims, and SSA guidance directs DDS offices to initiate development within one working day of receiving a CAL claim. Examiners also use expedited procedures for requesting and following up on requests for medical evidence for CAL claims, and may only require a minimal amount of medical evidence, for example, a biopsy report, to confirm the claimant's diagnosis of a CAL condition.

To assist examiners in deciding these claims, SSA has developed detailed descriptions of each of the CAL conditions, known as impairment summaries. (See appendix III for an example of an impairment summary.) Among other things, these summaries suggest specific medical evidence for the examiner to obtain to verify the CAL condition and indicate relevant medical listings. DDS examiners assess a CAL claimant's medical condition against SSA's medical listings and allow or deny the claim, per the general disability determination process previously noted.¹⁵

¹⁵As previously noted, a DDS examiner may consult with a medical professional, psychological professional, or both as part of this assessment.

CAL is one of several expedited processing initiatives SSA has implemented, consistent with SSA's focus on the timely processing of disability claims. For example, whereas CAL applies to claims of certain medical conditions, SSA's Terminal Illness (TERI) initiative focuses on claims involving terminal illnesses, and its Quick Disability Determination (QDD) initiative focuses on various characteristics of the case file, such as whether evidence of the claimant's allegation(s) is expected to be readily available.¹⁶ Claims flagged for CAL may also be flagged as TERI or QDD. SSA's annual performance report for fiscal years 2015 through 2017 states that the agency aims to improve the quality, consistency, and timeliness of its disability decisions to help achieve its strategic goal of serving the public through a stronger, more responsive disability program. SSA, in consultation with the Office of Management and Budget, has highlighted this objective as a focus area for improvement.

¹⁶SSA defines terminal illness as "a medical condition that is untreatable and expected to result in death." See SSA Program Operations Manual System (POMS) DI 23020.045. The QDD process electronically identifies disability cases in which there is a high probability that the claimant is disabled, evidence of the claimant's allegation(s) is expected to be readily available, and the case can be processed in an expedited manner by the DDS office.

SSA Lacks a Formal and Systematic Approach for Identifying CAL Conditions

SSA Relies on Advocates to Propose New CAL Conditions, But Provides Limited Information to Them on How to Do So

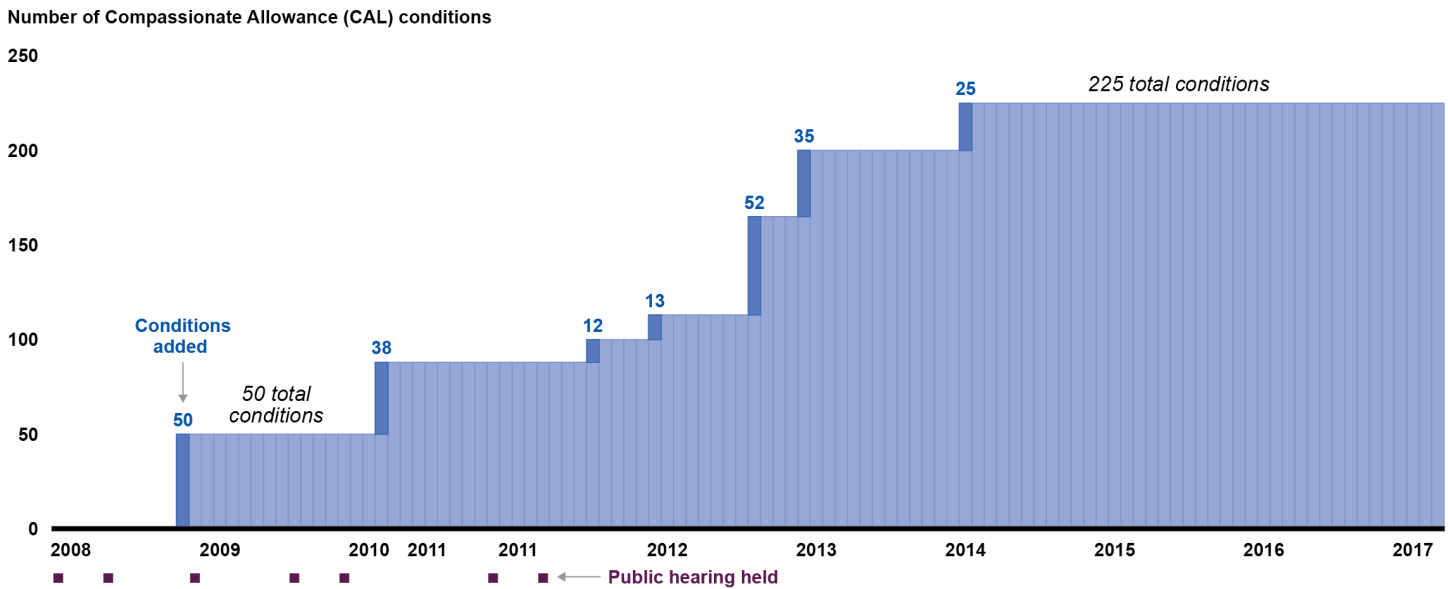
From 2007, the year prior to the initiative's inception, through 2011, SSA used public hearings to convene stakeholders and obtain information on categories of conditions identified by the agency for potential CAL consideration (see fig. 1).¹⁷ For example, SSA officials said that they decided to add 12 cardiac-related conditions to the CAL list on the basis of testimony received during their November 2010 hearing on cardiovascular disease and multiple organ transplants.¹⁸ SSA officials said that because of resource limitations, they have not convened a CAL hearing since March 2011, although they said that since that time, they have researched and added conditions to the CAL list that were suggested at the earlier hearings.¹⁹

¹⁷SSA convened CAL public outreach hearings on rare disease (December 4-5, 2007), cancers (April 7, 2008), brain injuries and stroke (November 18, 2008), early-onset Alzheimer's disease and related dementias (July 29, 2009), schizophrenia (November 18, 2009), cardiovascular disease and multiple organ transplants (November 9, 2010), and autoimmune diseases (March 16, 2011).

¹⁸Prior to this hearing, SSA published an announcement in the Federal Register explaining the purpose of the hearing and inviting the public to attend or submit written comments to SSA for their consideration. Compassionate Allowances for Cardiovascular Disease and Multiple Organ Transplants, Office of the Commissioner, Hearing, 75 Fed. Reg. 62,487 (Oct. 12, 2010).

¹⁹SSA last expanded the list of CAL conditions in 2014, and SSA officials said that they anticipate adding more conditions to the list in the future.

Figure 1: Number of Compassionate Allowance Initiative (CAL) Conditions Designated by SSA for Expedited Disability Processing and CAL Public Hearings, December 2007-March 2017



Source: GAO analysis of U.S. Social Security Administration data. | GAO-17-625

Since 2011, SSA has also relied on advocates for individuals with certain diseases and disorders to bring conditions to the agency’s attention, rather than proactively and systematically reviewing conditions to identify potential additions to the CAL list. Of the 137 conditions added to the CAL list since the agency stopped holding CAL hearings in 2011, 55 conditions were based on suggestions from the hearings; suggestions from advocates, including members of the public, account for 51 conditions; and the remainder resulted from suggestions made by SSA and DDS staff as well as other researchers.²⁰

Although it has relied on advocate suggestions to identify potential conditions to add to the CAL list in recent years, SSA has not clearly

²⁰SSA’s log of the sources of conditions added to the CAL list includes references to private citizens. SSA officials said these individuals may represent or otherwise be affiliated with an advocacy group, although they did not provide this information as part of their submission. We are including members of the public in our definition of advocates, although some may not be formally organized. Regarding suggestions from staff, SSA officials said that the agency encourages employees to submit recommendations for CAL conditions, for example, in response to issues arising from national health crises.

communicated this or provided guidance on how to make suggestions through its CAL webpage, which communicates information to the public. Advocates who are interested in having a disease or disorder considered for inclusion on the CAL list may contact SSA through a general purpose CAL email address included on the CAL webpage. While the webpage acknowledges advocates have previously recommended potential CAL conditions to SSA, it does not explicitly invite advocates to propose new conditions. Of representatives from the five advocacy organizations we interviewed that successfully had conditions added to the CAL list, representatives from four of these organizations said they had first learned about CAL through contact with SSA officials and others aware of the initiative, rather than through SSA's website.²¹ The website also does not describe what information advocates could present to the agency that would assist SSA's consideration of a condition. Without more explicit instructions, advocates may not provide information that is relevant for SSA's decision-making or that most strongly makes their case. One representative from an advocacy organization, for example, described meeting with agency officials and being surprised by SSA's focus on cancer grades—an indicator of how quickly cancer is likely to grow and spread—as she was not accustomed to discussing the condition she represents in these terms. Federal internal control standards state that agencies should use quality information to achieve their objectives.²² Absent clear guidance to advocates on how to make suggestions through its CAL webpage, SSA is missing an opportunity to gather quality information to inform its selection of CAL conditions.

Further, SSA has also not consistently communicated with advocates who have suggested conditions to add to the CAL list about the status of their recommendations, leading to uncertainty for some. SSA officials told us that they provide a written or oral response to advocacy organizations that have suggested a condition for inclusion on the CAL list to inform them whether the condition is approved. However, we spoke with advocates who had not received such a response from SSA and who found it challenging to connect with SSA officials to obtain information about the status of their suggestion. One representative from an advocacy organization told us that she was unable to reach SSA officials

²¹A representative from the fifth organization was not with her organization when it first submitted conditions for SSA's consideration, and she was not aware of how her organization first learned of CAL.

²²[GAO-14-704G](#).

to obtain any information on the status of her suggestion despite repeated attempts. In the absence of a response from SSA, she had resubmitted her condition and supporting documents to SSA every six months for three years since her initial submission in 2014. Representatives of the three other advocacy organizations we interviewed who had unsuccessfully attempted to get conditions added to the CAL list told us that they did not know if SSA's decision was final. Federal internal control standards state that agencies should communicate quality information externally so that external parties can help the agency achieve its objectives.²³ Without two-way communication between SSA and advocates, advocates are unclear on the status of their proposed CAL conditions and SSA may miss an opportunity to improve the quality of the information it obtains from advocates.

SSA has met with advocates to share information at the advocates' request, but has not conducted outreach efforts that are structured to reach all advocates. Since the last CAL public hearing in 2011, SSA has hosted teleconferences and webinars on CAL for 14 advocacy organizations, but because these are provided at the request of advocacy organizations, advocates need to be already aware of CAL in order to request them. Since 2007, SSA has also had a partnership with the National Organization for Rare Disorders (NORD), which serves as a liaison between SSA and the more than 260 rare disease organizations NORD represents, as well as affected patients, families, and medical professionals.²⁴ NORD officials told us that they have advised their member organizations on how to approach SSA regarding the potential addition of conditions to the CAL list and how to most effectively make their case. For example, one advocate told us that when she was unable to find information on SSA's CAL webpage about what information to include when submitting a condition to SSA for CAL consideration, she contacted NORD to learn what other member organizations had provided SSA. However, NORD membership is limited to patient groups that represent a rare condition and have medical advisors on their board, so not all advocates that may want to submit a condition to SSA for consideration have access to this resource.

²³GAO-14-704G.

²⁴Members of NORD's medical advisory committee have also recommended conditions that SSA has added to the CAL list.

