

May 2005

**SOCIAL SECURITY  
DISABILITY  
INSURANCE**

**SSA Actions Could  
Enhance Assistance to  
Claimants with  
Inflammatory Bowel  
Disease and Other  
Impairments**





Highlights of [GAO-04-495](#), a report to congressional committees

## Why GAO Did This Study

Advocates for patients with inflammatory bowel disease (IBD) believe that the Social Security Administration's (SSA) process for determining eligibility for Disability Insurance (DI) may treat some claimants unfairly. As a result, claimants with IBD believe they are likely to be denied benefits at the initial decision and reconsideration levels, making it necessary for them to appeal to SSA's hearings level to have their claims allowed. This congressionally mandated study focuses on (1) how SSA evaluates claims involving IBD to establish disability under Title II of the Social Security Act and (2) what unique challenges claimants with IBD encounter when applying for DI benefits, and what actions, if any, SSA has taken to address these challenges.

## What GAO Recommends

To help ensure that all claimants are informed of and provide SSA with information needed to assess fairly how impairments limit claimants' ability to work, GAO recommends that SSA emphasize the types and importance of information claimants must submit for their claim. SSA agreed with GAO's recommendations, but thought that some perspectives GAO provided on evaluating IBD claims were not relevant, and that GAO's characterization of one finding went too far. In response, GAO clarified its treatment of these issues.

[www.gao.gov/cgi-bin/getrpt?GAO-04-495](http://www.gao.gov/cgi-bin/getrpt?GAO-04-495).

To view the full product, including the scope and methodology, click on the link above. For more information, contact Robert Robertson at (202) 512-7215 or [robertsonr@gao.gov](mailto:robertsonr@gao.gov).

# SOCIAL SECURITY DISABILITY INSURANCE

## SSA Actions Could Enhance Assistance to Claimants with Inflammatory Bowel Disease and Other Impairments

### What GAO Found

SSA evaluates DI claims involving IBD just as it does all claims, using a five-step sequential evaluation process to determine whether: (1) the individual is working and earning an amount exceeding established thresholds, (2) the impairment or combination of impairments significantly limits a person's physical or mental ability to perform basic work activities, (3) the individual's impairment meets or equals a pre-established list of the medical criteria for impairments considered severe enough to prevent an individual from earning wages above the established threshold, (4) the claimant can return to previous work based on what the individual can still do in a work setting despite physical or mental limitations, or his or her "residual functional capacity," and (5) the claimant can do any work in the economy. As claims move through the five-step process, their assessment requires additional evidence and increasingly complex judgments on the part of adjudicators. For example, at step three, claimants with IBD who are diagnosed with Crohn's disease would meet the medical criteria if their weight fell below the minimum on SSA's weight table. In contrast, to determine the residual functional capacity of claimants with IBD at steps four and five, SSA adjudicators must assess claimants' mental and physical capacity and make judgments regarding allegations of pain and fatigue. Adjudicators at the initial, reconsideration, and hearings levels use the same five-step process, although differences exist between the levels that may affect decisions. For example, claimants may be represented by an attorney or nonattorney at the hearings level.

While claimants with IBD are somewhat less likely to be allowed DI benefits than claimants with other impairments, their experiences applying for disability benefits are not unique, and SSA has efforts under way that may address some claimant concerns. When we analyzed DI decisions in 2003 by decision-making levels, we found that claimants with IBD, like many others, experienced lower allowance rates at the initial and reconsideration levels compared to the hearings level, although the difference between the levels was more pronounced for claimants with IBD. Lower allowance rates at the initial levels and higher allowance rates at the hearings level may reflect challenges that claimants with IBD share with many other claimants in applying for disability benefits. For example, both claimants with IBD and other claimants are unlikely to be allowed at step five of the process at the initial levels but not at the hearings level. SSA is pursuing efforts that may address some claimant concerns. For example, the agency is currently updating the medical criteria used for many impairments, including IBD, and is proposing changes to its decision-making process that may improve consistency between decision-making levels. SSA is also trying to improve claimants' understanding of the disability claims evaluation process, but lacks assurance that the majority of claimants who file in person or over the phone understand and provide information critical to SSA's assessment of their claims as part of steps four and five of the process.

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**Figure**

Figure 1: Five-Step Sequential Evaluation Process Used at Initial, Reconsideration and Hearings Levels to Determine Disability

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**Abbreviations**

ADL	activities of daily living
ALJ	administrative law judge
CCS	Case Control System
DDS	Disability Determination Services
DI	Disability Insurance
IBD	inflammatory bowel disease
NAS	National Academy of Sciences
RFC	residual functional capacity
SGA	substantial gainful activity
SSA	Social Security Administration
SSAB	Social Security Advisory Board
SSI	Supplemental Security Income

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United States Government Accountability Office  
Washington, DC 20548

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May 31, 2005

The Honorable Charles E. Grassley  
Chairman  
The Honorable Max Baucus  
Ranking Minority Member  
Committee on Finance  
United States Senate

The Honorable Joe Barton  
Chairman  
The Honorable John D. Dingell  
Ranking Minority Member  
Committee on Energy and Commerce  
House of Representatives

The Honorable William M. Thomas  
Chairman  
The Honorable Charles B. Rangel  
Ranking Minority Member  
Committee on Ways and Means  
House of Representatives

In recent years, concerns have been raised that the process the Social Security Administration (SSA) uses to determine which claimants are eligible for Disability Insurance (DI) benefits may place some individuals at a disadvantage for receiving the benefits to which they are entitled. For example, advocates have recently stressed that the process of qualifying for DI benefits may treat some claimants with inflammatory bowel disease (IBD) unfairly. They believe that SSA field staff are not familiar with the nature of their illness and that the medical criteria used to establish disability for IBD patients do not take into account the specifics of their illness, such as its episodic and unpredictable nature. As a result, claimants with IBD believe that they are likely to be denied benefits at the initial decision and reconsideration levels, making it necessary for them to appeal to SSA's hearings level to have their claims allowed. This appeal delays the receipt of benefits and may require claimants to pay attorney fees. These concerns have arisen in spite of efforts by SSA, which manages the DI program and paid out \$78.2 billion to 7.9 million beneficiaries in 2004, to ensure that all claimants are assessed in a consistent manner.

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Partially in response to these concerns, the Congress passed the Research Review Act of 2004 (Pub. L. No. 108-427), which mandated that GAO study problems encountered by patients with IBD when applying for DI benefits under Title II of the Social Security Act and identify possible recommendations to improve the application process for these patients.<sup>1</sup>

This report will discuss (1) how SSA evaluates claims involving IBD to establish disability under Title II of the Social Security Act and (2) what unique challenges claimants with IBD encounter when applying for DI benefits, and what actions, if any, SSA has taken to address these challenges. To determine whether claimants with IBD were in fact treated differently than claimants with other impairments, we analyzed SSA data on all DI decisions made at three decision-making levels (initial, reconsideration, and hearings) in 2003 and compared allowance rates for claimants with IBD against those for claimants with other impairments.<sup>2</sup> We also reviewed a small, nonrepresentative sample of cases to better understand how both the claimants and SSA documented claims involving IBD. To identify problems IBD patients have encountered, we interviewed representatives of IBD patient advocacy groups such as the Crohn's and Colitis Foundation of America and the Digestive Disease National Coalition. We discussed these issues with officials at SSA and selected stakeholders with perspective on this issue, such as the National Association of Disability Examiners, the National Council of Disability Determination Directors, and the National Organization of Social Security Claimants' Representatives. To better understand the nature of the impairment and the experiences of those in the IBD community who apply for DI, we reviewed literature on IBD and SSA's application process and criteria as they pertain to claimants with IBD. We performed reliability tests on selected data for calendar year 2003 and found the data sufficiently reliable for use in this report. We conducted our work between January 2005 and May 2005 according to generally accepted government accounting standards.

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## Results in Brief

SSA evaluates claims involving IBD just as it does all claims, using a five-step sequential evaluation process to determine if the claimant's impairment or combination of impairments qualifies as a disability under

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<sup>1</sup>The Research Review Act of 2004 also mandated that GAO report on the Medicare and Medicaid coverage standards for certain therapies used by patients with IBD.

<sup>2</sup>See appendix I for a detailed description of the methods we used to analyze 2003 data.

