

Office of the Inspector General

August 25, 2000

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Deputy Commissioner
of Social Security

Inspector General

Status of the Social Security Administration's Updates to the Medical Listings
(A-01-99-21009)

Attached is a copy of our final report. Our objective was to evaluate the Social Security Administration's actions to update the medical listings used to determine whether an individual is disabled.

Please comment within 60 days from the date of this memorandum on corrective action taken or planned on each recommendation. If you wish to discuss the final report, please call me or have your staff contact Steven L. Schaeffer, Assistant Inspector General for Audit, at (410) 965-9700.

James G. Huse, Jr.

Attachment

**OFFICE OF
THE INSPECTOR GENERAL**

SOCIAL SECURITY ADMINISTRATION

**STATUS OF THE SOCIAL SECURITY
ADMINISTRATION'S UPDATES
TO THE MEDICAL LISTINGS**

August 2000

A-01-99-21009

**EVALUATION
REPORT**



EXECUTIVE SUMMARY

OBJECTIVE

Our objective was to evaluate the Social Security Administration's (SSA) actions to update the medical listings used to determine whether an individual is disabled.

BACKGROUND

SSA first included the Listing of Impairments (medical listings) in its regulations in 1968 to help expedite the processing of disability claims under the Disability Insurance (DI) program. The medical listings have also been used for the Supplemental Security Income (SSI) program since it began in 1974. The medical listings for each body system describe impairments that are considered severe enough to prevent an adult from doing any gainful activity or to cause marked and severe functional limitations in a child younger than 18 years of age. Most of the listed impairments are permanent or expected to result in death; but some include a specific statement of duration. For all others, the evidence must show that the impairment has lasted or can be expected to last for a continuous period of at least 12 months.

From 1968 to the mid-1980s, SSA made revisions to the medical listings for various reasons by adding and/or deleting information/criteria as necessary. The last major update of the medical listings occurred in 1985, at which time, expiration dates ranging from 3 to 8 years were inserted for medical listing sections. SSA stated that expiration dates were necessary to ensure that the Agency periodically reviews (and, if necessary, updates) the listings to take into consideration medical advances in the treatment and evaluation of disabilities and program experience.

By the late-1990s, the Office of the Inspector General (OIG), the General Accounting Office, and the Social Security Advisory Board were expressing concern that SSA was not updating the listings regularly, but was simply extending the expiration dates for a number of years before they expired. For example, in 1997, SSA submitted to the OIG for comments a regulation package to extend the expiration dates for eight medical listings. The OIG expressed its concern that blanket extension of listings, which have not been reviewed, frustrates the purpose of setting expiration dates.

RESULTS OF REVIEW

SSA has acknowledged that some medical listings have not been updated during the last 10 years. SSA staff attributed these delays to staff shortages, competing priorities, and research limitations. For example, SSA has not made a comprehensive revision of the adult mental disorders listings in the last 15 years, even though the adult mental

disorders listings are the most common basis for medical disability in initial claims filed by adults. SSA is now finalizing a partial update for the adult mental disorders listings. Also, SSA will propose a new rule to revise the rest of the adult mental disorders listings once further review and research have been completed. Out-of-date medical listings can lead to more lengthy medical evaluations and/or increase the risk of inappropriate decisions being made, as in the case of the obesity listing, which was deleted in 1999.

SSA has also taken steps to improve the listing update process by adding staff and establishing a strategy to complete the updates. Further, SSA has contracted for research on disability criteria to support some listing updates. SSA is also expanding its disability research on matters related to the process for deciding disability cases. The latter research could have a significant impact on medical listing updates in the future.

ISSUES IMPACTING MEDICAL LISTING UPDATES PRIOR TO 1998

SSA has acknowledged that some medical listings have not been updated timely due to low staffing levels. By the mid-1990s, the Office of Disability (OD) had lost some of its expertise in policy matters as a result of: (1) additional staff cutbacks; (2) retirement of older, experienced staff; and (3) diversion of OD staff to assist other components. In addition, medical listing updates became a less pressing issue as SSA shifted its attention and resources to implementing Disability Redesign and addressing new legislative mandates. Finally, OD did not have the staff or time to do necessary research on disability criteria and issues related to Disability Redesign.