Relying on advocates to bring conditions to SSA's attention introduces potential bias toward certain conditions and the possibility of missing others. Federal internal control standards state that agencies should collect complete and unbiased information and consider the reliability of their information sources.²⁵ All conditions that are potentially relevant for CAL consideration may not have advocacy organizations affiliated with them, and some advocates may be unaware of CAL, potentially resulting in SSA missing some conditions that are appropriate for CAL. As a result, some conditions may have a better chance of being considered than other, equally deserving ones that are not proposed, and individuals with those conditions may have to wait longer to receive approval for disability benefits.

According to some external researchers who work with SSA, an approach leveraging SSA's administrative data may help address the bias that is introduced by only using advocates. SSA has contracted with NIH and the National Academies for research using SSA administrative data on aspects of CAL, including the identification of potential CAL conditions, and the disability determination process generally. However, to date, SSA has not contracted for research that is sufficiently targeted to generate more than a small number of additions to the CAL list. For example, as part of an interagency agreement with SSA, NIH identified 27 potential CAL conditions—25 in 2011 and 2 in 2016—but of these, SSA has only added 4 to the CAL list. NIH identified the potential CAL conditions by comparing the likelihood of death during the adjudication process for claimants with non-CAL conditions to those with CAL conditions. Although likelihood of death relates to the definition of disability, SSA officials said it is not a factor specifically considered when designating conditions as CAL, and most of the conditions identified by NIH were not approved for CAL for various reasons.²⁶ For example, SSA officials told us that they did not add some of the recommended conditions to the CAL list because claims with some of these conditions could not be identified in an accurate and consistent manner based on the claimant's description of

²⁵[GAO-14-704G](#).

²⁶The definition of disability considers whether an individual's impairment has lasted, or is expected to last, 1 year, or is expected to result in death. Whereas SSA does not specifically consider the likelihood of death as a factor when designating conditions for CAL, SSA has separate expedited processing procedures for claims involving terminal illnesses under its TERI initiative.

his or her condition provided at the time the claim is submitted.²⁷ In addition to the NIH research efforts, SSA has a multiyear contract with the National Academies that is focused on the disability programs' adjudication process, rather than CAL in particular. In response to recommendations in a 2010 report from the National Academies, SSA added 4 conditions to the CAL list.²⁸

²⁷With regard to the 25 conditions NIH proposed for the CAL list in 2011, SSA officials said that some of the 21 conditions were already on the CAL list or could not be accurately identified by the CAL selection software using the descriptions claimants provide of their conditions at the time the claim is submitted. In 2016, NIH suggested an additional 2 conditions for the CAL list to SSA, based on additional SSA administrative data it reviewed from SSA. However, SSA officials told us that 1 of the 2 conditions was already on the CAL list and another was afforded expedited benefits through another agency initiative. SSA officials said that performing the same analysis using data on functional ability, as opposed to likelihood of death, is currently suspended until they can identify the appropriate data for such an analysis. SSA officials said that if these data are identified, SSA will evaluate at that point whether such a study has the potential to improve their selection of CAL conditions.

²⁸As part of its report on updating the human immunodeficiency virus (HIV) infection medical listings, the National Academies' (formerly Institute of Medicine) Committee on Social Security HIV Disability Criteria identified six HIV-induced conditions that it recommended SSA consider as "permanent" disabilities because they were severely disabling, had a high short-term mortality risk, and responded minimally to conventional treatment. Institute of Medicine, *HIV and Disability: Updating the Social Security Listings*, (Washington, D.C.: The National Academies Press, 2010). Of the six conditions, one was already on the CAL list, and SSA decided to add four of the five others to the list.

SSA Does Not Have Clear, Consistent Criteria for Designating CAL Conditions or a Formal Process for Documenting Its Decisions

SSA has generally described CAL conditions as those that “invariably qualify as allowances under the [agency’s] Listing of Impairments based on minimal objective medical evidence,” according to SSA officials.²⁹ However, SSA has not developed or communicated clear, consistent criteria for designating conditions as CAL conditions. As previously mentioned, SSA’s website has limited information on CAL, and the agency does not include information about specific CAL condition criteria.³⁰ Officials told us that they have informally considered allowance rates—the percentage of claimants asserting a certain condition who are approved for benefits—when identifying potential CAL conditions. However, SSA officials could not provide any documentation that shows that they have established an allowance rate minimum for CAL, or that they track data on allowance rates when assessing potential CAL conditions. Further, SSA officials and documents we reviewed refer to certain conditions being a good candidate for CAL if they have a high probability of being allowed, but cite inconsistent allowance rate cut-offs. For example, SSA officials told us that they aim to identify conditions for CAL in which approximately 92 percent of claimants asserting those conditions are allowed for disability benefits. However, a CAL process document states that conditions with over a 95 percent allowance rate, as well as those with 85 to 95 percent allowance rates, are considered for CAL.

SSA officials also cited their ability to program the selection software used to identify claims with a CAL condition as a secondary criterion for including it on the CAL list, although they did not indicate they have clearly or consistently defined this criterion. SSA officials said this criterion is important because they aim to reduce the number of false

²⁹According to SSA officials, they also assess all potential CAL conditions using the definition of disability as a foundational consideration.

³⁰SSA presents inconsistent information about CAL and its purpose, which may confuse advocates and others about the basis for SSA’s designation of conditions as CAL. The webpage states that “Social Security has an *obligation* to provide benefits quickly to applicants whose medical conditions are so serious that their conditions obviously meet disability standards” [emphasis added]. However, SSA commenced CAL on its own initiative in 2008, and in response to our questions about this statement, SSA officials in August 2016 said that the agency is not required to make CAL determinations. The officials said that they would revise the language on the agency’s website to clarify that it is their “goal to provide benefits quickly to applicants whose medical conditions are so serious that they invariably qualify under the Listing of Impairments based on minimal objective evidence.”

positives—claims that are erroneously flagged by the software for CAL processing.³¹ However, neither SSA officials nor SSA’s documentation of the steps taken to evaluate CAL conditions indicated a maximum threshold for false positives.

SSA also lacks a formal process for documenting its decisions on CAL conditions, as it does not have a template, checklist, or guidance—other than the medical listings—that its staff consult when preparing reports on potential CAL conditions.³² We reviewed 31 assessments of potential CAL conditions prepared by SSA medical consultants and found that they commented on various aspects of the conditions, including ease of identification through diagnostic testing as well as severity and rarity. However, there was no standard format used for these reports, and we were not able to determine the weight given to each of these factors nor whether all relevant information had been considered. Moreover, the reports did not cite allowance rates or the ability to program the selection software to identify these conditions as factors that were considered by the medical consultants.

Because SSA does not have consistent, clear criteria or clear documentation of its decision-making, those who have proposed conditions for CAL are sometimes confused as to why these conditions are not included on the CAL list. Although SSA officials told us the agency uses allowance rates and the ability to program the selection software to identify CAL conditions, SSA officials cited different reasons for not designating conditions as CAL in communications with those who proposed the conditions. For example, in an email provided to an advocacy organization that had attempted to get a condition added to the CAL list, SSA officials wrote that the condition was not being added because its symptoms, progression, and severity were variable and individual in nature. Another advocate told us that based on conversations with SSA officials, her understanding was that there was

³¹For example, SSA officials said that they determined that the musculoskeletal condition, ankylosing spondylitis with fixation of the dorsolumar of cervical spine at 45 degrees or more of flexion, was a potential candidate for CAL consideration, but they ultimately did not select it for CAL because they were unable to develop programming code to identify this condition. SSA officials said it is unlikely that a claimant with this condition would provide information with sufficient detail to identify this condition in the condition description on their claim.

³²The medical listings contain medical conditions that have been determined by the agency to be severe enough to qualify an applicant for disability benefits.

limited space on the CAL list for conditions that were not cancer related, and that SSA considered the number of people impacted by a condition as a criterion for CAL. Further, two of the four advocates we spoke with who unsuccessfully proposed conditions for the CAL list also said that they did not understand why these conditions were not added to the list while others were.

Unclear criteria and a lack of formal procedures for documenting decisions on potential CAL conditions can lead to confusion among advocates and other stakeholders and also may result in SSA missing conditions that could qualify for CAL or adding conditions for which claims are less likely to qualify as allowances or be expedited. Federal internal control standards state that agencies should define objectives in specific and measurable terms so that they are understood at all levels of the agency and performance toward achieving these objectives can be assessed. To help achieve these objectives, the standards state that agencies should also communicate key information to their internal and external stakeholders.³³

³³[GAO-14-704G](#).

SSA's Procedures Do Not Ensure All Claims are Accurately Identified for Expedited CAL Processing

Information Provided by Claimants Limits Effectiveness of the Software Program Used to Identify Disability Claims as CAL

SSA relies primarily on selection software to identify CAL disability claims based on a word-search of the impairment description included in a claim for benefits.³⁴ However, the software cannot identify all claimants asserting CAL conditions in part because text provided by claimants may be ambiguous, incomplete, or inaccurate.³⁵ This is because the same medical condition might be abbreviated or described in different ways by different claimants. For example, in our review of 74 claim files, we found one claim with the description "Stage 4 breast cancer/brain/lung/liver/kidney cancer" that was identified by the selection software for an advanced stage of lung cancer, among other CAL conditions, whereas claims describing "lung mass large mediastinal mass with suspected...brain metastis," "lung cancer stage 3-4," and "Lung Cancer terminal" were not identified by the software for CAL.³⁶ DDS officials we interviewed in 4 of 6 offices similarly said that some claims may not include a complete description of the condition or use the correct medical terms. A related challenge to identifying CAL conditions with the software is that some CAL conditions specify a certain disease stage or severity, but the text in the claim may not provide that information. For example, claimants with non-small cell lung cancer must be at a stage IIIB or IV

³⁴According to SSA officials, the software contains a master word dictionary developed by their contractor and looks at "catch all" terms in the allegations fields, including acronyms, alternative names, possessives, singulars and plurals, context mappings, word forms, and phrases to detect possible CAL conditions.

³⁵According to SSA officials, the selection software is currently maintained by a third-party contractor, but the agency is planning to develop internal selection software that will be managed in-house. As of March 2017, SSA officials said that they are in the process of testing their version of the selection software and do not have a timeline for implementing in-house management.

³⁶The claim identified by the selection software was flagged for "Lung Cancer (Metastases, Recurrent, Inoperable, Unresectable)."

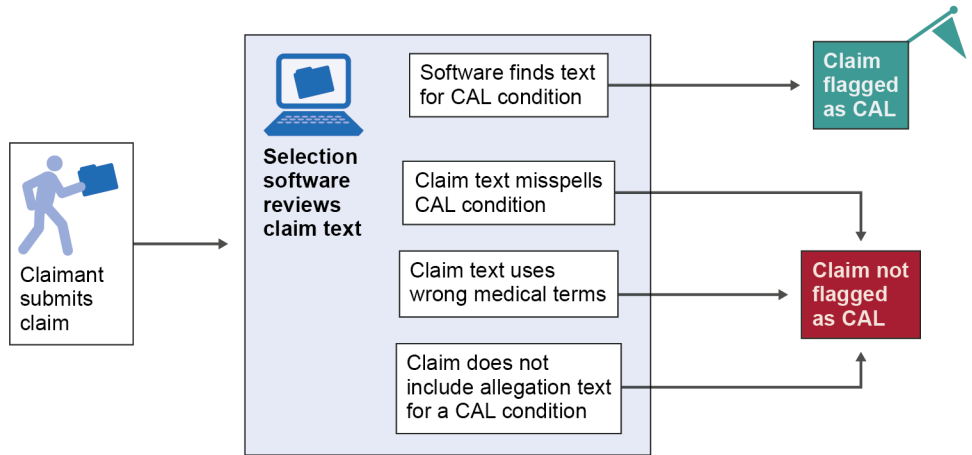
level of severity to qualify for CAL. SSA officials said that some applicants may not indicate the full extent of their impairments on their disability claim because they may not have come to terms with the gravity of their condition.