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Title II of the Social Security Act. For all claims, adjudicators establish first that the individual is not working and earning an amount exceeding established thresholds (engaged in “substantial gainful activity”), and second, whether the impairment(s) significantly limits the individual’s physical or mental ability to perform basic work activities. Then, at step three of the process, the individual’s impairment(s) is compared to pre-established medical criteria in SSA’s *Listing of Impairments*. Listed impairments are considered severe enough to prevent an individual from engaging in any gainful activity. For all claims, if the severity and duration of the individual’s impairment(s)—as documented by medical examinations, laboratory results, and other required evidence—meet or are equivalent to (equal) the criteria for an impairment on that list, the adjudicator would find the individual to be “disabled” under SSA’s rules and would allow the claim. For example, a claimant with IBD who is diagnosed with Crohn’s disease and whose weight is below the minimum on SSA’s weight table would be “disabled” under SSA’s rules. Claims that do not meet or equal the medical criteria move to step four, where adjudicators determine if the claimants can do previous work based on their “residual functional capacity”; i.e., what they can still do in a work setting despite physical or mental limitations, or their “residual functional capacity.” In assessing the residual functional capacity of a claimant with IBD, for example, SSA might assess the claimant’s ability to stand, sit, and lift, as well as his or her mental capacity, pain, and fatigue. If the claimant cannot return to previous work, SSA adjudicators move to step five to determine if the claimant can do any work in the national economy, based on his or her residual functional capacity and the “vocational factors” of age, education, and work experience—in addition to residual functional capacity. As claims move through the five-step process, the assessments generally require additional evidence and involve increasingly complex judgments on the part of adjudicators. For example, adjudicators might need additional information on daily activities and symptoms, such as fatigue, for claimants with IBD whose impairment(s) does not meet or equal the medical criteria of one of SSA’s listed impairments. The adjudicators will weigh this information along with medical evidence to assess how claimants’ impairments might limit their ability to function in a work setting. Adjudicators at the initial, reconsideration, and hearings levels use the same five-step process, although other differences exist between the decision-making levels that may affect how adjudicators decide on claims. For example, claimants may introduce new evidence and allegations at each stage of the appeals process and are more likely to be represented by an attorney or nonattorney during an appeal.

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While claimants with IBD are somewhat less likely to be allowed than claimants with other impairments, their experiences applying for disability benefits are not unique relative to others, and SSA has several efforts under way that may address some claimant concerns. When we analyzed disability decisions made in 2003 for all decision-making levels combined, we found that claimants with IBD had a somewhat lower overall allowance rate than that of all other claimants (33 percent versus 39 percent). When we made this same comparison for each decision-making level separately, we found that, much like for other claimants, the allowance rate for claimants with IBD was lower at the initial and reconsideration levels compared to the hearings level, although the difference in allowance rates between levels was greater for claimants with IBD. Lower allowance rates at the initial and reconsideration levels and higher allowance rates at the hearings level may reflect challenges that claimants with IBD share with many other claimants in applying for disability benefits. For example, both claimants with IBD and many claimants with other impairments are less likely to be allowed at step five of the process at the initial and reconsideration levels, but more likely to be allowed on this basis at the hearings level. SSA is pursuing efforts that may address some of the concerns of individuals with IBD and other claimants. For example, the agency is currently updating its *Listing of Impairments*, including the listings for IBD, and is taking into account the views of the public in so doing. The agency is also proposing changes to its decision-making process that may improve consistency between the initial and reconsideration levels and the hearings level. SSA has also taken steps to improve all claimants' understanding of the disability claims evaluation process. However, the agency's recently developed "Disability Starter Kit" and other information available to the majority of claimants who apply for benefits in person or over the phone do not explain the types and importance of information needed to assess claims at steps four and five of the process.

GAO is making several recommendations in this report to the Commissioner of Social Security that will help ensure that claimants with IBD and other claimants are made aware early in the process of the types and importance of information claimants must provide with their application. In commenting on the draft of this report, SSA agreed with our recommendations but also expressed some concerns. For example, SSA stated that our report discussed two issues the agency considered irrelevant to our study of DI claimants with IBD—listings for impairments other than IBD, and the decline in DI allowances based on medical criteria. We modified the text to address some of the agency's concerns, but we believe that a discussion of both of these issues is relevant because

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it provides perspective on whether claimants with IBD are treated differently than claimants with other impairments.

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## Background

DI is the largest federal program providing cash assistance to people with disabilities. Established in 1956, DI provides monthly payments to workers with disabilities (and their dependents or survivors) under the normal retirement age who have enough work experience to qualify for disability benefits.<sup>3</sup> The Social Security Act defines disability as the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment(s) (hereafter simply referred to as “impairment”) which is expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.<sup>4</sup>

IBD encompasses two chronic autoimmune diseases of the intestinal tract: ulcerative colitis and Crohn’s disease. The two diseases are often grouped together as IBD because of their similar symptoms, but each disease has very different surgical options, and may be treated with a spectrum of diverse medications. Common symptoms of IBD include, but are not limited to: abdominal pain, weight loss, fever, rectal bleeding, skin and eye irritations, fatigue, and diarrhea. IBD is characterized by intervals of active disease, or “flares,” and periods of remission. Although it is estimated that as many as one million Americans suffer from a form of IBD, most people with IBD are able to work, and few apply for DI benefits. In 2003, less than 1 percent of DI decisions (nearly 7,000) involved IBD patients.

To obtain DI benefits, a claimant must provide information through an application and adult disability report<sup>5</sup> filed on line, in an interview by telephone, or in person at a Social Security office. For claims taken by phone or in person, SSA field staff are responsible for assisting the claimant in filling out the application form and the adult disability report

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<sup>3</sup>SSA also manages Title XVI of the Social Security Act, which created the Supplemental Security Income (SSI) program in 1972. SSI is a means-tested, income assistance program that provides monthly payments to adults or children who are blind or who have other disabilities and whose income and assets fall below a certain level.

<sup>4</sup>The SSI program uses the same definition of disability as the DI program.

<sup>5</sup>For all disability claims, claimants must fill out the disability application form and the adult disability report.

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with complete information and for noting any relevant information about the claimant observed during the interview.

If the claimant meets the nonmedical eligibility criteria, the field staff forwards the claim to the appropriate Disability Determination Services (DDS) office. DDS staff—generally a team comprising a disability examiner and a medical consultant and, sometimes, a vocational specialist—review the claimant’s medical and other evidence, obtaining additional evidence as needed to assess whether the claimant’s impairment satisfies program requirements, and make the initial disability decision. If the claimant is not satisfied with this decision, the claimant may request a reconsideration of the decision within the same DDS.<sup>6</sup> Another DDS team will review the documentation in the case file, as well as any new evidence the claimant may submit, and determine whether the claimant meets SSA’s definition of disability.

If the claimant is not satisfied with the reconsideration determination, he or she may request a hearing before an administrative law judge (ALJ). The ALJ conducts a new review of the claimant’s file, including any additional evidence the claimant submitted after the DDS decision. At a hearing, the ALJ may hear testimony from the claimant, medical experts on the claimant’s medical condition, and vocational experts regarding whether the claimant could perform work he or she has done in the past or could perform other work currently available in the national economy. The majority of claimants are represented at these hearings by an attorney or other representative.<sup>7</sup>

SSA has faced long-standing problems in administering this complex, multilevel decision-making process. These problems center around a process that can be confusing and unwieldy, with many applicants appealing and waiting a long time for a final disability decision. In addition, many within and outside of SSA have long believed that differences between the adjudication levels might cause inconsistencies in

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<sup>6</sup>In September 2003, SSA’s Commissioner proposed eliminating reconsideration and the Appeals Council as part of a large set of revisions to the disability decision-making process.

<sup>7</sup>Under the current process, if the claimant is not satisfied with the ALJ’s decision, he or she may request a review of the decision by SSA’s Appeals Council, which is the final administrative appeal within SSA. If the Appeals Council denies the request for review or the claimant is not otherwise satisfied with the Appeals Council’s decision, the claimant may appeal to a federal district court. The claimant can continue legal appeals to the U.S. Circuit Court of Appeals, and ultimately to the Supreme Court of the United States.

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decision making, in turn resulting in too many claims being initially denied and then allowed upon appeal and delaying the time it may take for some deserving claimants to receive a final agency decision. Concerned with the length of time it takes disability claimants to receive a final agency decision, SSA has cited “improving service in its disability programs” as one of its highest priorities and established “making the right decision in its disability process as early as possible” as one of its strategic objectives.