STATUS OF THE MENTAL DISORDERS LISTINGS

SSA has been slow to update the medical listings related to adult mental disorders, impairments that account for the highest percentage of new disability awards. During 1998, approximately 24 percent of the adults awarded benefits under the DI program and 35 percent under the SSI program, were based on mental impairment disabilities. However, the last comprehensive revision of the adult mental disorders listings was in 1985. SSA proposed an update of the adult mental disorders listings in 1991, but this rule was never finalized. SSA staff and other disability experts acknowledge the need to update the mental disorders listings to improve equity in disability findings and eliminate outdated terminology.

STRATEGY FOR UPDATES SINCE 1998

In 1998, SSA initiated an ongoing effort to update the medical listings by requesting input on needed revisions from various SSA components and establishing a strategy and goals to accomplish the revisions. SSA has also added 15 full-time policy analysts to the OD division responsible for updating the medical listings. Further, SSA established a 3-phase strategy for the updates, though none of the phases have stated completion dates. In Phase I, SSA will finalize those portions of the 1991 proposed rule for adult mental disorders that require no further revisions or comments. In Phase II,

SSA will update the remaining portions of that rule. OD staff informed us that updating all of the mental disorders listings will require more time for review and research of disability criteria. OD has initiated additional work on the mental disorders listings and has not restricted its investigations to the remaining parts of the 1991 proposed rule.

As noted in its Annual Performance Plan (APP), SSA has also initiated a number of research activities in its overall strategy to "Promote policy changes, based on research, evaluation and analysis." Some of these efforts, which address the disability evaluation process, could have a significant impact on medical listings in the future. Keeping the medical listings up-to-date is one of OD's fundamental responsibilities. The update process for medical listings can be lengthy and requires adequate research of disability criteria to support any revisions contemplated. Given the importance of medical listings to the disability decision process, the status of the update process would be a useful performance indicator in SSA's APP. In this way, Congress could be assured that SSA is keeping the listings current and conducting the necessary research to support this update process.

CONCLUSIONS AND RECOMMENDATIONS

We commend SSA for making the medical listings a priority in 1998. Although SSA was slow to update some of the medical listings between 1985 and 1998, the Agency is now making progress in updating these listings. SSA's recently issued proposed and final rules, as well as their research efforts to better understand evolving medical and work-related environmental changes, are evidence of a commitment to move the process in the right direction. However, updating the rest of the mental disorders listings needs to remain a key concern for SSA given the current and potential number of claims based on this listing. In addition, SSA should provide a timetable indicating the planned start and completion dates for each section in its 3-phase plan, so that both SSA and the Congress have benchmarks for measuring the progress of the update process.

To ensure SSA remains focused on updating all the mental disorders listings, as well as enhancing the usefulness of future APPs, we recommend that SSA establish a performance measure for its initiative to update the medical listings, with a specific timetable for each of the planned phases.

AGENCY COMMENTS

In response to our draft report, SSA agreed that updating the rest of the mental disorders listings needs to remain a key concern and that SSA needs to keep a focus on updating the listings from a performance perspective. However, SSA did not agree to accomplish this through the establishment of a performance measure, with specific timetables for each of the phases. (See Appendix B for SSA's comments to our draft report.)

OFFICE OF THE INSPECTOR GENERAL RESPONSE

The Government Performance and Results Act of 1993 requires SSA to develop performance indicators that assess the relevant service levels and outcomes of each program activity. We believe that maintaining updated medical listings for assessing disability is a crucial function for the Agency in measuring its performance. Accordingly, we continue to believe that SSA should develop and report on a measure to assess the service level and outcomes of its listings update activities.

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INTRODUCTION

OBJECTIVE

Our objective was to evaluate the Social Security Administration's (SSA) actions to update the medical listings used to determine whether an individual is disabled.

BACKGROUND

SSA first included the Listing of Impairments (medical listings)¹ in its regulations in 1968 to help expedite the processing of disability claims under the Disability Insurance (DI) program.² The medical listings have also been used for the Supplemental Security Income (SSI) program³ since it began in 1974. The medical listings are objective medical criteria that help simplify the disability evaluation process for lay and medical people who process initial claims. The listings also help ensure that:

- determinations of disability have a sound medical basis;
- claimants receive equal treatment based on specific criteria; and
- disabled individuals can be readily identified and awarded benefits, if appropriate.