Because some claimants misspell words describing their conditions, the selection software may also omit a CAL flag on claims that should be flagged. For example, in its work with SSA on CAL, NIH found more than 170 misspellings of “adenocarcinoma,” a type of cancerous tumor that is present in some CAL conditions. In our claim file review, we found a claimant asserting a leiomyosarcoma, a soft tissue tumor that may be found in organs including the liver, lungs, and uterus, who misspelled the term as “leiomysarcoma” on the disability claim, which resulted in the software not flagging the claim as CAL, although liver and lung cancers are CAL conditions.³⁷ SSA’s Office of the Inspector General found this same issue in its 2010 report on CAL, as 60 percent of sampled claims appeared to assert a CAL condition but did not use the correct spelling or provide enough detail for SSA’s systems to automatically identify the claims as CAL. After the Office of the Inspector General’s report, SSA took steps to try to address the software’s limitations related to misspellings.³⁸ (See fig. 2.)

³⁷In this case, officials manually added the CAL flag to this claim once it was at the DDS office.

³⁸As part of their analysis, the Inspector General sampled 500 allowed claims that were not coded as CAL but had a diagnosis code that matched 1 of the 10 most common diagnosis codes of CAL claims. Social Security Administration, Office of the Inspector General. *Compassionate Allowance Initiative (A-01-10-21080)*. August 2010.

Figure 2: Social Security Administration Selection Software Process for Identifying Disability Claims for Expedited Compassionate Allowance Initiative (CAL) Processing



Source: GAO analysis of Social Security Administration policies and procedures. | GAO-17-625

SSA, through an inter-agency agreement with NIH, initiated an effort in 2016 to improve the current selection software, specifically to reduce the number of false CAL positives and negatives, among other goals.³⁹ According to NIH officials we spoke with, there are necessary tradeoffs between aiming for precision in the selection software that could exclude eligible claimants and inclusiveness that could flag claims that are not, in fact, CAL. As part of their ongoing analysis, NIH officials have identified strengths, and also limitations of some of the existing rules for the selection software, such as the key words and phrases that prompt the software to add a CAL flag, and recommended improvements to enhance the accuracy of the selection software. In March 2017, SSA officials told

³⁹According to NIH documents, the goal for this work was in part to build a new rule system that would reduce the number of false positives, minimize false negatives, and be as simple as possible. NIH officials defined a true positive as “a case that the new rule system flags for a CAL condition and the initial decision is an allowance,” and defined a false positive to be “a case that the new rule system flags for a CAL condition and the initial decision is a denial.” They defined a true negative as “a case that the existing CAL software flags for a CAL condition but not identified by the new rule system and the initial decision is a denial,” and defined a false negative as “a case that the existing CAL software flags for a CAL condition but not identified by the new rule system and the initial decision is an allowance.”

us that they had not yet determined if suggestions NIH had made would be included in updates to the selection software.

DDS officials we interviewed also indicated that they have noted instances where some claims are inaccurately flagged for CAL due to claimants' descriptions of their conditions in their claims. Officials we interviewed at 5 of 6 DDS offices said that they have seen claims inaccurately flagged for CAL when the claim text included words like "family history of [CAL condition]" though the CAL condition was not the claimant's current asserted condition. Further, an official at one DDS office stated that some claims with "pancreatitis" or "pancreatic pain" have been incorrectly flagged for the CAL condition "pancreatic cancer." The official noted that the software appeared to identify CAL conditions using words from the claim text out of order or without regard to specific phrases. In addition, officials at 4 of 6 DDS offices we spoke with said that they had processed claims in which they believe representatives or claimants coached by representatives added "please consider this case as CAL," or certain key words, to the claim in an attempt to get the claim flagged as CAL.⁴⁰ While some of the key terms may have been added appropriately, others may have been added with the intent of having the software flag a claim as CAL though the claimant was not asserting a CAL condition. For example, officials with one DDS office said that they had seen evidence that representatives had coached claimants to include key words, such as "liver" and "cancer" in their claims in the hopes of getting them flagged for CAL and allowed for benefits quickly, though the claimants may not have had "liver cancer," which is a CAL condition.

Although DDS officials' observations about weaknesses in the software could assist SSA in improving the software's accuracy in identifying CAL claims, SSA officials told us they have not asked DDS offices for input on the software, as they have not established a feedback loop to capture observations from DDS officials on weaknesses in the software. According to federal internal control standards, quality information about

⁴⁰Claimants may choose to appoint a representative—who may be an attorney or non-attorney—to assist them through the disability claim process and in their interactions with SSA. A representative may act on a claimant's behalf in a number of ways, including helping the claimant complete the disability claim. In our claim file review, we found one claim with "please expedite, is a CAL claim" in the allegation text, which was provided by a designated representative for the claimant and used key words to describe a condition that was flagged correctly for CAL by the selection software. GAO, *Social Security Disability Benefits: Agency Could Improve Oversight of Representatives Providing Disability Advocacy Services*, [GAO-15-62](#) (Washington, D.C.: Dec. 3, 2014).

the agency's operational processes should flow up the reporting lines from personnel to management to help management achieve the agency's objectives.⁴¹ Absent a mechanism to gather feedback from DDS offices nationwide, the agency may be missing an opportunity to gather important information that could help improve the software.

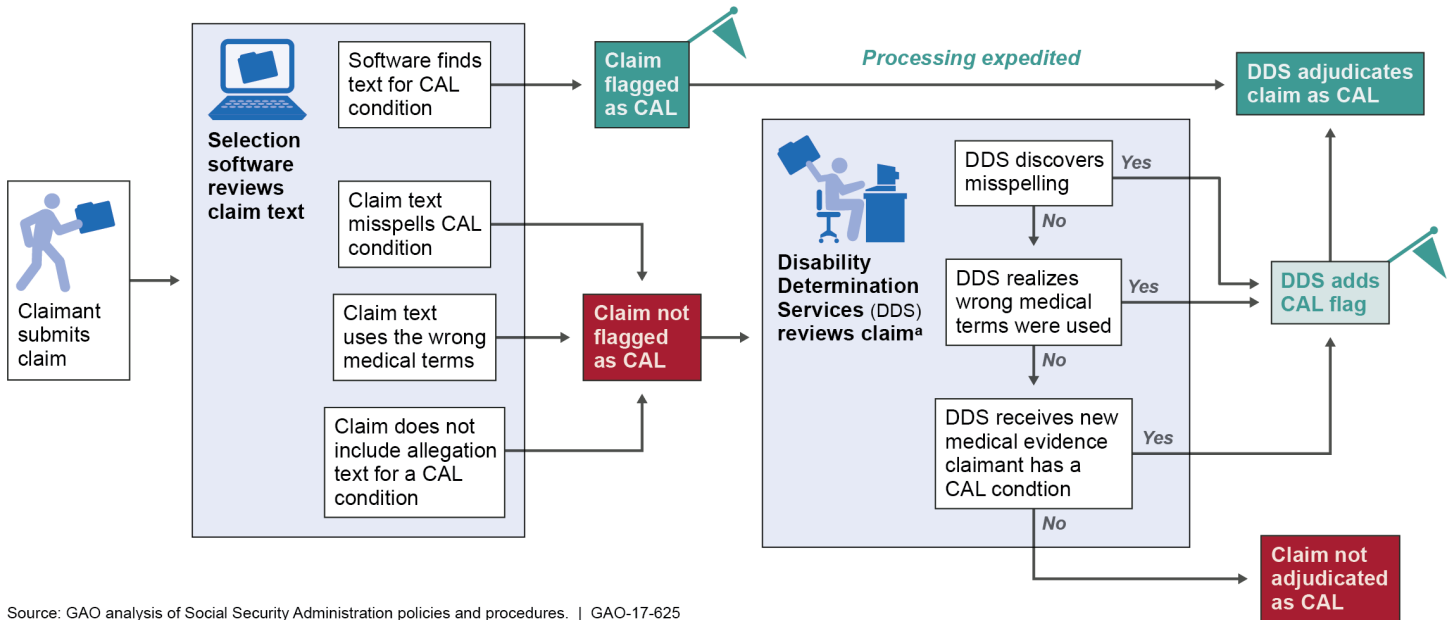
Staff Vary in When and Whether They Add or Remove CAL Status from Pending Disability Claims

DDS offices play an important role in helping to ensure that claims are correctly flagged for CAL since the selection software's effectiveness in identifying claims is impacted by the imprecise information submitted by some claimants. Further, ensuring claims are correctly flagged for CAL is important because the CAL flag reduces DDS processing time by about 10 weeks on average compared to the processing time for all claims, according to SSA data.⁴² SSA guidance directs DDS examiners to take steps to manually correct the CAL flag if they notice it has been incorrectly applied or omitted. For example, at one DDS office, examiners we interviewed said that a case asserting stage 4 cancer was not flagged for CAL by the software, but after reviewing the medical evidence, the examiners determined that the claimant had breast cancer—a CAL condition—and notified the supervisor to manually add a CAL flag to the claim. Similarly, these examiners described other claims that had been flagged for CAL by the software, but the medical evidence did not support the condition reported by the claimant, so they requested their supervisor remove the CAL flag. (See fig. 3.)

⁴¹Management should also monitor performance measures and indicators, and design program and data controls that support the integrity of these performance measures and indicators. [GAO-14-704G](#).

⁴²Further, new medical evidence of a CAL condition can be discovered during DDS processing of a claim, which would require the manual addition of a CAL flag. Processing times refer to claims decided at the initial determination level. According to SSA officials, due to data limitations, they are unable to provide processing times for CAL claims separate from non-CAL claims; as such, the average processing time for all claims includes CAL claims.

Figure 3: Social Security Administration Selection Software and Disability Determination Services Processes for Identifying Disability Claims for Compassionate Allowance Initiative (CAL) Processing



Source: GAO analysis of Social Security Administration policies and procedures. | GAO-17-625

^aSimilarly, if a claim is flagged for CAL and a DDS official realizes it should not be CAL, the official may request a supervisor remove the CAL flag, and the claim will no longer be adjudicated as CAL. If the DDS official does not notice that the flag should be removed and have the flag removed, the claim will be expedited as CAL even though the claimant does not have a CAL condition according to the medical evidence of record.

SSA's guidance includes a description of manual actions that can be taken by DDS staff to add, modify, remove, or reinstate a CAL flag on a claim; however, the guidance does not clarify when during the process these actions should take place, and we found that the point at which these changes occur during claim processing varies across DDS offices. For example, the information provided on removing a CAL flag includes instructions on the mechanical process for removing the flag based on the DDS examiner's review of the medical evidence in the claimant's file, but the guidance does not indicate how quickly this should be done after CAL status is clarified. SSA officials said that DDS officials have discretion to determine whether and when to remove a CAL flag, although SSA guidance advises DDS officials to remove the flag when it is not applicable. According to internal control standards, agencies should record transactions in an accurate and timely fashion, and communicate quality information throughout the agency. However, based on our discussions with the 6 selected DDS offices, we found that some

examiners did not understand the importance of making timely changes to a CAL flag designation to ensure faster claim processing for the appropriate claims and accurate tracking of CAL claims. For example, examiners at one DDS office said that they do not always add or remove a CAL flag when they determine a claim is erroneously designated because it adds another step to claim processing and the step seems unnecessary. In addition, an examiner at another DDS office told us that she will delay removal of an erroneous CAL flag from a claim in order to provide faster service through claims processing. Without clear guidance on when to make manual changes, DDS examiners may continue to take actions that are not timely and may hinder expedited processing for appropriate claims and accurate tracking of CAL claims.