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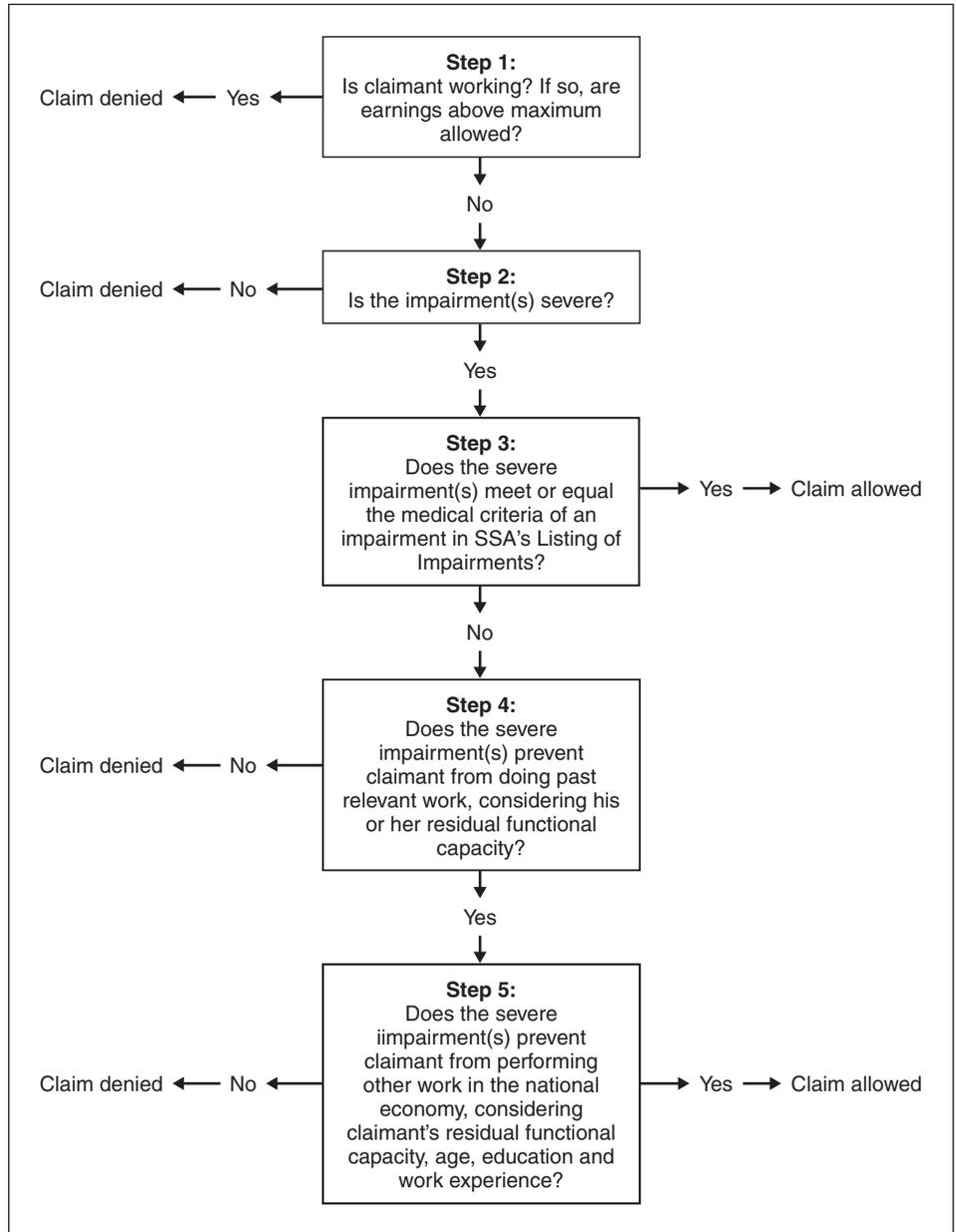
## SSA Evaluates IBD Claims Using the Same Evaluation Process as for All Claims

SSA evaluates claims involving IBD just as it does all claims, using a sequential evaluation process to determine if the claimant’s impairment qualifies as a disability under SSA’s definition.<sup>8</sup> This process—which is used at all adjudication levels—consists of five distinct steps, wherein the claimant’s employment status, medical condition, and functional limitations are considered. Figure 1 below gives an overview of how a claim moves through the five-step evaluation process.

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<sup>8</sup>The sequential claims evaluation process applies equally to DI and SSI claims.

**Figure 1: Five-Step Sequential Evaluation Process Used at Initial, Reconsideration and Hearings Levels to Determine Disability**



Source: GAO.

The first two steps of SSA's evaluation process allow SSA to screen out cases where the claimant clearly does not meet SSA's definition of

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disability. In step one, field staff determine whether the individual is engaged in substantial gainful activity.<sup>9</sup> If so, the individual does not meet the definition of disability and the claim is denied. If not, the claim moves to step two, and is forwarded to the DDS office, where the adjudicator obtains medical and other evidence and considers the severity of the impairment. If the impairment does not significantly limit the person's physical or mental ability to perform basic work activities, the impairment is considered not severe and the claim is denied. For example, a diagnosis of IBD alone is not sufficient; the condition must be severe, i.e., it must limit the person's ability to perform basic work activities, for the claim to be considered further. If the impairment is severe, the claim moves to step three.

At step three, the impairment is evaluated to see if it meets or equals in severity the medical criteria in SSA's *Listing of Impairments* (the listings). The listings describe impairments considered severe enough to prevent an individual from engaging in any gainful activity. If the severity and duration of the claimant's impairment, as documented by medical examinations, laboratory results, and other evidence meet the criteria of a listing or is equivalent in severity to a listing, the claim is allowed. For a claimant with IBD, there are different ways of meeting or equaling the medical criteria. For example, a claimant diagnosed with Crohn's disease whose weight is below the minimum weight on SSA's established weight tables would be allowed.

For all claimants, if the impairment does not meet or equal the criteria of a listing, the adjudicator must assess the claimant's "residual functional capacity" (RFC) to determine what an applicant can still do, despite physical and mental limitations, in a regular full-time work setting. The claim then moves to step four, where the adjudicator determines whether the claimant has the RFC to do any past relevant work. Assessing physical RFC requires adjudicators to judge individuals' ability to physically exert themselves in a variety of activities (such as sitting, standing, walking, lifting, carrying, pushing, and pulling) and to perform manipulative or postural functions (such as reaching, handling, stooping, and crouching). Assessing mental RFC requires adjudicators to judge, for example, the individual's ability to understand, remember, and carry out instructions and to respond appropriately to people and changes in work situations.

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<sup>9</sup>The 2005 substantial gainful activity (SGA) level for claimants who are not blind is \$830; SGA for blind claimants is \$1,380.

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Some IBD claims include allegations of pain and fatigue, which may greatly affect the claimant's RFC. Because these factors cannot be measured, the adjudicator may need to assess the "credibility" of the claimant's allegations by comparing such conditions or symptoms to other evidence in the file. If the adjudicator determines that in spite of the impairment, the claimant's RFC permits him or her to return to previous work, the claim is denied.

On the other hand, if the adjudicator determines that the claimant's RFC does not permit him or her to return to past relevant work, the claim moves to step five, where the adjudicator determines whether the claimant could do any other work in the national economy, based on the claimant's RFC and the vocational factors of age, education, and work experience. To do this, the adjudicator uses a complex system of rules set out in SSA's regulations, including a grid of medical and vocational factors that provides guidance for decision making. There are three grid tables, which are based only on exertional limitations (sedentary, light, and medium), and each table provides a variety of combinations of age, education, and work experience. If, despite the claimant's impairment and other factors, the grid indicates that there are jobs the claimant could do, the claimant would be denied; likewise, if the grid indicates that the claimant cannot do other work, the claimant would be allowed. However, for the majority of disability decisions, the grid is used only as guidance, because many claimants have limitations that the grid does not capture. For example, severe diarrhea necessitating frequent or extended trips to the bathroom may greatly reduce the productivity of claimants with IBD without necessarily causing any exertional limitations.

At any point after step one of the sequential evaluation, if the medical evidence initially provided by the claimant or obtained by the DDS is insufficient, the adjudicator may re-contact the claimant's own doctors or request a "consultative examination" paid for by SSA. If necessary—for example, for conditions or symptoms that are difficult to document or measure—the adjudicator may ask the claimant to provide more information by, for example, filling out a pain or fatigue questionnaire, or an activities of daily living (ADL) form. To corroborate a claimant's allegations of functional limitations, the adjudicator may ask third parties, such as friends or relatives, about the claimant's ability to perform various tasks in their daily lives. For a claimant with IBD, for example, the adjudicator may need such additional information to corroborate allegations of severe pain, fatigue, or diarrhea.

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Each step of the sequential evaluation process may require adjudicators to obtain and consider more and different types of evidence and to make increasingly complex judgments. For example, at the first step, only the amount of earnings is needed. In contrast, at steps four and five, adjudicators must evaluate medical evidence along with nonmedical evidence, including the claimant's activities of daily living and past work experience. In addition, the adjudicator may need to make difficult assessments of subjective factors, such as the claimant's physical or mental capacity with respect to a variety of settings and situations, the weight to place on treating source opinions, and the claimant's credibility with respect to allegations of pain, fatigue, and other symptoms.

While the five-step evaluation process is the same at all levels, there are differences between the decision-making levels that can affect how adjudicators make decisions on cases. For example, a report by the Social Security Advisory Board (SSAB) in 2001<sup>10</sup> identified some fundamental differences in the decision-making process between the DDS and hearings levels that could potentially affect the overall consistency of disability decision making between the two levels, including the following:

- Most DDS decisions are made without a face-to-face contact with the claimant, while the claimant typically appears at an ALJ hearing.
- Attorneys and other representatives are typically involved at the hearings level, but not at the DDS levels.
- The law allows claimants to introduce new evidence and allegations—of either new impairments or worsening of prior impairments over time—at each stage of the appeals process.
- Different quality assurance procedures are applied to the DDS- and hearings-level decisions.

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<sup>10</sup>Social Security Advisory Board, *Charting the Future of Social Security's Disability Programs: The Need for Fundamental Change* (Washington, D.C.: January 2001).

