



## Testimony

Before the Subcommittee on Social Security, Committee on Ways and Means, House of Representatives

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# SSA'S COMPASSIONATE ALLOWANCE INITIATIVE

## Actions Needed to Improve the Accuracy and Consistency of Expedited Processing of Disability Claims

Statement of Kathryn Larin, Director, Education,  
Workforce, and Income Security Issues

Accessible Version

Chairman Johnson, Ranking Member Larson, and Members of the Subcommittee:

I am pleased to be here today to discuss the Social Security Administration's (SSA) Compassionate Allowance initiative (CAL). SSA oversees two key federal programs for individuals with disabilities—Disability Insurance (DI) and Supplemental Security Income (SSI).<sup>1</sup> 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. As we have noted in our prior work, SSA has historically faced challenges with processing applications for benefits in a timely manner, resulting in significant backlogs and long waits for applicants to learn whether they qualify to obtain disability benefits.<sup>2</sup>

In light of these challenges, SSA in October 2008 implemented CAL, which fast-tracks through the disability determination process those applicants who are likely to be approved because they have certain medical conditions, such as specific cancers, Amyotrophic Lateral

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<sup>1</sup>DI is an insurance program that provides benefits to eligible individuals who have qualifying disabilities or who are blind and who have worked for a minimum amount of time in employment covered by Social Security, as well as their family members. SSI provides benefits to eligible individuals who are aged, blind, or have disabilities and have limited income and resources.

<sup>2</sup>For our prior work, see 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); *Social Security Administration: Long-Term Strategy Needed to Address Key Management Challenges*, [GAO-13-459](#) (Washington, D.C.: May 29, 2013); *Social Security Disability: Management of Disability Claims Workload Will Require Comprehensive Planning*, [GAO-10-667T](#) (Washington, D.C.: Apr. 27, 2010); *Social Security Disability: Additional Performance Measures and Better Cost Estimates Could Help Improve SSA's Efforts to Eliminate Its Hearings Backlog*, [GAO-09-398](#) (Washington, D.C.: Sept. 9, 2009); and *Social Security Disability: Better Planning, Management, and Evaluation Could Help Address Backlogs*, [GAO-08-40](#) (Washington, D.C.: Dec. 7, 2007).

Sclerosis (ALS), or early-onset Alzheimer's disease.<sup>3</sup> 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. However, a few years after CAL began, concerns were raised that SSA had not identified all cases that qualified for CAL processing and processed some cases through CAL that did not qualify.<sup>4</sup> More recently, concerns have been raised 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.

To apply for disability benefits through either of SSA's disability programs, individuals submit a claim, which includes the claimant's description of his or her impairment (or impairments), among other relevant information. SSA assesses the claimant's non-medical eligibility for benefits and sends the claim to a state disability determination services (DDS) office for a review of the claimant's medical eligibility and initial determination of disability.<sup>5</sup> Although SSA is responsible for the programs, the law generally calls for initial determinations of disability to be made by state agencies.<sup>6</sup> DDS examiners assess the applicant's medical condition against SSA's Listings of Impairments (medical listings), which contain medical conditions that have been determined by the agency to be severe

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<sup>3</sup>CAL is one of several expedited processing initiatives SSA has implemented, consistent with SSA's focus on the timely processing of disability applications, or claims. For example, whereas CAL applies to claims of certain medical conditions, SSA's Terminal Illness initiative focuses on claims involving a terminal illness, which SSA defines as "a medical condition that is untreatable and expected to result in death." See SSA Program Operations Manual System (POMS) DI 23020.045. In addition, SSA's Quick Disability Determination initiative 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 disability determination services office.

<sup>4</sup>SSA, Office of the Inspector General. *Compassionate Allowance Initiative (A-01-10-21080)*. August 2010.

<sup>5</sup>Non-medical eligibility requirements may include age, employment history, and performance of substantial gainful activity.