In addition, our analysis of SSA's data shows that DDS offices varied in their use of manual actions to add the CAL flag to claims. Specifically, we noted that over half of DDS offices nationwide that processed disability claims in fiscal year 2016 had one or zero claims with a manually added CAL designation in that year.⁴³ In comparison, 5 DDS offices together accounted for over 50 percent of all claims with a manual addition.⁴⁴ According to officials at one DDS office, one potential reason for such variance is that some examiners may be more knowledgeable about CAL than others. Specifically, staff said that less experienced examiners are at risk of not noticing claims in the general queue that should be flagged for CAL because they are less familiar with CAL conditions.⁴⁵ Because SSA has not undertaken a study of its manual action procedures on such claims, it is unclear why this variance exists among DDS offices. Such variance could result in some claimants who assert a CAL condition not receiving expedited processing because their claims were not identified

⁴³This includes 64 of 103 DDS offices. For the purposes of this analysis, we focused on DDS offices in the 50 United States and District of Columbia that had claims processed during fiscal year 2016. We excluded offices that did not have any disability claims processed that year, as well as offices from United States territories or other federal DDS offices that are not associated with a particular state.

⁴⁴Despite these variations in the number of manual additions and variations in the overall caseload at different DDS offices, the majority of DDS offices (almost 80 percent) had a similar proportion of CAL claims in their overall caseload—about 2 percent to 5 percent. The highest proportion of CAL claims was 6.3 percent.

⁴⁵Four of the 6 DDS offices we selected had separate units or selected staff that handle CAL claims.

by the selection software or DDS examiners as CAL.⁴⁶ By not analyzing these trends across DDS offices, SSA management is missing an opportunity to identify CAL conditions that more frequently require the manual addition of a CAL flag. Such an analysis could prompt consideration of ways to improve the selection software so the software flags these cases. Federal internal control standards state that agencies should establish and operate monitoring activities to monitor operations and evaluate results.⁴⁷

SSA Takes Some Steps to Ensure Accurate and Consistent CAL Decisions But Does Not Regularly Update CAL Condition Descriptions or Leverage Available Data

SSA Has Procedures to Ensure Accurate and Consistent Claim Decisions But Does Not Regularly Update CAL Condition Descriptions

SSA has various procedures in place, including the use of detailed CAL condition descriptions, to help ensure the accuracy and consistency of CAL claims decisions. SSA officials stated that the agency directs all DDS offices to follow the same procedures and to assign experienced examiners to process CAL claims. Further, to ensure the accuracy of CAL claims, as with non-CAL claims, both SSA and the DDS offices conduct quality assurance reviews of claim decisions. SSA also offers guidance and training. For CAL conditions in particular, because some of these are rare and seen infrequently by examiners, SSA developed impairment

⁴⁶Although some DDS officials told us that they are able to informally expedite claims without applying a CAL flag, claims flagged as CAL have received quicker processing—2 weeks versus 12 weeks, as previously noted.

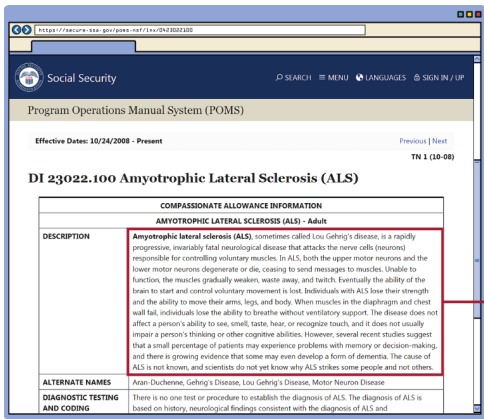
⁴⁷[GAO-14-704G](#).

summaries—detailed descriptions of CAL conditions—to help ensure accurate and consistent claim decisions. As previously noted, the impairment summaries suggest specific medical evidence for the examiner to obtain to verify the claimant’s asserted condition. Additionally, the summaries describe the CAL condition; provide alternate names, information on diagnostic testing and coding, and treatment options and disease progression; and reference relevant medical listings under which the claim may be allowed. SSA officials said that the impairment summary presents clear, easy to access, and relevant information for examiners to consider when making a decision, although the decision to allow or deny the claim remains with the examiner.⁴⁸ (See figure 4, as well as appendix III for examples.) Officials we interviewed at 6 selected DDS offices said that CAL impairment summaries are a key tool they consult when making determinations on CAL claims, and several described these as helping them to make decisions more efficiently.⁴⁹ For example, they said whereas an examiner might typically conduct an online search to learn about an unfamiliar condition, the summaries are desk guides that are intended to provide a more authoritative source of information relevant for evaluating a claim.

⁴⁸Each CAL impairment summary contains the disclaimer that, “Adjudicators [including examiners] may, at their discretion, use the Medical Evidence of Record or Listings suggested to evaluate the claim. The decision to allow or deny the claim rests with the adjudicator.”

⁴⁹SSA and DDS officials use the terms “impairment summary” and “CAL desk guide” interchangeably. We will use impairment summary throughout this report for consistency.

Figure 4: Example of a Social Security Administration Compassionate Allowance Initiative (CAL) Impairment Summary

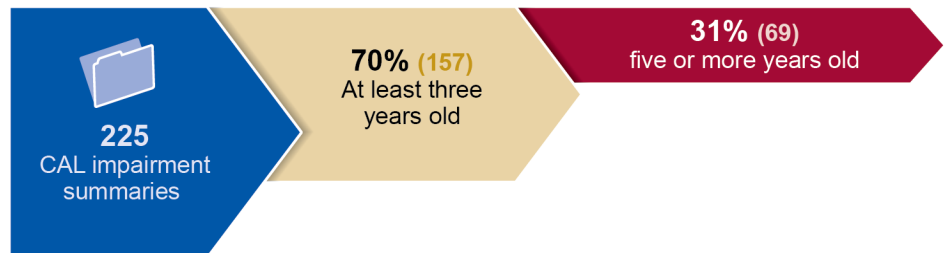


Amyotrophic lateral sclerosis (ALS), sometimes called Lou Gehrig's disease, is a rapidly progressive, invariably fatal neurological disease that attacks the nerve cells (neurons) responsible for controlling voluntary muscles. In ALS, both the upper motor neurons and the lower motor neurons degenerate or die, ceasing to send messages to muscles. Unable to function, the muscles gradually weaken, waste away, and twitch. Eventually the ability of the brain to start and control voluntary movement is lost. Individuals with ALS lose their strength and the ability to move their arms, legs, and body. When muscles in the diaphragm and chest wall fail, individuals lose the ability to breathe without ventilatory support. The disease does not affect a person's ability to see, smell, taste, hear, or recognize touch, and it does not usually impair a person's thinking or other cognitive abilities. However, several recent studies suggest that a small percentage of patients may experience problems with memory or decision-making, and there is growing evidence that some may even develop a form of dementia. The cause of ALS is not known, and scientists do not yet know why ALS strikes some people and not others.

Source: Social Security Administration Program Operations Manual System (POMS) . | GAO-17-625

Although CAL impairment summaries are a key tool used by examiners to make a decision on whether to allow or deny a CAL claim, SSA has not regularly updated the impairment summaries. This is because SSA does not have a process for regularly updating all of these summaries. As a result, since the initiative's inception in fiscal year 2009, about two-thirds of the summaries have not been updated. Specifically, since fiscal year 2009, SSA has updated impairment summaries for 74 of the current 225 CAL conditions, or about 33 percent. As of March 2017, we found that impairment summaries for 157 of the 225 conditions, or about 70 percent, are at least 3 years old, and among these, 69 conditions, or about 31 percent, were 5 or more years old (see fig. 5).

Figure 5: Age of Impairment Summaries for SSA Compassionate Allowance Initiative (CAL) Conditions, as of March 2017



Source: GAO analysis of Social Security Administration data. | GAO-17-625

SSA officials said that they update CAL impairment summaries in conjunction with agency updates to the medical listings used for all disability claims; however, this approach leaves the majority of CAL impairment summaries without updates.⁵⁰ For example, changes to the neurological listings in September 2016 prompted SSA to update the 62 CAL condition impairment summaries that reference the neurological listings. However, according to SSA officials, none of these revisions were substantive changes to the impairment summaries, but rather updates to the relevant medical listing numbers. The updates did not pertain to the descriptions of the specific CAL conditions, such as information on diagnostic testing, treatment options, and disease progression, or the suggested medical evidence of record for confirming the condition's diagnosis. In general, the medical listings are a broad guide that applies to all disability claims and does not provide the type of detailed information found in the impairment summaries. The listings are organized into 14 major body systems for adults and describe relevant conditions in each system, but they do not include an exhaustive list of all relevant conditions. For example, the broader category of neurodegenerative disorders of the central nervous system is included in the medical listings, and the CAL condition Huntington's disease is mentioned in the listings as an example of this category of impairments. However, stiff person syndrome, another CAL condition that SSA also considers a neurodegenerative disorder of the central nervous system, is not named in the medical listings. According to our analysis of SSA data, we found that one-quarter of SSA's CAL conditions directly align with specific medical listings. As such, three-quarters of the CAL conditions would not have their impairment summaries updated if SSA relies solely on this approach.

SSA officials said that they also rely on advocates, as well as DDS and SSA staff, to bring needed updates to the impairment summaries to the agency's attention. However, we found that since 2008, this approach has led to updates to few conditions. Advocates have provided updated

⁵⁰We previously found that SSA relies on outdated criteria to determine whether individuals qualify for disability benefits. In response to our findings, SSA aims to systematically update its medical listings and has set a goal of updating listings for each body system every 3 to 5 years. As of October 2016, we found that SSA has made progress in updating the listings for 13 of 14 body systems. For more information, see GAO, *Modernizing SSA Disability Programs: Progress Made, but Key Efforts Warrant More Management Focus*, [GAO-12-420](#) (Washington, D.C.: June 19, 2012) and GAO *High Risk Series: Progress on Many High-Risk Areas, While Substantial Efforts Needed on Others*, [GAO-17-317](#) (Washington, D.C.: Feb. 15, 2017).

information to SSA for four CAL conditions and two SSA staff have prompted updates to two CAL conditions. Furthermore, three of six advocates we interviewed were unaware that they could suggest updates to the impairment summaries to SSA, although they had relevant information or expertise to offer the agency.⁵¹ For example, officials from one of these advocacy organizations said that since the condition their advocacy organization represents was added to the CAL list, medical laboratories have started using a screening tool to rule out the presence of the condition, and they would have sought to have this information added to the condition's impairment summary if they knew such updates were encouraged. Other external entities also may have relevant information that could assist SSA in updating the impairment summaries. For example, consistent with SSA's approach for updating the medical listings, two experts who worked with the National Academies on efforts to improve SSA's disability determination process suggested that SSA could use external medical experts to recommend updates to the impairment summaries for CAL conditions.⁵²

Several advocates (4 of 6) and medical experts (2 of 3) we interviewed suggested that the impairment summaries should be updated every 1 to 3 years because medical research and advancements may have implications for disability determinations.⁵³ For example, an official from

⁵¹The other three advocates we spoke with were aware that they could provide updates to SSA's impairment summaries. In addition to speaking with six advocates who represent CAL conditions, we also spoke with three other advocates who advocate for conditions that were not added to the CAL list, and therefore, they were not in a position to provide us their opinion related to updates to impairment summaries for these conditions.