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## Claimants with IBD and Other Impairments Face Similar Challenges Applying for DI, and SSA Efforts May Address Some Claimant Concerns

While claimants with IBD have somewhat lower allowance rates than other claimants, the experiences of these individuals are not unique relative to claimants with other impairments. When we compared disability decisions for claimants with IBD with those for other claimants, we found that much like other claimants, claimants with IBD had lower allowance rates at the DDS (initial and reconsideration) levels, but higher allowance rates at the hearings level, although the differences between levels are more pronounced for claimants with IBD. Allowance rates that are lower at the DDS level and higher at the hearings level may reflect challenges that claimants with IBD share with other claimants. For example, IBD and other claimants face challenges meeting or equaling SSA's medical criteria at step three of the process at all adjudication levels. In addition, IBD and other claimants are less likely to be allowed at step five of the process at the DDS levels compared to the hearings level. Also like many other claimants, claimants with IBD may not be sufficiently aware of the types and importance of information they need to provide to support an allowance at step five of the process at the DDS levels. SSA is pursuing efforts that may address some of the difficulties encountered by IBD and other claimants.

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## While the Experience of Claimants with IBD Is Not Unique, Their Overall Allowance Rate Is Somewhat Lower Compared to Other Claimants

Our analysis showed that, although the experience of claimants with IBD is not unique, they tend to be allowed at lower rates compared to many other claimants. For example, when we analyzed overall allowance rates,<sup>11</sup> we found that claimants with IBD were allowed 33 percent of the time, whereas all other claimants were allowed 39 percent of the time. Because impairments with low allowance rates and a very large number of claims associated with them, such as hypertension or epilepsy, could skew these results, we also calculated individual overall allowance rates for IBD and 216 other impairments to determine whether they were significantly higher than, lower than, or similar to the overall allowance rate for claimants with IBD.<sup>12</sup> As shown in table 1, while we found that the majority of impairments had statistically higher overall allowance rates, many other impairments had similar or lower overall allowance rates.

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<sup>11</sup>To calculate overall allowance rates, we divided the number of allowances at all levels (initial, reconsideration, and hearings) by the number of decisions at all levels.

<sup>12</sup>The number of impairments we included in this analysis (218, including the two IBD impairments, ulcerative colitis, and Crohn's disease) was determined by identifying all primary impairments listed in the 2003 decisions, minus those involving fewer than 100 decisions in 2003.

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**Table 1: Comparison of Overall Allowance Rates for IBD versus Other Impairments**

<b>Other impairments compared to IBD</b>	<b>Number of impairments</b>	<b>Total decisions</b>
Significantly higher	122	<b>1,034,956</b>
Statistically similar	29	<b>61,941</b>
Significantly lower	65	<b>885,633</b>

Source: GAO analysis.

Notes: Analysis based on SSA DI disability decisions in 2003 at DDS and hearings levels.

Impairments are classified as having higher, similar or lower allowance rates than IBD, based on results from statistical models that estimate the direction, size, and significance of the difference between each impairment and IBD. Higher and lower impairments are those whose difference from IBD is significant at the .05 level.

When we analyzed allowance rates by adjudication level (DDS versus hearings levels), we found that, like many claimants with other impairments, claimants with IBD experienced lower allowance rates at the DDS and higher allowance rates at the hearings level.<sup>13</sup> At the same time, we found that the differences between claimants with IBD and all other claimants were more pronounced when we analyzed the DDS and hearings levels separately than when we combined them. Specifically, at the DDS (initial and reconsideration) levels, the allowance rate for claimants with IBD was 12 percentage points lower than the average allowance rate for all other claimants (see table 2). In contrast, at the hearings level, the allowance rate for claimants with IBD was 10 percentage points higher than the average rate for all other claimants included in this analysis. However, when we computed the overall allowance rate, the two levels offset each other, resulting in a difference of only 6 percentage points.

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<sup>13</sup>Although the allowance rate at the DDS is lower than the rate at the hearings level, this does not mean that fewer people were allowed at the DDS than at the hearings level. In fact, of the 2,257 claimants with IBD who were allowed at either level in 2003, 55 percent (or 1,241) were allowed at the DDS level. Similarly, of those claimants with other impairments who were allowed at either level, 76 percent (584,613) were allowed at the DDS level.

**Table 2: Allowance Rates for Claimants with IBD versus Other Claimants by Decision-Making Level**

Decision-making level	Allowance rate		Percentage point difference between allowance rates for claimants with IBD and other claimants
	Claimants with IBD	Other claimants	
DDS (initial & reconsideration)	22%	34%	-12*
Hearings	86%	76%	10*
All levels	33%	39%	-6*

Source: GAO analysis.

Notes: Analysis based on SSA DI disability decisions in 2003 at DDS and hearings levels.

Asterisks indicate differences between claimants with IBD and claimants with other impairments that are significant at the .05 level. The error associated with the estimated allowance rates for claimants with IBD is +/- 2 percent or less; the error associated with the estimated allowance rates for all other claimants is +/- 1 percent or less.

There may be legitimate reasons for some of the differences in allowance rates between adjudication levels and between claimants with IBD and claimants with other impairments at the different levels, but pinpointing these reasons through data analysis is difficult. Relatively high allowance rates at the hearings level could be due to new evidence reflecting new impairments or worsening of alleged impairments or the fact that the evidence covers a longer period of time, a potentially important factor for individuals with episodic impairments like IBD. With respect to variance in allowance rates between impairment groups, given the different types and characteristics of impairments, it is reasonable that all impairments should not necessarily have the same allowance rate, regardless of adjudication level. Further, rather than analyzing claims filed in a given year and following their outcomes through the various decision-making levels, we analyzed data representing decisions at all levels for 1 year. As a result, decisions at each level generally involved different claimants with varying characteristics (such as age, impairment severity, and work history) that influence decisions and might account for some of the differences. To analyze whether differences in IBD allowance rates by level are legitimate would require a much more complex analysis, following a year of applicants through the entire process and controlling for many factors that may influence the decision-making process. Even with such an analysis, it would be difficult to draw firm conclusions because some key data—such as detailed information on changes in the claimant’s medical condition at the different decision-making levels—are not readily available for analysis.

**Claimants with IBD and Other DI Claimants Encounter Similar Challenges in the Evaluation Process**

Lower allowance rates at the DDS and higher allowance rates at the hearings level may reflect challenges that IBD and many other claimants encounter in SSA’s disability evaluation process. For example, many claimants do not meet or equal SSA’s medical criteria at step three of the process, regardless of adjudication level. In addition, claims that do not meet or equal the medical criteria at step three and are evaluated at steps four and five are less likely to be allowed at step five at the DDS than at the hearings level. Finally, claimants may not be made sufficiently aware of the importance of documenting how the impairment limits their ability to work, information that is critical to steps four and five of the evaluation process. This lack of documentation may place them at a disadvantage, particularly at the DDS level.

**Challenges Encountered at Step Three**

Both DI claimants with IBD and many other claimants face challenges meeting or equaling SSA’s medical criteria at step three of the sequential evaluation process when their impairments are evaluated according to SSA’s medical criteria. Our analysis showed that the allowance rate at step three was low (20 percent or less) for claimants with IBD, as well as for claimants with other impairments, regardless of adjudication level (see table 3).

**Table 3: Allowance Rates for Disability Decisions at Step Three by Decision-Making Level**

Decision-making level	Allowance rate at step three	
	IBD	Other impairments
DDS (initial & reconsideration)	16%*	20%
Hearings	17%	17%
All levels	16%*	20%

Source: GAO analysis.

Notes: Analysis based on SSA DI disability decisions in 2003 at DDS and hearings levels.

Allowance rates at step three were derived by dividing allowances at step three by all claims considered at step three. Asterisks indicate differences between claimants with IBD and claimants with other impairments that are significant at the .05 level. The error associated with the estimated allowance rates for claimants with IBD is +/- 2 percent or less; the error associated with the estimated allowance rates for all other claimants is +/- 1 percent or less.

To further analyze whether claimants with IBD experienced similar challenges meeting or equaling SSA’s medical criteria at step three relative to other claimants, we calculated how many other types of impairments had statistically higher, similar, or lower allowance rates overall and by adjudication level. As shown in table 4, over 45 percent of other

impairments had similar or lower allowance rates at step three, regardless of adjudication level.

**Table 4: Comparison of Allowance Rates at Step Three for IBD versus Other Impairments by Decision-Making Level**

<b>Decision-making level</b>	<b>Allowance rates of other impairments compared to IBD</b>	<b>Number of impairments</b>	<b>Total decisions</b>
DDS (initial & reconsideration)	Significantly higher	115	<b>710,132</b>
	Statistically similar	31	<b>109,838</b>
	Significantly lower	70	<b>918,970</b>
Hearings	Significantly higher	48	<b>64,061</b>
	Statistically similar	124	<b>36,204</b>
	Significantly lower	44	<b>143,325</b>
All levels	Significantly higher	117	<b>803,653</b>
	Statistically similar	23	<b>88,237</b>
	Significantly lower	76	<b>1,090,640</b>

Source: GAO analysis.

Notes: Analysis based on SSA DI disability decisions in 2003 at DDS and hearings levels.

Allowance rates at step three were derived by dividing allowances at step three by all cases considered at step three.