<sup>6</sup>See 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.

enough to qualify an applicant for disability benefits.<sup>7</sup> Based on this assessment, a DDS examiner decides whether to medically allow or deny a claim for DI or SSI benefits.<sup>8</sup>

CAL claims may be processed more quickly than other claims, in part because they are given priority status. 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 indicating the claimant has a CAL condition. These claims are given priority in disability examiners' and medical consultants' queues of incoming claims, and SSA guidance directs DDS offices to initiate development of CAL claims within one work day of receipt. Examiners may only require a minimal amount of medical evidence, for example, a biopsy report, to confirm the claimant's diagnosis of a CAL condition.

My testimony today summarizes findings from our August 2017 report on CAL that is being released today.<sup>9</sup> This statement addresses 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, regulations, and guidance; analyzed SSA data on disability decisions for CAL claims from fiscal years 2009 through 2016 and on CAL claims flagged by staff for manual addition or removal of the CAL designation in fiscal year 2016; reviewed a nongeneralizable sample of 74 claim files with fiscal year 2016 initial determinations; and interviewed medical experts, representatives from patient advocacy groups, and SSA officials in headquarters and six DDS offices selected for geographic dispersion and varied CAL caseloads. Our work was

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<sup>7</sup>However, 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, examiners 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 examiner finds that the impairment does not meet or equal a listing, the examiner 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.

<sup>8</sup>A DDS examiner may consult with a medical professional, psychological professional, or both as part of this assessment.

<sup>9</sup>GAO, *SSA's Compassionate Allowance Initiative: Improvements Needed to Make Expedited Processing of Disability Claims More Consistent and Accurate*, [GAO-17-625](#) (Washington, D.C.: Aug. 11, 2017).

performed in accordance with generally accepted government auditing standards. More details on our scope and methodology can be found in the issued report.

In brief, although CAL appears to be effectively expediting benefit processing for disability claims receiving this designation, we found several weaknesses in SSA's procedures for identifying conditions for the CAL list and claims for CAL processing. We also found weakness in the agency's procedures for ensuring the accuracy and consistency of CAL decisions. My statement will highlight eight recommendations that SSA can implement to make the expedited processing of disability claims through CAL more consistent and accurate.

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## SSA Lacks a Formal and Systematic Approach for Identifying CAL Conditions

SSA has in recent years relied on advocates for individuals with certain diseases and disorders to bring potential CAL conditions to its attention. However, SSA has not clearly communicated this or provided guidance on how to make suggestions through its CAL webpage, which communicates information to the public. Without more explicit instructions, we noted that advocates may not present information that is relevant for SSA's decision-making or that most strongly makes the case for these conditions to be included on the CAL list. 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.<sup>10</sup> We concluded that 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.

In addition, we found that relying on advocates to bring conditions to SSA's attention also introduces potential bias toward certain conditions and the possibility of missing others. Some conditions that are potentially

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<sup>10</sup>GAO, *Standards for Internal Control in the Federal Government*, [GAO-14-704G](#) (Washington, D.C.: Sept. 2014).

deserving of CAL consideration may not have advocacy organizations affiliated with them, and some advocates may be unaware of 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. Federal internal control standards state that agencies should collect complete and unbiased information and consider the reliability of their information sources.<sup>11</sup> 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 the National Institutes of Health and the National Academies of Sciences, Engineering, and Medicine for research using SSA administrative data, which has led to the identification of potential CAL conditions. However, we noted that to date, the research SSA has contracted has not been sufficiently targeted to generate more than a small number of additions to the CAL list.<sup>12</sup> In our August 2017 report, we recommended that SSA develop a formal and systematic approach to gathering information to identify potential conditions for the CAL list, including sharing information through SSA's website on how to propose conditions for the list and using research that is directly applicable to identifying CAL conditions. SSA agreed with this recommendation and has begun to make revisions to its website.

We also found that 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, some of the advocates we spoke to had not received such a response from SSA and found it challenging to connect with SSA officials to obtain information about the status of their suggestions. For example, one representative from an advocacy organization told us that she was unable to reach SSA officials 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.

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<sup>11</sup>[GAO-14-704G](#).

<sup>12</sup>SSA administrative data include information on disability claims, such as the number of allowances and denials for claims with certain conditions that were allowed or denied for benefits.