⁵²SSA asked the National Academies to study its medical procedures and criteria for determining disability and to make recommendations for improving the timeliness and accuracy of its disability decisions. The National Academies published its report for improving SSA's disability decision process, which included multiple recommendations related to SSA's medical listings, in 2007. Institute of Medicine, *Improving the Social Security Disability Decision Process*, (Washington, D.C.: 2007). In April 2015, the Institute of Medicine changed its name to the National Academy of Medicine; as such, we refer to this organization as the "National Academies."

⁵³Officials from three other advocacy groups we interviewed indicated that a longer time period is likely appropriate for updates to CAL impairment summaries. Specifically, advocates from two organizations we spoke with stated a review every 10 years of the summaries for their specific diseases, which include genetic disorders and a hereditary brain disease, would be sufficient. Further, one medical expert stated a review every 5 years would be adequate for a specific HIV dementia disorder for which medical advancements are unlikely to occur. Advocates for the three advocacy organizations we spoke with that did not have conditions added to the CAL list and one disability expert did not provide us their opinion on the appropriate frequency for updates of impairment summaries.

an advocacy group representing aplastic anemia told us that SSA should reevaluate impairment summary information for this condition at least once every 3 years because scientific research for treating this disease is under continuous development. Officials from an advocacy group representing early onset Alzheimer's stated that it is useful to scan for updates in medical research for this condition once per year because there is much research underway and there have been changes in how the condition is diagnosed in recent years.⁵⁴ Federal internal control standards also state that as changes in the agency's environment occur, management should make necessary changes to the information requirements to address the modified risks.⁵⁵ Given the pace of medical research for certain CAL conditions, in the absence of a systematic and regular mechanism to update CAL impairment summaries, SSA potentially faces the risk of making inaccurate and inconsistent disability determinations based on outdated information.

SSA Does Not Leverage Available Data to Identify Challenges to Making Accurate and Consistent Decisions on CAL Claims

SSA and DDS officials review some data to monitor CAL claims processing, but these efforts are limited in ensuring accuracy and consistency of decisions on CAL claims. SSA prepares a monthly report for SSA's high-level executives that includes the total number of CAL claims, claims flagged for CAL by the selection software, and claims manually flagged by staff as CAL.⁵⁶ This report does not provide information on the accuracy and consistency of CAL claims decisions. SSA officials from one of the offices that we spoke to that receives the report said that they were not familiar with it, suggesting it may not be regularly reviewed. Further, while managers at the 6 DDS offices we selected use available data to monitor the performance of disability claims processing, they generally do not use these data to identify issues and challenges related to CAL claims decisions. For example, officials from 5 of the 6 DDS offices we interviewed said that they do not use available data to specifically monitor CAL claims. Officials we spoke with in the 1

⁵⁴SSA revised the early-onset Alzheimer's impairment summary in November 2016. The revision focused on updates to medical listing numbers. This is the first revision since this condition was first added to the CAL listings in February 2010.

⁵⁵[GAO-14-704G](#).

⁵⁶Given that CAL was started, in part, to address disability claims backlogs, SSA previously had a formal performance measure related to the percentage of cases identified as CAL. Although officials said that they have continued to track the volume of claims processed through CAL, they are no longer officially using this as a performance measure.

DDS office that uses available data to monitor CAL said that they review the timeliness of CAL claims processing to evaluate examiners' individual performance, but they did not indicate that the data were used to identify trends or challenges related to CAL.

SSA officials said that CAL has been viewed as low risk, and management has confidence in the process in part because of findings related to CAL claims processing accuracy. The agency conducted a study in 2009 that found that CAL claims had a higher accuracy rate than other types of disability claims. According to SSA officials, based on these results, SSA decided not to perform additional CAL studies.⁵⁷ However, the 2009 study was conducted at a time when there were 50 CAL conditions, whereas there were 225 CAL conditions as of April 2017. In addition, as previously noted, SSA relies on the agency's quality review sampling procedures to review the accuracy of disability determinations, including those for CAL claims, on an ongoing basis.⁵⁸ Yet, the sample selected for quality review is intended to reflect all disability decisions, and therefore, review findings are not generalizable to all CAL claims.⁵⁹

In our analysis of SSA's available data, which SSA does not leverage to assess CAL, we found evidence of challenges that may affect the

⁵⁷SSA performed a CAL special study between October 27, 2008 through January 27, 2009 to evaluate phase I of CAL, which included the first 50 CAL conditions – comprised of rare diseases and cancers. The special study was designed to select 100 percent of the CAL cases, but ultimately reviewed 70 percent of the CAL cases due to sample selection issues. The examiners reviewed each sampled case for accuracy as well as adherence to CAL instructions and disability program policy. The results of the CAL case reviews were compared with other types of disability case reviews. SSA found that the error rate of 0.33 percent of the sampled CAL cases compared to a 2.5 percent error rate for other types of disability cases. SSA concluded that the difference between the two case types was statistically significant and that the study validated the selection criteria for cancers and rare diseases under CAL.

⁵⁸In addition to determining payment accuracy on an ongoing basis, SSA reports annually on improper payments, including both overpayments and underpayments, based on its stewardship reviews of the non-medical aspects of the DI and SSI programs. SSA reports that the leading causes of overpayments for both programs include the failure to inform SSA of changes in earnings, as well as increases in financial accounts for SSI recipients. To assess the medical aspects of the disability programs, SSA conducts continuing disability reviews to determine whether individuals continue to meet the programs' medical eligibility criteria. As with other disability benefit recipients, recipients with CAL conditions are subject to continuing disability reviews.

⁵⁹According to SSA officials, SSA quality reviewers collect all evidentiary information related to the randomly selected claims and assess the original determination's compliance with policy, as well as its consistency with the facts of the case.

accurate and consistent adjudication of claims with certain CAL conditions. For example, our analysis of SSA's data on denial rates for CAL conditions showed that certain conditions may be challenging to accurately and consistently adjudicate, and advocates we spoke to who represent these conditions explained why challenges may exist. While the vast majority of CAL claims are allowed—about 92 percent in fiscal year 2016, data we reviewed on claims adjudicated in that year showed 37 conditions for which claims asserting these had a greater than 30 percent denial rate, including 17 conditions for which claims asserting these had a greater than 50 percent denial rate.⁶⁰ We spoke with officials from advocacy groups representing two of the asserted conditions with high denial rates and found that issues with identifying these conditions may lead to challenges with accurately and consistently adjudicating claims with those conditions. For example, in fiscal year 2016, 34 percent of claimants that alleged they had aplastic anemia were denied. Officials from an advocacy group for aplastic anemia sufferers told us that this CAL condition is frequently confused with anemia, a much more common and non-life threatening condition that would be less likely to result in an allowance decision. They said aplastic anemia is a rare condition, affecting about 1,500 new patients per year, and is difficult to identify. In addition, 37 percent of claimants who alleged they had adult non-Hodgkin lymphoma were denied in fiscal year 2016. Officials from a lymphoma research and advocacy organization suggested that the CAL condition of adult non-Hodgkin lymphoma may be too broadly defined in SSA's impairment summary. They said that there are 98 sub-types of adult non-Hodgkin lymphoma, so a disability examiner may not make an accurate disability decision without the appropriate contextual information about the different sub-types.

Further, we found that denial rate data in combination with processing time data point to CAL conditions with claims that could be more challenging to adjudicate. Specifically, our review of SSA data showed a 21 percent denial rate for early-onset Alzheimer's disease claims for fiscal year 2016. In addition, in our case file review, we identified three CAL claims of early-onset Alzheimer's disease that had longer than average processing times, in which DDS staff had requested additional psychological evaluations before making determinations on the claims.

⁶⁰CAL claims may be denied for various reasons, such as if the claimant does not meet the applicable non-medical program requirements, if there is insufficient medical evidence in the file to adjudicate the claim, or if the impairment the claimant alleges does not reflect the claimant's actual diagnosis.

DDS officials we spoke to confirmed challenges adjudicating claims for this condition exist. Although SSA officials indicated that they select conditions for the CAL list for which a disability decision can be made on the basis of minimal objective medical evidence, officials we interviewed from 2 of 6 DDS offices said claims with early-onset Alzheimer's disease can be challenging to adjudicate because the claimant's medical evidence is not always sufficient to confirm the diagnosis. For example, a general practitioner may not have performed a detailed neuropsychological evaluation when the claimant was diagnosed. When the medical evidence in a claimant's file is insufficient on its own to allow for a determination, DDS officials may request additional medical evaluations, which adds processing time. If sufficient evidence of a qualifying disability cannot be obtained, the claim will be denied.

Through our analysis of SSA's average CAL claim processing time by DDS office and our discussions with selected DDS offices, we also found that potential misunderstandings of CAL guidance may cause inconsistency in the CAL claims decision-making process. For example, officials from 1 of the 6 DDS offices did not expedite medical information requests for CAL claims even though SSA guidance instructs DDS offices to do so. As a result, a claimant at this office will likely experience a longer wait time for a disability decision than a claimant with the same CAL condition at a DDS office that follows SSA guidance. Specifically, this DDS office had an average processing time of nearly 6 weeks for CAL claims, compared to the national average of about 2 weeks for CAL claims in fiscal year 2016.

According to federal internal control standards, management should obtain relevant data based on identified information requirements and process these data into quality information that can be used to make informed decisions and evaluate the agency's performance in achieving key objectives and addressing risks.⁶¹ SSA collects potentially useful and informative data on CAL, such as allowance and denial rates for claims by condition, as well as claims processing time data. Without regular analyses of available data to identify potential challenges to accurate and consistent CAL decision-making, SSA risks missing opportunities to address such challenges through guidance, training, or other methods.

⁶¹[GAO-14-704G](#).

Conclusions

CAL is viewed positively by SSA and many stakeholders, and appears to be effectively expediting benefit processing for disability claims receiving this designation. However, because SSA has considered the initiative to be working well, it has monitored the initiative less actively, and as a result, there are weaknesses in CAL that likely result in unintended consequences. For example, because of SSA's recent reliance on advocates to propose new CAL conditions, some conditions may have a better chance of being considered than other, equally deserving ones that are not proposed. Further, SSA has not provided clear guidance to advocates regarding information needed for the agency to consider a condition, effectively communicated the agency's decisions to those who have proposed conditions, nor fully utilized research to identify new CAL conditions. As a result, SSA is currently missing opportunities to gather quality information to inform its selection of conditions. In addition, SSA lacks clear, consistent criteria for designating conditions as CAL, and as a result, may miss conditions that could qualify for CAL or add conditions for which claims are less likely to qualify as allowances or be expedited. Further, because conditions that are designated as CAL allow claimants with these conditions to receive priority over other claimants, limitations in the CAL condition selection process raise potential equity considerations.