Medical Listings and the Sequential Evaluation Process

The medical listings for each body system describe impairments that are considered severe enough to prevent an adult from doing gainful work or to cause marked and severe functional limitations in a child younger than 18 years of age. Most of the listed impairments are permanent or expected to result in death; but some include a specific statement of duration. For all others, the evidence must show that the impairment has lasted or is expected to last for a continuous period of at least 12 months.

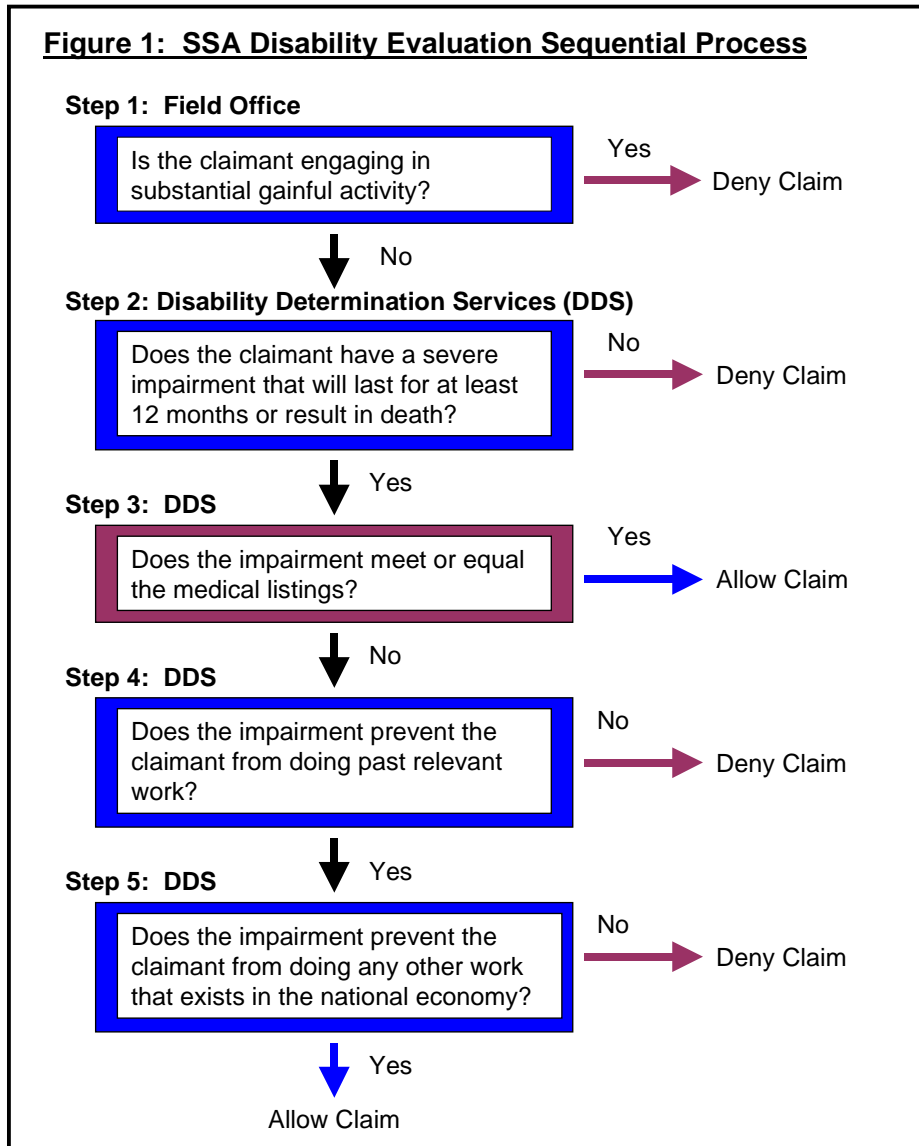
The medical listings apply only to Step 3 of the 5-step sequential evaluation process for determining disability (see Figure 1). At Step 3, the presence of an impairment(s) that meets the criteria for a listing, or that is medically equivalent in severity to that of any listed impairment (or, in the case of a child under age 18, that is functionally equivalent

¹ 20 Code of Federal Regulations, Chapter III, Part 404, Appendix 1 to Subpart P - Listing of Impairments. This DI program regulation also applies, by reference, to the SSI program.