Federal internal control standards state that agencies should communicate quality information externally so that external parties can help the agency achieve its objectives.<sup>13</sup> We concluded that without two-way communication between SSA and advocates, advocates are unclear on the status of their proposed CAL conditions and SSA may be missing an opportunity to improve the quality of the information it obtains from advocates. In our August 2017 report, we recommended that SSA develop formal procedures for consistently notifying those who propose conditions for the CAL list of the status of their proposals. SSA agreed with this recommendation.

Our review also found that SSA has not developed or communicated clear, consistent criteria for deciding which potential conditions will be included on the CAL list. Officials told us that they have informally considered criteria such as allowance rates—the percentage of claimants asserting a certain condition who are approved for benefits—when identifying potential CAL conditions. However, we reviewed 31 assessments of potential CAL conditions prepared by SSA medical consultants and found that they did not cite consistent criteria. There was no standard format used for these reports, and SSA does not have a template, checklist, or guidance—other than the medical listings—that its staff consult when preparing them. Further, SSA officials have cited different reasons for not designating conditions as CAL in communications with those who proposed conditions, which led to confusion regarding CAL condition criteria for staff from some advocacy organizations we interviewed. 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. We concluded that absent clear criteria for designating CAL conditions, advocates and other stakeholders may be confused as to why some conditions are not included on the CAL list and SSA may miss conditions that could qualify for CAL. In our August 2017 report, we recommended that SSA develop and communicate internally and externally criteria for selecting conditions for the CAL list. SSA agreed with this recommendation.

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<sup>13</sup>[GAO-14-704G](#).

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

To identify disability claims for expedited CAL processing, SSA primarily relies on software that searches for key words in claims. However, because text provided by claimants may be ambiguous, incomplete, inaccurate, or misspelled, the software is hindered in its ability to flag all claimants with CAL conditions and may also flag claimants for CAL processing that should not be flagged.<sup>14</sup> For example, officials we interviewed at 5 of the 6 selected 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 asserted by the claimant. In addition, in our claim file review, we found a claimant asserting a leiomyosarcoma, a soft tissue cancerous tumor that may be found in organs including the liver, lungs, and uterus, who misspelled the term as “leiomyosarcoma” on the disability claim, which resulted in the software not flagging the claim as CAL, although liver and lung cancers are CAL conditions.<sup>15</sup>

SSA officials told us that they have not established a feedback loop to capture observations from DDS officials on weaknesses in the software. However, DDS officials we spoke with have observed weaknesses in the software that, if shared, could assist SSA in improving its accuracy in identifying CAL claims. For example, an official at one DDS office noted that the software appears to identify CAL conditions using words from the claim text out of order or without regard to specific phrases. Specifically, the official stated that some claims with “pancreatitis” or “pancreatic pain” have been incorrectly flagged for the CAL condition “pancreatic cancer.” According to federal internal control standards, quality information about the agency’s operational processes should flow up the reporting lines from personnel to management to help management achieve the

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<sup>14</sup>According to SSA officials, the software contains a master word dictionary developed by their contractor and looks at “catch all” terms in certain fields, including acronyms, alternative names, possessives, singulars and plurals, context mappings, word forms, and phrases to detect possible CAL conditions.

<sup>15</sup>In this case, officials manually added the CAL flag to this claim once it was at the DDS office.

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agency's objectives.<sup>16</sup> We concluded that absent a mechanism to gather feedback from DDS offices nationwide, the agency may be missing an opportunity to obtain important information that could help improve the software. In our August 2017 report, we recommended that SSA 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. SSA agreed with this recommendation.

We also found that DDS offices play an important role in helping to ensure that claims are accurately flagged for CAL by manually correcting flagging errors made by the software, but SSA's guidance on how to make such corrections does not address when they should occur. For example, 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 does not indicate how quickly this should be done after CAL status is clarified. Based on our discussions with officials in 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 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. Ensuring claims are correctly flagged for or not 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.<sup>17</sup> According to federal internal control standards, agencies should record transactions in an accurate and timely fashion, and communicate quality information throughout the agency. We concluded that 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 and accurate tracking of CAL claims. In our August 2017 report, we recommended that SSA clarify written policies and procedures regarding

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<sup>16</sup>Management 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](#).

<sup>17</sup>Further, 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.

when manual addition and removal of CAL flags should occur on individual claims. SSA agreed with this recommendation.