For those claimants who assert conditions that SSA has designated as CAL conditions, SSA's processes for identifying their claims as CAL and ensuring they receive accurate and consistent decisions also have limitations that potentially lead to unintended consequences. Because the agency has missed opportunities to clarify guidance and use available information to improve both its selection software and manual process for identifying CAL claims, consistent access to expedited processing for these claims is hindered. As a result, some who should benefit from expedited CAL processing do not and others may be benefitting who should not be. Further, although SSA has provided DDS examiners with CAL impairment summaries—an important tool to assist them in making accurate and consistent decisions on CAL claims—because the agency has not systematically and regularly updated these summaries, examiners risk making inaccurate and inconsistent disability determinations based on outdated information. Finally, although SSA collects useful data on CAL claims, because the agency does not regularly analyze these data to identify potential challenges to accurate and consistent CAL decision-making, SSA is missing opportunities to address such challenges. In the absence of improvements to SSA's implementation of CAL, some individuals with CAL conditions will inadvertently wait longer to receive approval for disability benefits—

hindering SSA's goal of moving these claimants that invariably qualify for benefits quickly through the process.

Recommendations for Executive Action

We recommend that the Acting Commissioner of Social Security take the following actions to ensure expedited processing of disability claims through CAL is consistent and accurate:

1. Develop a formal and systematic approach to gathering information to identify potential conditions for the CAL list, including by sharing information through SSA's website on how to propose conditions for the list and by utilizing research that is directly applicable to identifying CAL conditions.
2. Develop formal procedures for consistently notifying those who propose conditions for the CAL list of the status of their proposals.
3. Develop and communicate internally and externally criteria for selecting conditions for the CAL list.
4. Take steps to obtain information that can help refine the selection software for CAL claims, for example by using management data, research, or DDS office feedback.
5. Clarify written policies and procedures regarding when manual addition and removal of CAL flags should occur on individual claims.
6. Assess the reasons why the uses of manual actions vary across DDS offices to ensure that they are being used appropriately.
7. Develop a schedule and a plan for updates to the CAL impairment summaries to ensure that information is medically up to date.
8. Develop a plan to regularly review and use available data to assess the accuracy and consistency of CAL decision-making.

Agency Comments

We provided a draft of this report to SSA for review and comment. In its written comments, reproduced in appendix IV, SSA agreed with our eight recommendations. SSA officials stated that they are committed to looking for opportunities to strengthen CAL. In addition, SSA provided technical comments, which we incorporated as appropriate.

As agreed with your office, unless you publicly announce the contents of this report earlier, we plan no further distribution until 30 days from the report date. At that time, we will send copies to the Acting Commissioner of Social Security, appropriate congressional committees, and other interested parties. In addition, the report will be available at no charge on the GAO website at <http://www.gao.gov>.

If you or your staff have any questions about this report please contact me at (202) 512-7215 or larink@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 key contributions to this report are listed in appendix V.

Sincerely yours,

A handwritten signature in black ink that reads "Kathryn A. Larin". The signature is written in a cursive style with a large, looping initial "K".

Kathryn A. Larin
Director
Education, Workforce, and Income Security Issues

Appendix I: Objectives, Scope, and Methodology

We were asked to review several aspects of the Compassionate Allowance initiative (CAL). This report examines the extent to which the Social Security Administration (SSA) has procedures for (1) identifying conditions for the CAL list; (2) identifying claims for CAL processing; and (3) ensuring the accuracy and consistency of CAL decisions.

To better understand CAL and address these objectives, we reviewed relevant federal laws and regulations, as well as SSA policies, procedures, training materials, and other guidance for CAL. We reviewed relevant information, such as transcripts, from SSA's seven CAL public hearings held between 2007 and 2011, and information from SSA on the number and sources of conditions added to the CAL list over time, as well as the number and sources of updates to the CAL impairment summaries. We also reviewed 31 assessments of potential CAL conditions by SSA medical and psychological consultants, as well as medical policy analysts, including 15 for conditions that were added to the list and 16 for conditions that were not added to the list.¹ Further, we reviewed prior relevant SSA, SSA Office of Inspector General, and GAO reports related to CAL and SSA's medical listings.² We assessed SSA's actions against its internal guidance and GAO's published standards for internal controls in the federal government.³

In addition, we analyzed management information data relevant to CAL; interviewed SSA and disability determination services (DDS) staff,

¹We requested that SSA provide recent examples of its assessments for conditions that were added and not added to the CAL list. The analyses they provided pertain to conditions considered for the most recent expansion of the CAL condition list, which occurred in January 2014.

²These included: SSA, Office of Quality Performance and Office of Disability Programs. *Compassionate Allowance Special Study October 27, 2008 – January 27, 2009*; SSA, Office of the Inspector General. *Compassionate Allowance Initiative (A-01-10-21080)*. August 2010; SSA, Office of the Inspector General. *Status of Compassionate Allowance and Quick Disability Determination Expedited Cases (A-01-16-50051)*, March 2016; GAO, *Modernizing SSA Disability Programs: Progress Made, but Key Efforts Warrant More Management Focus*, [GAO-12-420](#) (Washington, D.C.: June 19, 2012); GAO, *Social Security Administration: Long-Term Strategy Needed to Address Key Management Challenges*, [GAO-13-459](#) (Washington, D.C.: May 29, 2013); GAO, *Social Security Disability Programs: SSA Could Take Steps to Improve Its Assessment for Continued Eligibility*, [GAO-14-492T](#) (Washington, D.C.: Apr. 9, 2014); and GAO, *Supplemental Security Income: An Overview of Program Integrity and Management Challenges*, [GAO-15-632T](#) (Washington, D.C.: June 3, 2015).

³GAO, *Standards for Internal Control in the Federal Government*, [GAO-14-704G](#) (Washington, D.C.: Sept. 2014).

advocates, and medical and disability experts with relevant research organizations; and reviewed a non-generalizable sample of disability claim files, as discussed more fully below.

Management Information Data

We analyzed SSA data on CAL from SSA's Management Information Disability database, including the number of allowance (approval) and denial decisions for disability claims identified with CAL conditions from fiscal year 2009, when CAL was implemented, through fiscal year 2016.⁴ We analyzed these data to determine the percentage of CAL claims with allowance decisions, and to identify conditions with high absolute numbers of claims allowed and denied, as well as those with high allowance and denial rates.

We also analyzed SSA data on the average processing time of CAL claims and all claims overall at the initial determination level, as well as the average processing time of CAL claims for each of the 6 DDS offices we selected (see below for how we selected these offices). For processing time data, we focused on the length of time between when a claim is transferred to the DDS office and when a determination is made.

To learn more about DDS office use of manual actions related to CAL, we also analyzed the number of CAL claims with manual additions, overall and by DDS office, from fiscal year 2016 and compared this to the total number of CAL claims received in that year. Manual actions include manual additions, removals, modifications and reinstatements of the CAL flag. For our analyses, we focused primarily on the number of manual additions of the CAL flag by DDS office.

We assessed the reliability of these data by interviewing knowledgeable SSA officials and reviewing related documentation and internal controls. We also conducted a claim file review, described below, to further assess the reliability of CAL management data. We determined these data were sufficiently reliable for our purposes.

⁴SSA implemented CAL in October 2008, the beginning of fiscal year 2009.

Interviews with SSA and DDS Staff

To gather information on how SSA identifies conditions for the CAL list, identifies claims for CAL processing, and ensures the accuracy and consistency of CAL decisions, we conducted interviews with staff from SSA headquarters and select DDS offices. Specifically, we interviewed staff from SSA's Office of Disability Policy; Office of Disability Determinations; Office of Research, Demonstration, and Employment Support; Office of Applications and Supplemental Security Income Systems; and the Office of Quality Review. In addition, we conducted interviews with DDS examiners, supervisors, and quality review staff from 6 DDS offices: Austin, Texas; Bismarck, North Dakota; Columbus, Ohio; Fairfax, Virginia; Raleigh, North Carolina; and Stockton, California.⁵ We selected these offices primarily based on SSA region (to ensure geographic dispersion), and to provide variation in the number of CAL claims receiving initial determinations and the proportion of CAL claims compared to the DDS's overall caseload. We also aimed to include offices with varied numbers of claims that had a CAL flag manually added. The views of staff from these DDS offices are not generalizable to all DDS offices nationwide. To gain additional perspectives from DDS and SSA field office staff, we also interviewed officials from the National Association of Disability Examiners and the National Council of Social Security Management Associations, respectively.⁶

⁵According to SSA officials in July 2017, there are 119 DDS offices that serve the 50 states, District of Columbia, and the U.S. territories. Some states have centralized DDS offices which serve the entire state, whereas other states have several decentralized locations.

⁶The National Association of Disability Examiners is primarily associated with DDS staff. According to the National Association of Disability Examiners website, its vision is to be "committed to continually achieve innovative methods for improving the disability programs incorporated under the Social Security Act, enhancing the disability profession for our members, and providing timely, effective, and quality public service." The National Council of Social Security Management Associations is primarily associated with SSA field office staff, as well as teleservice center staff. According to the National Council of Social Security Management Associations website, its mission is to "improve management and program administration in SSA by assuring the knowledge and experience of front-line management are included in all phases of agency planning and decision making."

Interviews with Selected Advocates and Medical and Disability Experts

To gather additional information on implementation of CAL, we interviewed representatives from disease and disorder patient advocacy groups, selected based on their affiliation with asserted CAL conditions with high allowance or denial rates, as well as with conditions that SSA considered but did not add to the CAL list. Specifically, we interviewed representatives from the Aplastic Anemia and MDS International Foundation, Alzheimer's Association, Desmoid Tumor Research Foundation, Huntington's Disease Society of America, Lymphoma Research Foundation, M-CM Network, National MPS Society, National Organization of Rare Disorders, and Parents and Researchers Interested in Smith-Magenis Syndrome. In total, eight of these nine organizations had suggested at least one condition to SSA for inclusion on the CAL list. Five of the nine organizations had one or more condition added by SSA, and four had one or more condition not added to the list. Another one of the organizations represented an asserted CAL condition with a high denial rate; SSA had consulted this organization for information about the condition in the past, although the group had not proposed the condition for the list. The views of the selected advocates we interviewed are not generalizable to all advocates who have interacted with SSA regarding CAL.⁷

We also interviewed medical experts from the National Institutes of Health, which has performed work to identify potential conditions for the CAL list and refinements for the selection software, under an inter-agency agreement with SSA. SSA has also contracted with the National Academies of Sciences, Engineering, and Medicine (National Academies) to recommend improvements to the disability determination process, among other things, and therefore we interviewed medical and disability experts who have served on relevant National Academies committees.

Claim File Review

We conducted a non-generalizable review of 74 claim files with fiscal year 2016 initial determinations to confirm our understanding of how claims are identified as CAL by the selection software and manually by DDS officials and to assess the reliability of CAL management data. Our sample included claims for Disability Insurance (DI) and Supplemental Security

⁷In addition, we requested interviews with officials at the American Cancer Society and the American Academy of Neurology who declined our request because they did not think that they had relevant information on CAL.

Income (SSI) benefits. We sampled claims from the following four categories:

1. claims in which the CAL flag was manually added to the claim;
2. claims in which the CAL flag was manually removed from the claim;
3. claims that involved the four asserted CAL conditions with the most denied claims and denial rates of 20 percent or greater in fiscal year 2016; and
4. claims with the specific asserted CAL conditions that staff from the six selected DDS offices we interviewed said were challenging to adjudicate.

To sample claim files, we worked with SSA staff to create custom data queries from SSA's Management Information Disability database to extract claims that fit the criteria for each of the four categories above and used a random number generator to select claims from each category. Where possible, we also accessed information on claims through the Policy Feedback System, a web-based case management program that is updated daily with data from SSA's Structured Data Repository. We only sampled claims that fit at least one of the above criteria. For example, if there were no claims at a specific DDS office that fit our criteria for category 1, we did not record any claims in our data collection instrument and made a note that no claims existed. The details of our claim sampling methodology for each category are described below.