Impairments are classified as having higher, similar or lower allowance rates than IBD, based on results from statistical models which estimate the direction, size and significance of the difference between each impairment and IBD. Higher and lower impairments are those whose difference from IBD is significant at the .05 level.

Meeting or equaling SSA’s medical criteria may be a problem for many DI claimants, although the reasons may vary by impairment. Originally, the medical criteria were developed as a way to quickly screen the large majority of cases that could be allowed on reasonably objective medical tests. However, over the years, SSA has experienced a general decline in the percentage of DI claims awarded on the basis of meeting or equaling the medical criteria at the DDS level, from 82 percent to 58 percent between 1983 and 2000. There are many factors that may have contributed to the decline in allowance rates at step three, including advances in medicine that can affect the applicability or usefulness of listings, the general aging of the baby boomer generation, the mix of impairments over the years, the addition of functional criteria to some listings that make it more difficult for claimants to meet or equal the listings, changes in or clarifications of SSA policies, and economic swings that may affect the number or percentage of claimants with very severe disabilities.

Challenges Encountered at Steps Four and Five

In addition, claimants with IBD and other claimants may encounter problems meeting or equaling the medical criteria in part because SSA’s criteria may not be up to date and complete. According to doctors in the IBD community, the IBD medical criteria in step three do not consider some symptoms of IBD that may prevent a claimant from working, such as severe diarrhea. For example, a claimant diagnosed with IBD may experience a level and frequency of diarrhea that precludes working, but that symptom is not part of the medical criteria for IBD. In general, we previously reported that SSA’s progress in updating its IBD and other medical listings has been slow and may not be keeping pace with medical advancements.<sup>14</sup> However, we did not determine and do not know whether updates to non-IBD listings would improve the likelihood of DI claimants meeting or equaling SSA’s medical criteria at step three of the process.

Claimants with IBD and others who are evaluated at steps four and five of the sequential evaluation process may also encounter challenges being allowed at the DDS versus the hearings level. As shown in table 5, our analysis found that step five allowance rates were higher at the hearings level than at the DDS levels for both claimants with IBD and claimants with other impairments, but the difference is even greater for claimants with IBD.

**Table 5: Allowance Rates for Disability Decisions at Step Five by Decision-Making Level**

Decision-making level	Allowance rate at step five	
	Claimants with IBD	Other claimants
DDS (initial & reconsideration)	13%*	25%
Hearings	85%*	74%
All levels	27%*	32%

Source: GAO analysis.

Notes: Analysis based on SSA DI disability decisions in 2003 at DDS and hearings levels.

Because only denial decisions are possible at step four, allowance rates at step five were derived by dividing allowances at step five by all claims considered at steps four and five. Asterisks indicate differences between claimants with IBD and claimants with other impairments that are significant at the .05 level. The error associated with the estimated allowance rates for claimants with IBD is +/- 2 percent or less; the error associated with the estimated allowance rates for all other claimants is +/- 1 percent or less.

<sup>14</sup>GAO, *SSA and VA Disability Programs: Re-Examination of Disability Criteria Needed to Help Ensure Program Integrity*, GAO-02-597 (Washington, D.C.: Aug. 9, 2002).

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The relatively high allowance rates at step five of the hearings level may be due to a number of factors, including the presence of an attorney or nonattorney representative at the hearings level or the fact that the evidence covers a longer period of time, a potentially important factor for individuals with episodic impairments like IBD. As noted earlier, each step of the process requires increasingly complex judgments by adjudicators, and being represented by an attorney or nonattorney who is familiar with SSA's complex rules and decision-making process may help claimants better present their cases. A GAO report in 2003<sup>15</sup> found that claimants who were represented by an attorney (or a person who is not an attorney, such as a legal aide, relative, or friend) were more likely to be allowed than claimants who had no representative. The report also noted three possible reasons for the increased likelihood of being awarded benefits for those represented by an attorney: attorneys provide assistance with the development of evidence over and above SSA's efforts to develop evidence; attorneys prepare claimants, to improve their effectiveness and credibility as witnesses; and attorneys may screen cases to select claimants with strong cases. In 2004, for 68.4 percent of all hearings-level decisions, the claimant was represented by either an attorney or a nonattorney. In contrast, claimants generally do not acquire attorneys or other representation to assist them with filing their claims at the DDS levels, although they are allowed to do so.

In the past, SSA and GAO have reported that potential inconsistencies between the interpretation and application of standards at the DDS levels versus the hearings level might explain higher allowance rates at step five at the hearings level.<sup>16</sup> For example, GAO reported on SSA studies that found that ALJs were more likely than DDS adjudicators to find that claimants are credible with respect to allegations of pain, fatigue, and other symptoms not identifiable in laboratory tests or confirmable by medical observations.<sup>17</sup> In addition, past SSA studies have found that the different roles that medical staff play at the two levels can affect

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<sup>15</sup>GAO, *SSA Disability Decision Making: Additional Steps Needed to Ensure Accuracy and Fairness of Decisions at the Hearings Level*, [GAO-04-14](#) (Washington, D.C.: Nov. 12, 2003).

<sup>16</sup>Secretary of Health and Human Services, *Implementation of Section 304 (g) Public Law 96-265, Social Security Disability Amendments of 1980, the Bellmon Report* (Washington, D.C.: January 1982).

<sup>17</sup>GAO, *Social Security Disability: SSA Must Hold Itself Accountable for Continued Improvement in Decision-making*, [GAO/HEHS-97-102](#) (Washington, D.C.: Aug. 12, 1997).

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allowance rates at step five. Specifically, SSA studies have found that DDS medical staff (who generally perform assessments of claimants' RFC themselves) tend to find that claimants had higher capacities to function in the workplace than ALJs (who may consult with medical experts, but have sole authority to make the RFC finding), even when these different adjudicators were given the same cases to review.

To help address these inconsistencies, SSA began process unification efforts in 1994 to ensure that both levels more consistently interpreted and applied SSA's policy guidance. These efforts included creating additional policy guidance by publishing rulings and regulations to clarify such policy areas as credibility, pain, and the weight given to the opinion of the treating physician. However, GAO reported in 2004<sup>18</sup> that SSA has not adequately assessed the impact of its process unification efforts and has yet to perform assessments that provide a clear understanding of the extent or causes of possible inconsistencies in decisions between adjudicative levels.

## Difficulties Understanding the Application Process

Challenges associated with claimants understanding the application process and providing critical information to support their claim, particularly at steps four and five, are common among claimants, regardless of their impairment. Having complete information to support a step five allowance is particularly significant because, according to the Social Security Advisory Board,<sup>19</sup> the percentage of claims allowed at step five has more than doubled, from 18 percent of all awards in 1983 to nearly 42 percent in 2000. However, representatives of stakeholder groups we spoke with believe that many claimants, including those with IBD, may be unaware of the importance of including detailed information on how their impairment limits their ability to work. In fact, some doctors and officials in the IBD advocacy community whom we interviewed believed that if a claimant's impairment did not meet or equal the medical listings, the claim would be denied. They were unaware of steps four and five in the sequential claim evaluation process, where nonmedical factors are considered.

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<sup>18</sup>GAO, *Social Security Administration: More Effort Needed to Assess Consistency of Disability Decisions*, [GAO-04-656](#) (Washington, D.C.: July 2, 2004).

<sup>19</sup>Social Security Advisory Board, *Disability Decision Making: Selected Aspects of Disability Decision Making* (Washington, D.C.: January 2001).

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Unless sufficiently prompted by SSA, claimants might not provide enough information when they file their claim about how their impairment limits their ability to work, which could reduce the likelihood of an allowance at step five at the DDS level. In our review of 20 disability claim folders for claims decided in 2003, we found that the prior version of the adult disability report did not clearly state the importance of providing detailed and complete information about how the impairment limited the ability to work. In responding to the question on the paper disability report then used, some claimants provided only minimal information, sometimes just a few words. For example, one claimant responded to the question about how his impairment limited the ability to work by saying “pain, limited movement.” In another case that was denied at the initial DDS level, the claimant provided minimal information concerning how the impairment limited work activities.

In contrast, the new interactive adult disability report on the agency’s Web site contains instructions, explanations, and examples that assist claimants in filling out the report. For example, in asking about how the impairment limits the claimant’s ability to work, the report notes: “This is one of the most important pages in the report.” It goes on to explain that, “You can help your case by giving us a detailed description of all of your conditions, and any symptoms that limit your ability to work. Please do not assume that your condition is self-explanatory.” The report also provides examples of how to document the conditions and symptoms that may limit the ability to work, including the type of information and level of detail needed, such as “I have trouble concentrating and have become more and more forgetful. My friend at work reminds me about important work assignments. Once I forgot to take the daily receipts to the bank. Sometimes I can’t remember how to add or subtract.” However, to view the on-line instructions, explanations and examples given in the interactive adult disability report, a claimant must provide a name and legitimate Social Security number, fill out the report, and reach the section asking how the impairment limits the ability to work. Further, these more detailed instructions and examples are directly available only to those claimants who apply on line, which accounts for only about two percent of claimants, according to an SSA official. Since the majority of applicants apply in person or over the phone, most claimants never see this information.