² Title II of the Social Security Act.

³ Title XVI of the Social Security Act.

to a listed impairment) is sufficient to establish that an individual who is not working is disabled. However, if the severity of the impairment(s) does not meet or equal a listing, in the case of individuals seeking DI benefits or adults seeking SSI disability benefits, the sequential evaluation process continues until the disability issue is resolved at



Step 4 or Step 5.

The medical listings comprise two parts. Part A contains criteria that apply mainly to the evaluation of adult impairments but may be used appropriately to evaluate impairments in children under 18 years old if the disease process is similar in both adults and children. Part B contains medical criteria that apply to the evaluation of impairments of children under 18 years old where Part A criteria are inappropriate. The medical listings for a given body system only contains examples of some of the most frequently encountered impairments in the disability program and are not meant to be

inclusive of all possible impairments under that body system. See Table 1 for a listing of the body systems.

Table 1: Medical Listing Sections for Adults and Children

Part A Medical Listings – Adults	Part B Medical Listings – Children
	100.00 Growth Impairment
1.00 Musculoskeletal System	101.00 Musculoskeletal System
2.00 Special Senses and Speech	102.00 Special Senses and Speech
3.00 Respiratory System	103.00 Respiratory System
4.00 Cardiovascular System	104.00 Cardiovascular System
5.00 Digestive System	105.00 Digestive System
6.00 Genito-urinary System	106.00 Genito-urinary System
7.00 Hemic and Lymphatic System	107.00 Hemic and Lymphatic System
8.00 Skin	
9.00 Endocrine System	109.00 Endocrine System
10.00 Multiple Body Systems	110.00 Multiple Body Systems
11.00 Neurological	111.00 Neurological
12.00 Mental Disorders	112.00 Mental Disorders
13.00 Neoplastic Diseases	113.00 Neoplastic Diseases
14.00 Immune System	114.00 Immune System

Source: SSA Publication 64-039, “Disability Evaluation under SSA,” January 1998 (commonly known as the “Blue Book”).

History of the Medical Listings

Since the outset of the DI program in 1955, SSA has used a list of impairment criteria to determine a claimant’s disability in regard to his or her initial application. These early listings were based mostly on “advice from a national group of medical advisors and partly on the experience of other agencies administering their own disability programs.”⁴ As SSA gained additional operating experience, it reviewed and revised the listings periodically to reflect that experience and to meet new requirements resulting from changes in the Social Security Act.

In 1968, SSA reviewed and revised all of the early listings based on the additional years of experience and incorporated the new Listing of Impairments into the Code of Federal Regulations (CFR). Use of the criteria became mandatory immediately for the DI program and, from its inception, for the SSI program.⁵ Childhood medical listings were

⁴ 50 Federal Register (FR) 50068

⁵ The Listing of Impairments was added to the title II regulations in CFR Chapter III, Appendix 1 to Subpart P of Part 404. The SSI program adopted the criteria when it began in 1974. SSA included the same Listing of Impairments in the title XVI regulations in 20 CFR as Appendix 1 of Subpart I of Part 416. The Listing was again updated in 1979 to reflect advances in the medical treatment of and in the evaluation of some listed conditions. SSA re-codified the subparts in 1980, taking the medical criteria for the SSI

added in 1977. By that time, it became evident through program experience that separate listings for children were needed because most disease processes affected children differently than adults, or the disease was found only in children.

SSA has periodically ensured that the medical information and the structure of the listings were both acceptable for program purposes and consistent with current medical thinking. From 1968 to the mid-1980s, SSA made revisions to the medical listings for various reasons by adding and/or deleting information/criteria as necessary. The last general update of the medical listings occurred in 1985, when expiration dates ranging from 3 to 8 years were inserted. SSA staff informed us that based on the decreasing number of staff expected after the 1985 revisions, OD chose a range of years that was commensurate with their workload and limited resources to accomplish the updates.