1. Claims in which the CAL flag was manually added to the claim

For category 1, we identified the three conditions that most frequently resulting in a CAL flag being manually added to a claim. For fiscal year 2016, these were lung cancer (metastases, recurrent, inoperable, unresectable), acute leukemia, and head and neck cancer (distant metastases, inoperable, unresectable). For each of the six selected DDS offices, we randomly sampled two claims, as available, that included any of these conditions that had the CAL flag manually added, and two claims, as available, that included any of these conditions that did not have a CAL flag.

2. Claims in which the CAL flag was manually removed from the claim

We repeated the same methodology for category 2 but analyzed the three conditions that most frequently related to a CAL flag being manually removed from a claim to better understand potential reasons why a CAL

flag may be applied incorrectly and what information DDS officials might use to identify this. For fiscal year 2016, these conditions were adult non-Hodgkin lymphoma, early-onset Alzheimer's disease, and breast cancer (distant metastasis or recurrent). For each of the six selected DDS offices, we randomly sampled two claims, as available, that included any of these conditions that had the CAL flag manually removed, as well as two claims, as available, that had the CAL flag applied by the selection software but was not removed. We also randomly sampled one claim from each DDS office that had one of these three conditions and was denied, as available.

3. *Claims that involved the four asserted CAL conditions with the most denied claims and denial rates of 20 percent or greater proportion of denied claims to denied and allowed claims in FY 2016*

For category 3, we used SSA management information data to determine asserted CAL conditions with 1) the most denied claims adjudicated in FY 2016 and also 2) the high denial rates (20 percent or greater proportion of denied claims to denied and allowed claims). We selected the first four conditions that met these criteria: Adult Non-Hodgkin Lymphoma (37 percent), Aplastic Anemia (34 percent), Early-Onset Alzheimer's Disease (21 percent), and Idiopathic Pulmonary Fibrosis (21 percent). For each of these conditions, we randomly sampled one allowed claim and two denied claims that were adjudicated in any DDS office nationwide.

4. *Claims with specific asserted CAL conditions that staff from selected DDS offices we interviewed said were challenging to adjudicate*

During our interviews with staff from selected DDS offices, we requested information on particular asserted CAL conditions that each office's staff found difficult to adjudicate: Adult Non-Hodgkin Lymphoma (two offices identified this condition), Leukemia (one office identified this condition), Head and Neck Cancer (two offices identified this condition), and Early-Onset Alzheimer's Disease (two offices identified this condition). For category 4, we queried claims adjudicated at each of the selected DDS offices specifically asserting the condition or conditions officials at that office noted as challenging, then we calculated the average number of days it took to adjudicate claims for this condition at the particular DDS office. We randomly sampled two claims, as available, that took longer than the average number of days to adjudicate for each condition.

For each of the sampled claims, we reviewed summary information from the electronic claim file including: if the claimant was applying for SSI, DI, or both benefit programs; if the claim was also flagged for the Quick Disability Determination (QDD) fast-track initiative; the decision (allowance or denial); claim filing date; decision date; age of the claimant; and the name, state and region of the adjudicating DDS office. In addition, we reviewed if there was a CAL flag present, CAL condition name (as applicable), and if the CAL flag was manually added or removed. We also reviewed the alleged impairment(s) and our observations on the Medical Evidence of Record that were recorded in the claim file.

Appendix II: Social Security Administration's 225 Compassionate Allowance Initiative (CAL) Conditions as of April 2017

Acute Leukemia
Adrenal Cancer with distant metastases or inoperable, unresectable, or recurrent
Adult Non-Hodgkin Lymphoma
Adult Onset Huntington Disease
Aicardi-Goutieres Syndrome
Alexander Disease (ALX) - Neonatal and Infantile
Allan-Herndon-Dudley Syndrome
Alobar Holoprosencephaly
Alpers Disease
Alpha Mannosidosis - Type II and III
Alstrom Syndrome
ALS/Parkinsonism Dementia Complex
Alveolar Soft Part Sarcoma
Amegakaryocytic Thrombocytopenia
Amyotrophic Lateral Sclerosis (ALS) – Adult
Anaplastic Adrenal Cancer - Adult with distant metastases or inoperable, unresectable or recurrent
Angelman Syndrome
Angiosarcoma
Aortic Atresia
Aplastic Anemia
Astrocytoma - Grade III and IV
Ataxia Telangiectasia
Atypical Teratoid/Rhabdoid Tumor
Batten Disease
Beta Thalassemia Major
Bilateral Optic Atrophy - Infantile
Bilateral Retinoblastoma
Bladder Cancer with distant metastases or inoperable or unresectable
Breast Cancer with distant metastases or inoperable or unresectable
Canavan Disease (CD)
Carcinoma of Unknown Primary Site
Cardiac Amyloidosis - AL Type
Caudal Regression Syndrome – Types III and IV
Cerebro Oculo Facio Skeletal (COFS) Syndrome
Cerebrotendinous Xanthomatosis
Child Lymphoblastic Lymphoma

Appendix II: Social Security Administration's
225 Compassionate Allowance Initiative (CAL)
Conditions as of April 2017

Child Lymphoma

Child Neuroblastoma with distant metastases or recurrent

Chondrosarcoma

Chronic Idiopathic Intestinal Pseudo Obstruction

Chronic Myelogenous Leukemia (CML) - Blast Phase

Coffin-Lowry Syndrome

Congenital Lymphedema

Cornelia de Lange Syndrome – Classic Form

Corticobasal Degeneration

Creutzfeldt-Jakob Disease (CJD) -Adult

Cri du Chat Syndrome

De Sanctis Cacchione Syndrome

Degos Disease

Dravet Syndrome

Early-Onset Alzheimer's Disease

Edwards Syndrome

Eisenmenger Syndrome

Endometrial Stromal Sarcoma

Endomyocardial Fibrosis

Ependyoblastoma (Child Brain Cancer)

Erdheim Chester Disease

Esophageal Cancer

Esthesioneuroblastoma

Ewing Sarcoma

Farber Disease (FD) - Infantile

Fatal Familial Insomnia

Fibrodysplasia Ossificans Progressiva

Follicular Dendritic Cell Sarcoma

Friedreichs Ataxia (FRDA)

Frontotemporal Dementia (FTD), Picks Disease -Type A- Adult

Fryns Syndrome

Fucosidosis - Type I

Fukuyama Congenital Muscular Dystrophy

Fulminant Giant Cell Myocarditis

Galactosialidosis - Early and Late Infantile Types

Gallbladder Cancer

Gaucher Disease (GD) - Type 2

Giant Axonal Neuropathy

Appendix II: Social Security Administration's
225 Compassionate Allowance Initiative (CAL)
Conditions as of April 2017

Glioblastoma Multiforme (Brain Cancer)

Glioma Grade III and IV

Glutaric Acidemia - Type II

Head and Neck Cancers

Heart Transplant Graft Failure

Heart Transplant Wait List - IA/IB

Hemophagocytic Lymphohistiocytosis - Familial Type

Hepatoblastoma

Hepatopulmonary Syndrome

Hepatorenal Syndrome

Histiocytosis Syndromes

Hoyeal-Hreidarsson Syndrome

Hutchinson-Gilford Progeria
Syndrome

Hydranencephaly

Hypocomplementemic Urticarial Vasculitis Syndrome

Hypophosphatasia - Perinatal (Lethal) and Infantile Onset Types

Hypoplastic Left Heart Syndrome

I Cell disease

Idiopathic Pulmonary Fibrosis

Infantile Free Sialic Acid Storage Disease

Infantile Neuroaxonal Dystrophy (INAD)

Infantile Neuronal Ceroid Lipofuscinoses

Inflammatory Breast Cancer

Intracranial Hemangiopericytoma

Jervell and Lange-Nielsen Syndrome

Joubert Syndrome

Junctional Epidermolysis Bullosa -Lethal Type

Juvenile Onset Huntington Disease

Kidney Cancer

Krabbe Disease (KD) - Infantile

Kufs Disease Type A and B

Late Infantile Neuronal Ceroid Lipofuscinoses

Leigh's Disease

Leiomyosarcoma

Leptomeningeal Carcinomatosis

Lesch-Nyhan Syndrome (LNS)

Lewy Body Dementia

Appendix II: Social Security Administration's
225 Compassionate Allowance Initiative (CAL)
Conditions as of April 2017

Liposarcoma - metastatic or recurrent
Lissencephaly
Liver Cancer
Lowe Syndrome
Lung Cancer - metastatic or recurrent
Lymphomatoid Granulomatosis -Grade III
Malignant Brain Stem Gliomas -Childhood
Malignant Ectomesenchymoma
Malignant Gastrointestinal Stromal Tumor
Malignant Germ Cell Tumor
Malignant Multiple Sclerosis
Malignant Renal Rhabdoid Tumor
Mantle Cell Lymphoma (MCL)
Maple Syrup Urine Disease
Marshall-Smith Syndrome
Mastocytosis - Type IV
MECP2 Duplication Syndrome
Medulloblastoma - with metastases
Menkes Disease - Classic or Infantile Onset Form
Merkel Cell Carcinoma - with metastases
Merosin Deficient Congenital Muscular Dystrophy
Metachromatic Leukodystrophy (MLD) - Late Infantile
Mitral Valve Atresia
Mixed Dementia
MPS I Hurler Syndrome
MPS II Hunter Syndrome
MPS III Sanfilippo Syndrome
Mucosal Malignant Melanoma
Multicentric Castleman Disease
Multiple System Atrophy
Myoclonic Epilepsy with Ragged Red Fibers Syndrome
Neonatal Adrenoleukodystrophy
Nephrogenic Systemic Fibrosis
Neurodegeneration with Brain Iron Accumulation - Type 1 and Type 2
NFU-1 Mitochondrial Disease
Niemann-Pick Disease (NPD) – Type A
Niemann-Pick Disease-Type C
Nonketotic Hyperglycinemia

Appendix II: Social Security Administration's
225 Compassionate Allowance Initiative (CAL)
Conditions as of April 2017

Obliterative Bronchiolitis

Ohtahara Syndrome

Oligodendroglioma Brain Cancer - Grade III

Ornithine Transcarbamylase (OTC) Deficiency

Orthochromatic Leukodystrophy with Pigmented Glia

Osteogenesis Imperfecta (OI) - Type II

Osteosarcoma, formerly known as Bone Cancer - with distant metastases, or inoperable or unresectable

Ovarian Cancer - with distant metastases or inoperable or unresectable

Pallister-Killian Syndrome

Pancreatic Cancer

Paraneoplastic Pemphigus

Patau Syndrome

Pearson Syndrome

Pelizaeus-Merzbacher Disease - Classic Form

Pelizaeus-Merzbacher Disease - Connatal Form

Peripheral Nerve Cancer - metastatic or recurrent

Peritoneal Mesothelioma

Peritoneal Mucinous Carcinomatosis

Perry Syndrome

Phelan- McDermid Syndrome

Pleural Mesothelioma

Pompe Disease - Infantile

Primary Central Nervous System Lymphoma

Primary Effusion Lymphoma

Primary Progressive Aphasia

Progressive Bulbar Palsy

Progressive Multifocal Leukoencephalopathy

Progressive Supranuclear Palsy

Prostate Cancer – Hormone Refractory Disease - or with visceral metastases

Pulmonary Atresia

Pulmonary Kaposi Sarcoma

Retinopathy of Prematurity - Stage V

Rett (RTT) Syndrome

Revesez Syndrome

Rhabdomyosarcoma

Rhizomelic Chondrodysplasia Punctata

Roberts Syndrome

Salivary Cancers

Appendix II: Social Security Administration's
225 Compassionate Allowance Initiative (CAL)
Conditions as of April 2017