For the majority of claimants who apply in person or over the phone, SSA field staff have the option of reviewing and reading to claimants examples that illustrate the types and importance of information requested. However, the Social Security Advisory Board and others believe that field

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staff lack the time to sufficiently explain program rules and procedures so that applicants can understand what items of information they need to document their case. SSA does not track, and we did not determine, the extent to which SSA field staff read this information to claimants applying in person or over the phone.

Brochures and other information are available on line and routinely provided by SSA to claimants when they arrange an appointment to file a disability claim. SSA provides this information in order to help ensure that claimants can gather the information needed and have it available when they meet with the claims representative to complete the application. However, this information does not explain the type of information and level of detail needed if the impairment does not meet or equal the medical criteria at step three and the claim must be decided at steps four and five. As a result, claimants may not be sufficiently informed to give SSA enough information at the time of application to support the allegation that their impairment makes them unable to work.

Another opportunity exists for the DDS to collect information from claimants that is relevant to steps 4 and 5 in the evaluation of the initial claim. Specifically, DDS procedures call for the adjudicator to request additional information from the claimant, if (1) it is warranted based on the disability alleged by the claimant and (2) the information is not already in the adult disability report completed by the claimant or by field staff for the claimant. Requested information might include responses to a pain or fatigue questionnaire or an activities of daily living form. Again, SSA does not track, and we did not determine, the extent to which this is done.

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### SSA's Efforts May Address Some Challenges Faced by Claimants with IBD and Others

SSA is pursuing efforts that may address some but not all the difficulties encountered by claimants with IBD and other claimants. The agency is currently updating the medical criteria used at step three for all impairments, including IBD and is taking into account the views of the public in so doing. However, SSA officials told us that agency rules prohibit the discussion of specific changes prior to their publication. The process of updating criteria is lengthy, and the updates to the medical criteria for IBD may not be completed until late in 2005.

SSA also has broader efforts under way that may affect future changes to medical criteria. For example, SSA has begun holding public meetings to discuss changes in medical criteria for certain impairments, such as mental conditions and immune disorders, including HIV/AIDS. According to SSA officials, this approach allows SSA to obtain valuable input from

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outside the agency, prior to the drafting of proposed changes to medical criteria. In addition, SSA has contracted with the Institute of Medicine, part of the National Academy of Sciences (NAS), to conduct a broad review of its medical criteria. This review will study such things as developing the process for determining when the criteria need to be updated, establishing feedback mechanisms to continuously assess and evaluate the criteria, and examining the advisability of integrating functional assessment into the criteria.

In addition to changes that affect IBD and other medical criteria, SSA has several proposed changes currently under consideration that may improve the consistency of decisions between the DDS and hearings levels. Specifically, in 2004, GAO reported<sup>20</sup> that most SSA stakeholders believe the following proposals—announced by the Commissioner in 2003—may increase the extent to which DDS and hearings-level adjudicators arrive at similar decisions on similar cases

- requiring DDS adjudicators to more fully develop and document their decisions;
- changing the quality control process for hearings-level decisions in a way that makes it more consistent with that of the DDS level;
- providing both the DDS and the hearings levels with equal access to more centralized medical expertise; and
- requiring ALJs to address agency reports that recommend either denying the claim or outlining the evidence needed to fully support the claim.

SSA is also trying to improve all claimants' understanding of the disability claims evaluation process, through the interactive adult disability report and other information available on SSA's Web site. SSA's Web site contains information on various aspects of the DI program, including the evaluation process, and SSA periodically reviews and updates information provided on its Web site. However, except for the interactive adult disability report, SSA's Web site does not provide claimants with detailed instructions, explanations, and examples to assist them with completing the adult disability report.

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<sup>20</sup> [GAO-04-656](#).

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Moreover, SSA recently developed a Disability Starter Kit, available on the Web site and also given to all disability claimants who apply in person or by phone, which provides answers to frequently asked questions and materials to help them prepare for the disability interview. However, the Disability Starter Kit does not include the instructions, explanations, and examples available on the interactive adult disability report, for describing how an impairment limits the ability to work and the importance of providing this information.

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## Conclusions

Claimants with IBD believe that SSA tends to initially deny their claims, only to allow them at the hearings level, and our analysis of 2003 DI decisions confirms that most IBD claims are denied at the initial level, and a high rate of claims are allowed upon appeal. However, we also found that the experience of claimants with IBD is much like that of claimants with many other impairments. This situation may be due in part to a general shift away from allowing cases at the DDS level based on meeting or equaling the medical criteria in the listings. This in turn results in more and more cases being assessed at step five of the process—a step that involves complex judgments concerning the RFC of the claimant and assessments of factors like pain and the credibility of the claimant. Past studies have found that relative to counterparts at the hearings level, DDS adjudicators have been less inclined to find that claimants are credible or cannot perform past or other work in the national economy, and therefore less likely to allow claimants on these bases at step five of the sequential process. Inconsistencies in how adjudicators at different levels make decisions may help explain the relatively low allowance rates at the DDS levels and high allowance rates at the hearings level for IBD and other claimants whose impairments do not fit neatly into SSA's medical criteria and generally require adjudicators to perform more complex and subjective assessments. SSA has some efforts under way that may address some of these issues, but it is too early to gauge success. For example, SSA is updating its medical criteria for IBD and other impairments, but SSA is unable to discuss any changes prior to publication. SSA also contracted with the NAS to conduct a broad review of its medical criteria. However, this effort is in its initial stages, and the NAS report is not expected until March of 2006. SSA has also proposed several changes to its decision-making process that may address inconsistencies in how adjudicators at different levels view cases. However, as we previously recommended, SSA needs to collect better information to help it determine whether problems with inconsistency have been resolved.

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We also found that SSA's application and claims evaluation process may not be well understood by many claimants, and thus some claimants may not provide SSA with all the information necessary for their initial decisions. SSA's on-line adult disability report provides useful instructions, explanations, and examples to the small percentage of claimants who actually fill out the report on line. However, that information cannot easily be viewed on SSA's Web site and is not available in the other materials provided to applicants. Further, for the majority of claimants who file in person or on the phone, SSA lacks assurance that SSA field staff explain to claimants the types and importance of information needed to support a claim assessed at steps four and five of the process. As a result, claimants may not be providing sufficient information on how their impairments prevent them from working, and SSA may be missing the opportunity to gather key information for meeting one of its key strategic objectives, that is, to make the right decision in the disability process as early as possible.

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## Recommendations

To help ensure that claimants with IBD and other claimants are informed of and ultimately provide SSA with information critical to a complete assessment of their impairment at the earliest possible point in the decision-making process, SSA should implement the following three recommendations:

- Update its Web site to include more accessible information that clarifies the type and importance of information that claimants must submit for steps four and five of the sequential evaluation process. SSA should also consider making the information currently in its interactive adult disability report—including instructions, explanations and examples—more readily available to all claimants on its Web site.
- Update the Disability Starter Kit—which is provided to all claimants who apply by phone or in person—to include an explanation of the types and importance of information that claimants must submit for steps four and five of the sequential evaluation process. SSA should consider adding instructions, explanations, and examples that are currently available in the on-line form, to the extent that it is cost-effective to do so.
- Explore options for ensuring that field office and DDS staff appropriately explain and collect the types of information needed to assess how claimants' impairments impact their ability to work.

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## Agency Comments and Our Evaluation

We provided a draft of this report to SSA for comment. SSA agreed with our recommendations. Specifically, SSA agreed with our first recommendation and will take the steps necessary to ensure that, at a minimum, the information currently available in the interactive adult disability report is available to all claimants on the Web site. In its response to our second recommendation, SSA said that it would consider the inclusion of information and/or instructions along with other suggestions to the Disability Starter Kit that would address the importance of obtaining information from the disability applicant about steps four and five of the sequential evaluation process, taking into account factors such as expense and space. SSA agreed with our third recommendation and will continue to emphasize and train DDS and Social Security employees on the importance of appropriately explaining all aspects of the disability process to claimants and ensuring that the appropriate information is provided to and received from the claimants.

Although SSA agreed with our recommendations, the agency expressed concern with two statements in our report. SSA stated that our report discussed issues the agency considers irrelevant to our study of DI claimants with IBD—the addition of functional criteria to the listings for impairments other than IBD and the decline in DI allowances based on medical criteria. To respond to agency concerns, we de-emphasized our discussion of functional criteria in the listings by simply identifying it as one of many reasons for the decline in allowance rates at step three. We also clarified in our “Conclusions” section that we were discussing a decline in allowances at step three, rather than a decline in allowances based on medical criteria. However, we believe that the addition of functional criteria to the listings is relevant to our study, as is the decline in allowance rates at step three, because they provide perspective on whether claimants with IBD are treated differently than claimants with other impairments. SSA also expressed concern with how we characterized part of our analysis in the “Conclusions” section, and we modified the text in the “Conclusions” to be more specific about what our analysis found.

SSA provided additional general comments, which we have included (along with our responses to them) in appendix II and addressed in the body of our report where appropriate. SSA also provided technical comments that we have incorporated in the report as appropriate.