In 1985, SSA inserted the sunset provisions, which provided that each section of the medical listings would no longer be effective after its respective expiration date unless extended by the Secretary of Health and Human Services (now the Commissioner), or revised and promulgated again. The sunset provisions were inserted so that the listing sections would be periodically reviewed (and, if necessary, updated) to take into account medical advances in the treatment and/or evaluation of disabilities, and past program experience.

Since 1985, SSA has reviewed (and revised as necessary) individual medical listings and categories of impairments⁶ to make:

- criteria changes that affect the number of claimants being found disabled;
- technical corrections;
- clarifications and language improvements;
- revisions that reflect changes in the law and program experience; and/or
- extensions of expiration dates.

However, most changes did not affect the number of claimants being found disabled, but were technical corrections and/or extensions of the listings' expiration dates. A recent exception was the 1999 update to the endocrine section, which deleted obesity as a listing-level impairment. Specifically, SSA deleted the obesity medical listing and added guidance on the evaluation of obesity to the prefaces of the musculoskeletal, respiratory, and cardiovascular body system listings.

disability program out of Part 416 and leaving them only in Appendix 1 of Subpart P of Part 404 of 20 CFR. The SSI regulations reference the DI Listing of Impairments. Because the same medical criteria apply to both disability programs, the re-codification eliminated unnecessary repetition in the regulations.

⁶ For example, since 1985, the following medical listings have been updated: cardiovascular disorders in 1994, endocrine and obesity in 1993, respiratory in 1993, immune in 1993, and endocrine in 1999. In addition, SSA revised the childhood (Part B) mental disorders listings in 1990, and on May 19, 2000, added a multiple body system section to the Part A listings.

As a result of program experience, SSA concluded that about 20 percent of the individuals found disabled based on the prior obesity listing did not have the functional limitation that would prevent them from engaging in gainful work. The listing was also difficult to administer, and was subject to misinterpretation. Since the update in 1999, individuals who claim an obesity impairment have their claims assessed under the

appropriate body system listing(s). SSA estimated that deletion of the obesity listing would reduce program outlays and result in DI program savings of \$250 million over a 5-year period, starting in FY 2000.

By the late-1990s, the Office of the Inspector General (OIG), General Accounting Office (GAO), and Social Security Advisory Board (SSAB) were expressing concern that SSA was not updating the listings regularly, but was simply extending the expiration dates for a number of years when the listings expired. For example, in 1997 SSA submitted to the OIG for comments a regulation package to extend the expiration date for eight medical listings. The OIG expressed its concern that blanket extension of listings, which have not been reviewed, frustrates the intention of the sunset provision. In 1998, GAO expressed concern about SSA's delay in revising the listings, particularly the childhood listings, and noted that this was a long-standing problem they had reported on 3 years earlier.⁷

Other organizations have also noted the need for SSA to stay current with medical developments. According to the National Academy of Social Insurance (NASI),⁸

“...experts agree that the medical and vocational criteria used in determining disability need to be reviewed and periodically updated to ensure that past experience, new research and state-of-the art knowledge are systematically incorporated into the disability evaluation process.”

In particular, NASI's Disability Policy Panel suggested that priority for review should be given to categories of impairments that account for a significant portion of the disability rolls or have rapid growth, such as mental impairments.

The SSAB has also pointed out the need for SSA to maintain a research base to support its disability programs into the future. The SSAB recommended⁹ that research be conducted on issues related to disability redesign, including the process for deciding disability cases. For example, the research would address issues, such as:

- how advances in medical treatment for severe impairments affect one's ability to work;
- the effect on program costs of increasing numbers of younger beneficiaries with mental impairments coming into the disability program and staying in it longer; and

⁷ GAO/HEHS-98-123, “Supplemental Security Income: SSA Needs a Uniform Standard for Assessing Childhood Disability,” May 6, 1998.

⁸ NASI Disability Policy Panel, “Balancing Security and Opportunity: The Challenge of Disability Income Policy,” 1996.

⁹ SSAB, “Strengthening Social Security Research: The Responsibilities of the Social Security Administration,” 1998.