Sandhoff Disease
Schindler Disease - Type 1
Seckel Syndrome
Severe Combined Immunodeficiency - Childhood
Single Ventricle
Sinonasal Cancer
Sjögren-Larsson Syndrome
Skin Malignant Melanoma
Small Cell Cancer (Large Intestine, Prostate, or Thymus)
Small Cell Cancer of the Female Genital Tract
Small Cell Lung Cancer
Small Intestine Cancer
Smith Lemli Opitz Syndrome
Soft Tissue Sarcoma - with distant metastases or recurrent
Spinal Nerve Root Cancer – metastatic or recurrent
Spinocerebellar Ataxia
Stiff Person Syndrome
Stomach Cancer - with distant metastases or inoperable, unresectable or recurrent
Subacute Sclerosing Panencephalitis
Tabes Dorsalis
Tay Sachs Disease - Infantile Type
Thanatophoric Dysplasia - Type 1
Thyroid Cancer
Transplant Coronary Artery Vasculopathy
Tricuspid Atresia
Ullrich Congenital Muscular Dystrophy
Ureter Cancer - with distant metastases or inoperable or unresectable or recurrent
Usher Syndrome - Type I
Ventricular Assist Device Recipient -Left, Right, or Biventricular
Walker Warburg Syndrome
Wolf-Hirschhorn Syndrome
Wolman Disease
X-Linked Lymphoproliferative Disease
X-Linked Myotubular Myopathy
Xeroderma Pigmentosum
Zellweger Syndrome

Source: Social Security Administration. | GAO-17-625

Appendix III: Example of a Compassionate Allowance Initiative (CAL) Condition Impairment Summary

When a claim has been identified as asserting a CAL condition, the Social Security Administration's (SSA) system that transfers claim information from the field office to the Disability Determination Services (DDS) office automatically links the claim to a detailed description of this condition, referred to as an impairment summary. This summary describes the CAL condition; provides alternate names, information on diagnostic testing and coding, and treatment options and disease progression; suggests medical evidence of record for confirming the diagnosis; and references relevant medical listings, as shown below in table 1 for Amyotrophic Lateral Sclerosis (ALS). SSA officials said examiners may use their judgment in evaluating a CAL claim, but that the impairment summary presents relevant information for them to consider when making a decision. For example, the description of ALS in the related impairment summary explains how the condition typically impacts function and presents related research findings. SSA maintains impairment summaries for each of the 225 CAL conditions. (For a complete list of CAL conditions, see appendix II.)

Table 1: Social Security Administration Impairment Summary for the Compassionate Allowance Condition Amyotrophic Lateral Sclerosis (ALS)

COMPASSIONATE ALLOWANCE INFORMATION	
AMYOTROPHIC LATERAL SCLEROSIS (ALS) - ADULT	
DESCRIPTION	Amyotrophic lateral sclerosis (ALS) , sometimes called Lou Gehrig's disease, is a rapidly progressive, invariably fatal neurological disease that attacks the nerve cells (neurons) responsible for controlling voluntary muscles. In ALS, both the upper motor neurons and the lower motor neurons degenerate or die, ceasing to send messages to muscles. Unable to function, the muscles gradually weaken, waste away, and twitch. Eventually the ability of the brain to start and control voluntary movement is lost. Individuals with ALS lose their strength and the ability to move their arms, legs, and body. When muscles in the diaphragm and chest wall fail, individuals lose the ability to breathe without ventilatory support. The disease does not affect a person's ability to see, smell, taste, hear, or recognize touch, and it does not usually impair a person's thinking or other cognitive abilities. However, several recent studies suggest that a small percentage of patients may experience problems with memory or decision-making, and there is growing evidence that some may even develop a form of dementia. The cause of ALS is not known, and scientists do not yet know why ALS strikes some people and not others.
ALTERNATE NAMES	Aran-Duchenne, Gehrig's Disease, Lou Gehrig's Disease, Motor Neuron Disease
DIAGNOSTIC TESTING AND CODING	There is no one test or procedure to establish the diagnosis of ALS. The diagnosis of ALS is based on history, neurological findings consistent with the diagnosis of ALS and electrophysiological and neuroimaging testing to rule out other impairments that may cause similar signs and symptoms. The diagnosis may be supported by electrophysiological studies (electromyogram [EMG] and nerve conduction study [NCS]) but these tests may be negative or only suggestive of the diagnosis.

Appendix III: Example of a Compassionate Allowance Initiative (CAL) Condition Impairment Summary

COMPASSIONATE ALLOWANCE INFORMATION

AMYOTROPHIC LATERAL SCLEROSIS (ALS) - ADULT

TREATMENT No cure has yet been found for ALS. However, the FDA has approved the first drug treatment for the disease-riluzole (Rilutek). Clinical trials with ALS patients showed that riluzole prolongs survival by several months. Riluzole does not reverse the damage already done to motor neurons, and patients taking the drug must be monitored for liver damage and other possible side effects. However, this first disease-specific therapy offers hope that the progression of ALS may one day be slowed by new medications or combinations of drugs. Other treatments for ALS are designed to relieve symptoms and improve the quality of life for patients. Multidisciplinary teams of health care professionals can design an individualized plan of medical and physical therapy and provide special equipment aimed at keeping patients as mobile and comfortable as possible. Physicians can prescribe medications to help reduce fatigue, ease muscle cramps, control spasticity, and reduce excess saliva and phlegm. Drugs also are available to help patients with pain, depression, sleep disturbances, and constipation.

PROGRESSION Regardless of the part of the body first affected by the disease, muscle weakness and atrophy spread to other parts of the body as the disease progresses. Most individuals with ALS die from respiratory failure, usually within 3 to 5 years from the onset of symptoms.

SUGGESTED PROGRAMMATIC ASSESSMENT *

Suggested MER for Evaluation: Documentation of a clinically appropriate medical history, neurological findings consistent with the diagnosis of ALS, and the results of any electrophysiological and neuroimaging testing.

Suggested Listings for Evaluation:

DETERMINATION	LISTING	REMARKS
Meets Listing	11.10	Amyotrophic lateral sclerosis.

Medical Equals

* Adjudicators may, at their discretion, use the Medical Evidence of Record or Listings suggested to evaluate the claim. However, the decision to allow or deny the claim rests with the adjudicator.

Last Updated:
9/10/08

Source: SSA Program Operations Manual System (POMS) DI 23022.100. | GAO-17-625

Appendix IV: Comments from the Social Security Administration



SOCIAL SECURITY
Office of the Commissioner

July 14, 2017

Ms. Kathryn A. Larin, Director
Education, Workforce, and Income Security Issues
United States Government Accountability Office
441 G. Street, NW
Washington, DC 20548

Dear Ms. Larin,

Thank you for the opportunity to review the draft report, "SSA'S COMPASSIONATE ALLOWANCE INITIATIVE: Improvements Needed to Make Expedited Processing of Disability Claims More Consistent and Accurate" (GAO-17-625). Please see our attached comments.

If you have any questions, please contact Gary S. Hatcher, Senior Advisor for the Audit Liaison Staff, at (410) 965-0680.

Sincerely,


Stephanie Hall
Acting Deputy Chief of Staff

Attachment

SOCIAL SECURITY ADMINISTRATION BALTIMORE, MD 21235-0001

**COMMENTS ON THE GOVERNMENT ACCOUNTABILITY OFFICE
DRAFT REPORT, "SSA'S COMPASSIONATE ALLOWANCE INITIATIVE:
IMPROVEMENTS NEEDED TO MAKE EXPEDITED PROCESSING OF
DISABILITY CLAIMS MORE CONSISTENT AND ACCURATE"**
(GAO-17-625)

GENERAL COMMENTS

We established the Compassionate Allowance (CAL) initiative to quickly identify and prioritize medical conditions that invariably qualify for disability under our rules. The CAL initiative helps deliver our services by making benefit decisions, often times within days, to eligible individuals with the most serious disabilities.

In 2008, we launched the CAL initiative with a list of 50 medical conditions including certain cancers, adult brain disorders, a number of rare genetic disorders of children, early-onset Alzheimer's disease, immune system conditions, and other disorders. As noted in the report, we have approved more than 500,000 claims through the CAL process, for an average allowance rate of 92 percent. We continue to identify new CAL conditions each year, and now have 225 CAL conditions. We plan to add several new conditions in 2017.

Since launching the CAL initiative, we have remained focused on our goal of providing benefits quickly to eligible individuals with the most serious disabilities, and we have refined our procedures for identifying new CAL conditions. While we have not held a public hearing recently, we continue to receive input from the public, advocacy organizations and medical and research communities through a variety of communication options. Currently, we host discussions, including webinars with various groups, and encourage members of the public to contact us via our website. We developed a Disability Determination Process Small Grant Program to improve the disability process through innovative research by graduate students focusing on topics such as CAL. We also engage in research with organizations such as the National Institutes of Health, to analyze our data and improve our case selection process.

In summary, we are committed to making quick and accurate disability decisions for eligible individuals with the most serious disabilities. While we have made changes to our process, moving forward we will remain steadfast to this commitment and continually pursue opportunities to enhance the process. We appreciate GAO's recognition of our progress in this area and will consider the recommendations as we continuously look to strengthen the CAL process. Below are our responses to the recommendations. We provided technical comments to GAO at the staff level.

RECOMMENDATION RESPONSES

Recommendation 1

Develop a formal and systematic approach to gathering information to identify potential conditions for the CAL list, including by sharing information through SSA's website on how to propose conditions for the list and by utilizing research that is directly applicable to identifying CAL conditions.

Response

We agree.

Recommendation 2

Develop formal procedures for consistently notifying those who propose conditions for the CAL list of the status of their proposals.

Response

We agree.

Recommendation 3

Develop and communicate internally and externally criteria for selecting conditions for the CAL list.

Response

We agree.

Recommendation 4

Take steps to obtain information that can help refine the selection software for CAL claims, for example by using management data, research, or DDS office feedback.

Response

We agree.

Recommendation 5

Clarify written policies and procedure regarding when manual addition and removal of CAL flags should occur on individual claims.

Response

We agree.

Recommendation 6

Assess the reasons why the uses of manual actions vary across DDS offices to ensure that they are being used appropriately.

Response

We agree.

Recommendation 7

Develop a schedule and plan for updates to the CAL impairment summaries to ensure that information is medically up-to-date.

Response

We agree.

Recommendation 8

Develop a plan to regularly review and use available data to assess the accuracy and consistency of CAL decision-making.

Response

We agree.

Appendix V: GAO Contact and Staff Acknowledgments

GAO Contact

Kathryn A. Larin at (202) 512-7215 or larink@gao.gov

Staff Acknowledgments

In addition to the contact named above, Rachel Frisk (Assistant Director), Kristen Jones (Analyst in Charge), Randy De Leon, and Michelle Loutoo Wilson made key contributions to this report. Additional contributors include Susan Aschoff, James Bennett, Sherwin Chapman, Alexander Galuten, Sheila McCoy, Monique Nasrallah, Monica Savoy, and Kelly Snow.

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