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We are sending copies of this report to the appropriate congressional committees, the Social Security Administration, and other interested parties. We will also make copies available to others on request. In addition, the report will be available at no charge on GAO's Web site at <http://www.gao.gov>.

If you or your staff have any questions concerning this report, please contact me or Michele Grgich, Assistant Director, at (202) 512-7215. You may also reach us by e-mail at [robertsonr@gao.gov](mailto:robertsonr@gao.gov) or [grgichm@gao.gov](mailto:grgichm@gao.gov). Other major contributors to this assignment were Jill D. Yost, Ann T. Walker, Corinna Nicolaou, Daniel Schwimer, Doug Sloane, and Shana Wallace.



Robert E. Robertson  
Director, Education, Workforce,  
and Income Security Issues

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# Appendix I: Scope and Methods

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To determine whether claimants with IBD were treated differently than claimants with other impairments, we analyzed SSA data from 2003 on all Disability Insurance (DI) decisions made at three decision-making levels (initial, reconsideration, and hearings), and compared allowance rates for claimants with IBD to those for claimants with other impairments. This appendix describes (1) the sources of the data we used, (2) the scope of our analysis, (3) steps we took to ensure data reliability, and (4) our methods for analyzing the data.

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## Data Sources

We collected information from two sources on all DI decisions made in 2003 at the three decision-making levels

- SSA's 831 file (also referred to as the National Disability Determinations Services System), which contains an electronic record of all initial and reconsideration decisions made at the DDS and
- SSA's Case Control System (CCS), which contains an electronic record of all decisions made at the hearings level.

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## Scope

The Research Review Act mandated GAO to study problems encountered by patients with IBD when applying for DI benefits under Title II of the Social Security Act. Therefore, we limited our data analyses to decisions that involved Title II (Disability Insurance or DI) claims.<sup>1</sup> We restricted our analyses to DI decisions that resulted in an allowance or a denial at one of the five steps<sup>2</sup> in the sequential process and excluded cases denied for such reasons as lack of cooperation or failure to follow prescribed treatment, because such denials are not associated with one of the five steps.

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## Data Reliability

We determined that the 831 and CCS files were sufficiently reliable based on reliability assessments of specific variables and records pertinent to our analyses that we had performed for a previous report.<sup>3</sup> For that report,

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<sup>1</sup>Some of these DI decisions involved a concurrent claim, that is, the claimant filed for DI and SSI concurrently and a decision of disability is the same for both programs.

<sup>2</sup>Although most step one denials were made at an SSA field office and were not included in our analysis, a small number of claims (1,563, or less than 0.1 percent) were denied at step one at the DDS and hearings levels.

<sup>3</sup>GAO, *SSA's Disability Programs: Improvements Could Increase the Usefulness of Electronic Data for Program Oversight*, [GAO-05-100R](#) (Washington, D.C.: Dec. 10, 2004).

we reviewed reports by GAO, the SSA Office of Inspector General, and SSA contractors on data quality. We also interviewed staff responsible for managing and using the data to assess the controls and processes in the disability system and performed electronic testing of some variables. In addition, for this report, we performed the following:

- We reviewed records in the 831 and CCS files representing DI decisions made in 2003 to identify missing data for the three variables used in this study: impairment, decision, and step of the sequential evaluation process (i.e., regulation basis code). We did not find any instances of missing data for these three variables.
- We reviewed impairment codes used for 2003 decisions and found records that did not indicate a specific diagnosis (e.g., 6490, “impairment unknown; insufficient medical evidence”). Because there were a large number of records with such impairment codes, we retained them in our analyses which compared claimants with IBD with all other claimants. After we determined the differences in allowance rates based on the total number of decisions regardless of impairment, we conducted a second analysis of allowance rates that considered the allowance rate for each impairment code. In the second analysis, we used impairment codes for which there were 100 or more decisions in 2003, including those impairment codes that did not indicate a specific diagnosis.
- We compared decision outcomes with the regulation basis code indicating at which step the decision was made, and found cases with obvious conflicts between the decision and the step. Specifically we found records that were denied at step three (one case) or allowed at step four (1,021 cases). The five-step evaluation process does not permit denials at step three or allowances at step four, so we excluded these records from our analysis. Given the large number of claims (approximately 2 million), the error produced by the exclusion of these cases is very small.

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## Methods of Analysis

In order to determine whether claimants with IBD were in fact treated differently than claimants with other impairments, we compared decision outcomes in two ways: (1) claimants with IBD versus all other claimants, and (2) IBD impairments versus 216 other individual impairments.

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### Claimants with IBD versus All Other Claimants

To determine the extent to which claimants with IBD were allowed at a different rate than other claimants, regardless of impairment type, we compared the allowance rate of claimants with IBD to that of all other claimants. The allowance rate for IBD was calculated by combining

decisions for the two IBD impairments—Crohn’s disease and ulcerative colitis. We then compared the percentage of claims allowed for those impairments with the percentage allowed for all other claimants combined. We estimated the sampling error associated with these percentages, given the size of the samples on which they were based, and tested the significance of the difference between them using a simple chi-square statistic. The error associated with the estimated allowance rate for claimants with IBD is +/- 2 percent or less. The error associated with allowance rates for all other claimants is +/- 1 percent or less. We tested the significance of the differences between claimants with IBD and other claimants using the .05 level of significance.

As indicated in table 6 below, a total of nine comparisons were made using these calculations. As noted in the table, the denominator for step three comparisons included only cases considered at step three (i.e., cases that were not denied at steps one and two), whereas the denominator for step five included cases considered at steps four and five. The reason for the difference is that assessments performed at steps four and five are highly inter-related; for example, the RFC assessment performed at step four would be used to support a denial at either step four or five, or an allowance at step five. As such, it seemed appropriate to consider allowances at step five relative to all decisions made at steps four and five.

**Table 6: Types of Comparisons Used in Report for IBD versus Other Impairments**

	<b>Allowance rate for all steps of the sequential evaluation process</b>	<b>Allowance rate at step three</b>	<b>Allowance rate at step five</b>
DDS (initial and reconsideration) level	DDS allowances divided by all DDS decisions	DDS allowances at step three divided by all cases considered at the DDS level at step three	DDS allowances at step five divided by all cases considered at the DDS level at steps four and five
Hearings level	Hearings allowances divided by all hearings decisions	Hearings allowances at step three divided by all cases considered at the hearings level at step three	Hearings allowances at step five divided by all cases considered at the hearings level at steps four and five
Overall (all decision-making levels)	2003 allowances divided by all 2003 decisions	2003 allowances at step three divided by all 2003 decisions considered at step three	2003 allowances at step five divided by all 2003 decisions considered at steps four and five

Source: GAO.

## IBD Impairment versus 216 Other Individual Impairments

We performed separate analyses to determine whether claimants with IBD had an allowance rate that was different from the allowance rates for claimants with other impairments, or whether the allowance rate for claimants with IBD was higher than for some other impairments, but lower for others. We performed this extra step because we did not know whether certain impairments might have a large number of records associated with them, and therefore might have greatly influenced the allowance rates for claimants with impairments other than IBD. This additional analysis reveals where claimants with IBD fall in the range of allowance rates by impairment, regardless of the number of claims associated with each impairment.

The allowance rate for claimants with IBD was calculated as we did in the first analysis described above. We used this allowance rate as the reference category and employed categorical logistic regression models, with 216 dummy variables for the other categories of impairments, to test the direction and significance of the difference in allowance rates between each of the other impairments and IBD. These models used Wald statistics and .05 level of significance to test differences, and were able to classify

other impairments as having significantly higher, statistically similar, or significantly lower allowance rates than IBD.

A total of four comparisons were made by impairment: overall allowance rate (all sequential evaluation steps and decision-making levels combined), and step three at the DDS, hearings, and combined levels. We reported the overall comparison as an extra test of the results of our first analysis. We reported comparisons of impairments at step three because this step involves an assessment by SSA adjudicators of medical criteria by impairment. Although we also compared impairments at step five, we did not report the comparison because we found the results to be consistent with our analysis of claimants with IBD versus other claimants.

# Appendix II: Agency Comments



## SOCIAL SECURITY

The Commissioner

May 11, 2005

Mr. Robert E. Robertson  
Director, Education, Workforce  
and Income Security Issues  
U.S. Government Accountability Office  
Room 5-T-57  
441 G Street, NW  
Washington, D.C. 20548

Dear Mr. Robertson:

Thank you for the opportunity to review and comment on the draft report "SOCIAL SECURITY DISABILITY INSURANCE: SSA Actions Could Enhance Assistance to Claimants with Inflammatory Bowel Disease and Other Impairments" (GAO-05-495). Our comments on the report are enclosed.

If you have any questions, please have your staff contact Candace Skurnik, Director, Audit Management and Liaison Staff at (410) 965-4636.

Sincerely,

A handwritten signature in black ink that reads "Jo Anne B. Barnhart".