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 that were not initially flagged for CAL by the software. Specifically, we found 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.<sup>18</sup> In comparison, 5 DDS offices together accounted for over 50 percent of all claims with a manual addition. Such variance could result in some claimants who assert a CAL condition not receiving expedited processing because their claims were not flagged for CAL by the selection software or DDS examiners.<sup>19</sup> We found that because SSA had not undertaken a study of its manual action procedures on such claims, it was unclear why this variance existed among DDS offices. Federal internal control standards state that agencies should establish and operate monitoring activities to monitor operations and evaluate results.<sup>20</sup> In our August 2017 report, we recommended that SSA assess the reasons why the uses of manual actions vary across DDS offices. SSA agreed with this recommendation.

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

In our August 2017 report, we found that 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, but has not regularly updated the summaries. These summaries suggest specific medical evidence for the DDS

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<sup>18</sup>This includes 64 of 103 DDS offices. For the purposes of this analysis, we focused on DDS offices in the 50 states and District of Columbia that had claims processed during fiscal year 2016.

<sup>19</sup>Although 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, as previously noted—2 weeks versus 12 weeks.

<sup>20</sup>[GAO-14-704G](#).

examiner to obtain to verify the claimant's asserted CAL condition and help examiners make decisions about whether to allow or deny a claim. However, we found that because SSA has not regularly updated the impairment summaries, nearly one-third are 5 or more years old. 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.<sup>21</sup> In addition, federal internal control standards state that as changes in the agency's environment occur, management should make necessary changes to the information requirements to address the modified risks.<sup>22</sup> We concluded that 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. In our August 2017 report, we recommended that SSA develop a schedule and a plan for updates to the CAL impairment summaries to ensure that information is medically up to date. SSA agreed with this recommendation.

We also found that SSA does not leverage data it collects to identify potential challenges to accurate and consistent decision-making on CAL claims. SSA and DDS officials review some data to monitor CAL claims processing, such as the total number of CAL claims and claims flagged for CAL by the selection software, but these efforts do not address the accuracy and consistency of decisions on CAL claims. In contrast, our analysis of SSA's data on outcomes for claims with asserted CAL conditions suggested that a review of data on allowance and denial rates for these claims may help identify conditions that are challenging to accurately and consistently adjudicate. For example, while the vast majority of claims asserting CAL conditions are allowed—about 92 percent were approved in fiscal year 2016—data we reviewed showed that there was a lower percentage of claims allowed for certain asserted CAL conditions. Specifically, SSA denied more than 30 percent of claims

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<sup>21</sup>Representatives from two advocacy organizations we spoke with stated that 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 that a review every 5 years would be adequate for a specific human immunodeficiency virus dementia disorder for which medical advancements are unlikely to occur.

<sup>22</sup>[GAO-14-704G](#).

asserting 37 CAL conditions, and 17 of these conditions had denial rates that were greater than 50 percent.<sup>23</sup> Advocates we spoke to who represent some of these conditions explained why challenges adjudicating these claims may exist. For example, officials from one of these advocacy groups told us that the CAL condition they represent is frequently confused with a much more common and non-life threatening condition that is less likely to be allowed. According to federal internal control standards, management should obtain relevant data based on identified information requirements, 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.<sup>24</sup> We concluded that without regular analyses of available data, SSA is missing an opportunity to ensure the accuracy and consistency of CAL decision-making. In our August 2017 report, we recommended that SSA develop a plan to regularly review and use available data to assess the accuracy and consistency of CAL decision-making. SSA agreed with this recommendation.

Chairman Johnson, Ranking Member Larson, and Members of the Subcommittee, this concludes my prepared statement. I would be pleased to respond to any questions you may have at this time.

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<sup>23</sup>CAL claims may be denied for various reasons, for example, 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.

<sup>24</sup>[GAO-14-704G](#).

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## GAO Contact and Staff Acknowledgments

For questions about this statement, please contact Kathryn A. Larin at (202) 512-7215 or [larink@gao.gov](mailto:larink@gao.gov). Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this statement. Individuals making key contributions to this testimony include Rachel Frisk, Assistant Director; Kristen Jones, Analyst-in-Charge; and Michelle Loutoo Wilson.

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