Jo Anne B. Barnhart

Enclosures (2)

SOCIAL SECURITY ADMINISTRATION BALTIMORE MD 21235-0001

**COMMENTS ON THE GOVERNMENT ACCOUNTABILITY OFFICE (GAO)  
DRAFT REPORT "SOCIAL SECURITY DISABILITY INSURANCE: SSA  
ACTIONS COULD ENHANCE ASSISTANCE TO CLAIMANTS WITH  
INFLAMMATORY BOWEL DISEASE AND OTHER IMPAIRMENTS"  
(GAO-05-495)**

We appreciate the opportunity to comment on the GAO draft report concerning the Social Security Administration's (SSA) actions in adjudicating claims for Disability Insurance (DI) benefits filed by individuals with inflammatory bowel disease (IBD). We agree with the recommendations and commend GAO for doing the work and writing the report in so short a time.

See comment 1.

However, we do have two relatively major concerns with statements in the draft. First, we believe the report should not address general listings issues. On pages 16 and 23 of the draft report, the report addresses why the proportion of allowances based on the Listing of Impairments (the listings) has been falling over the past 20 years while the proportion of allowances at step 5 has been increasing. We strongly advise that you consider removing these discussions because they are not relevant to the study in this report. Further, as the report notes, we currently have a contract with the Institute of Medicine, National Academy of Sciences, to address this specific issue.

See comments 1 and 2.

The bulk of the text that addresses this issue repeats the theory that the listings have changed from their "original intent" and that there has been a "general shift away from allowing cases based on medical criteria;" that is, there has been a shift toward using more functional criteria in the listings. Even if these assertions were accurate, they would not be relevant to the study on IBD because the criteria in the listings for IBD--listings 5.06 and 5.07--are in fact solely medical; that is, they consist entirely of clinical and laboratory findings. Moreover, there has been no shift in the "intent" of the listings related to IBD because listings 5.06 and 5.07 have not changed since they were published in 1979. For these reasons, even if it were the case that other listings had shifted to a more functional basis and away from a solely medically based analysis, it would not be true of the listings we use to evaluate IBD. Further, the third sentence of the conclusion paragraph on page 23 of the draft ("This situation may be due in part to a general shift away from allowing cases based on medical criteria.") would be clearly erroneous with regard to the IBD listings.

See comments 1 and 2.

Other statements in the draft about the general listings issue are also incorrect. For example, one individual believed that the original intent of the listings was to match the statutory standard of "inability to work" and that the current intent is "inability to function," a standard that the individual believed was "much more stringent." However, that is not the case. Since 1980, §404.1525(a) of our regulations has provided that the listings describe impairments that are severe enough to prevent a person from doing "any gainful activity," not just "any substantial gainful activity." This is by definition a more stringent standard than the statutory definition of inability to work. (For a further discussion of this policy and why it was not new even in 1980, see the preamble to the publication of the 1980 regulations, 45 FR 55566, at 55575-55576 (1980).) In any case,

the discussion of function in the listings appears to shift the report away from the Congressional mandate to evaluate issues that claimants with IBD face.

See comments 1 and 2.

Therefore, we recommend that you delete this discussion entirely. However, if you still believe that it is necessary to include it, we recommend that you do so in a footnote so that readers do not erroneously conclude that the discussion of function in the listings affects people suffering from IBD.

See comment 3.

Second, the analysis in the draft report does not confirm the belief of claimants with IBD that they must go to the administrative law judge (ALJ) hearing level in order to win their cases. Thus, we question the last part of the first sentence of the "Conclusions" section on page 23 of the draft report: "IBD claimants believe that SSA tends to initially deny their claims, only to allow them at the hearings level, and our analysis of 2003 DI decisions confirms this." (Emphasis added.) The first part of the sentence implies that claimants believe they must go to the ALJ hearing level in order to be found disabled. This is confirmed by the report on page 1 that: "As a result, claimants with IBD believe that they are likely to be denied benefits at the initial decision and reconsideration levels, making it necessary for them to appeal to SSA's hearings level to have their claims allowed."

See comment 4.

We do not question the report's findings that people with IBD are allowed at a lower *rate* at the initial level and a higher *rate* at the ALJ hearing level. We also take this information quite seriously, and we appreciate that the report notes that we are considering public input as we revise the IBD listings for final publication in the relatively near future. However, the body of the report does not appear to support the conclusion that claimants must go to the ALJ hearing level in order to be found disabled. Further, we believe the data you used do not support this conclusion. The data in the report tell only about the relative proportions of people who were allowed in 2003, not the numbers of people who were allowed, so they do not appear to address this issue at all. However, the underlying data for the percentages you report--i.e., the data showing the *numbers* of people who were allowed at each level--show that, of the people with IBD who qualified in 2003, the majority were allowed by Disability Determination Services (DDS), and that, by far, most of those individuals were allowed at the initial level. In other words, most people with IBD who were allowed "won" their cases on their first try without having to appeal.

See comment 5.

Therefore, we believe it is not accurate for the report to say your analysis "confirm[ed]" the claimants' belief, and we recommend that GAO revise it to more accurately state what the data showed. Also, we note that the conclusion section does not refer to the analysis on page 14 of the draft report, which spells out many of the legitimate reasons why there may be differences in allowances *rates* between adjudication levels.

We have the following comments on the GAO recommendations.

**Recommendation 1: SSA should update its Web site to include more accessible information that clarifies the type and importance of information that claimants must submit for steps four and five of the sequential evaluation process. SSA should also consider making information currently in its interactive adult disability report - - including instructions, explanations and examples -- more readily available to all claimants on its Web site.**

Response

We agree on the importance of providing claimants with complete and accurate information about all aspects of the disability process. We currently provide links (More Information about Disability and the Application Process and How the Disability Application Process Works), which provide an explanation of the sequential evaluation process in detail and other application processing information under SSA's Online Claims and Services web page via the Adult Disability and Work History Report. This section of the web site can be further expanded to include similar information currently available in the interactive disability reports. SSA will take the steps necessary to ensure that, at a minimum, the information currently available in the interactive adult disability report is available to all claimants on the web site

**Recommendation 2: SSA should update the Disability Starter Kit -- which is provided to all claimants who apply by phone or in person -- to include an explanation of the types and importance of information that claimants must submit for steps four and five of the sequential evaluation process. SSA should consider adding instructions, explanations and examples that are currently available in the on-line form, to the extent that it is cost-effective to do so.**

Response

We will consider the inclusion of information and/or instructions along with other suggestions to the starter kit that would address the importance of obtaining information from the disability applicant about steps four and five of the sequential evaluation process, taking into account factors such as expense and space.

**Recommendation 3: SSA should explore options for ensuring that field office and DDS staff appropriately explain and collect the types of information needed to assess how claimants' impairments impact their ability to work.**

Response

We appreciate the comments and will continue to emphasize and train DDS and Social Security employees on the importance of appropriately explaining all aspects of the disability process to claimants and ensuring that the appropriate information is provided to and received from the claimants. Each Regional Office web site currently provides access to a "Disability Interview Guide" for the FO claims representative (CR). CRs are

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accustomed to using this resource kit for the front-end interview process. The DDS generally submits functional reports to applicants which address limitations in activities of daily living and symptom questionnaires to further address limitations. We recognize the need for (and are now conducting) additional FO training regarding the disability interview process to further assist the DDSs in their determination process.

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**GAO Comments**

1. In response to SSA's comments, we de-emphasized our discussion of functional criteria in the listings by simply identifying it as one of many reasons for the decline in allowance rates at step three. Although we agree that functional elements have not been added to the medical criteria for the IBD listings, we believe that the addition of functional criteria to some listings is relevant to our study because they provide perspective on whether claimants with IBD are treated differently than claimants with other impairments. We also clarified our text in the "Conclusions" section to discuss the decline in allowances based on meeting or equaling the medical criteria in the listings (i.e., step three allowances), instead of allowances based on medical criteria. In any case, we commend SSA for contracting with the Institute of Medicine of the National Academy of Sciences to study issues related to the listings.
2. We agree that a shift away from medical criteria toward more functional criteria is only one of many possible explanations for the downward trend of allowances at step three for DI claimants, and may not specifically apply to claimants with IBD. As discussed in comment 1, we modified our text in the body of the report and in the "Conclusions" section to place less emphasis on this particular explanation.
3. We revised the text in the "Conclusions" section to state more specifically what our analysis of 2003 decisions found.
4. We agree that, of those allowed, a larger number of allowances are made at the initial level for claimants with IBD as well as for other claimants, and we added a footnote to the body of the report confirming this. However, SSA's point that most allowances occur at the initial level does not detract from the importance of our discussion of relative rates. The low rate of allowances at the DDS level means that a large majority of claimants were initially denied, many of whom likely did not appeal their initial decision. Our analysis does not allow us to say whether the high allowance rate at the hearings level is a function of the merit of the appealed cases or, if more of those denied claims had been appealed to the hearings level (where more than half of claims are allowed), a larger number of claims might have been allowed at the hearings level, and therefore claims allowed by the DDS would be a smaller percentage of the total number of allowed claims. Thus, reporting only the total number of claims allowed at the different decision-making levels may not accurately represent the situation.
5. See comment 3. We did not revise the "Conclusions" section further because we believe the report sufficiently identifies a number of

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legitimate reasons that may explain some of the differences in allowance rates between adjudication levels.

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