- the impact that changes in the nature of work have on employment of the disabled as the economy shifts from manufacturing and production industries to service industries.

SCOPE AND METHODOLOGY

To accomplish our objective, we:

- Reviewed sections of the Social Security Act and SSA's regulations, rules, policies and procedures pertaining to the medical listings;
- Interviewed SSA staff responsible for maintaining and updating the medical listings;
- Interviewed a former Disability Determination Services (DDS) disability examiner;
- Interviewed SSA staff regarding research being conducted on disability issues; and
- Obtained outside medical experts' perspectives of the mental disorders listings and the proposed 1991 revision of the mental disorders listings.

We performed our evaluation in Baltimore, Maryland; and Boston, Massachusetts between August 1999 and February 2000. We conducted our evaluation in accordance with the *Quality Standards for Inspections* issued by the President's Council on Integrity and Efficiency.

RESULTS OF REVIEW

SSA has acknowledged that some medical listings have not been updated during the last 10 years. SSA staff attributed these delays to staff shortages, competing priorities, and research limitations. For example, SSA has not made a comprehensive revision of the adult mental disorders listings in the last 15 years, even though the adult mental disorders listings are the most common basis for medical disability in initial claims filed by adults. SSA is now finalizing a partial update for the adult mental disorders listings. Also, SSA expects to propose a new rule to revise the rest of the adult mental disorders listings once further review and research have been completed. Out-of-date medical listings can lead to more lengthy medical evaluations and/or increase the risk of inappropriate decisions being made, as in the case of the obesity listing, which was deleted in 1999.

Since 1998, OD has resumed updating the medical listings after falling behind in the 1990s. Keeping the listings current is one of OD's fundamental responsibilities. In June 1998, SSA initiated a major top-to-bottom review of the medical listings. SSA has also taken steps to improve the listing update process by adding staff and establishing a 3-phase strategy to accomplish the concurrent updates. The 1998 initiative is still ongoing, but no completion dates have been set for any of the phases or individual medical listings.

ISSUES IMPACTING MEDICAL LISTING UPDATES PRIOR TO 1998

SSA staff has agreed that some medical listings currently in use have not been updated timely and do not reflect the latest advances in medical treatments and diagnoses. Prior to 1998, three issues impacted SSA's ability to do concurrent updates of all the listings: insufficient staff, competing priorities, and lack of adequate research on disability issues.

According to SSA, after the last general update of the medical listings in 1985, the decreasing number of OD staff was adversely impacting its ability to accomplish periodic, comprehensive updates to the medical listings. By the mid-1990s, OD had also lost some of its expertise in policy matters as the number of staff was reduced further by one half. As noted by the SSAB¹⁰ and GAO,¹¹ these losses were due to:

¹⁰ SSAB, "Increasing Public Understanding of Social Security," September 1997.

¹¹ GAO/T-HEHS-00-22, "Social Security Disability, SSA Has Had Mixed Success in Efforts to Improve Caseload Management," October 21, 1999.

- staffing cutbacks in the mid-1990s;
- retirement of older, experienced staff; and
- diversion of OD staff to assist other components.

SSA staff stated that another issue impacting medical listing updates relates to shifting priorities at SSA, such as Disability Redesign and legislative mandates taking precedence. The Disability Redesign plan anticipated a change in the way disability would be evaluated. The plan, among other things, placed great emphasis on assessing one's ability to function, despite the presence of a medically determinable impairment. Many SSA staff assumed that under this plan, pared-down medical listings would emerge and eventually replace the current listings. However, by the late 1990s, SSA realized that this aspect of Disability Redesign would not work as planned.

SSA also had to address new legislative mandates during the 1990s, such as the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (Public Law 104-193), which is commonly known as the Welfare Reform law. This law required SSA to redetermine the eligibility of children who were found eligible for SSI benefits based on an individualized functional assessment or based on consideration of maladaptive behavior in the personal/behavioral domain of certain listings. As part of the new legislative requirements, OD had to redirect staff to:

- issue a regulation to implement the new childhood criteria;
- provide additional guidance to SSA components;
- train staff on the new procedures; and
- issue a Social Security Ruling to clarify issues related to these redeterminations.

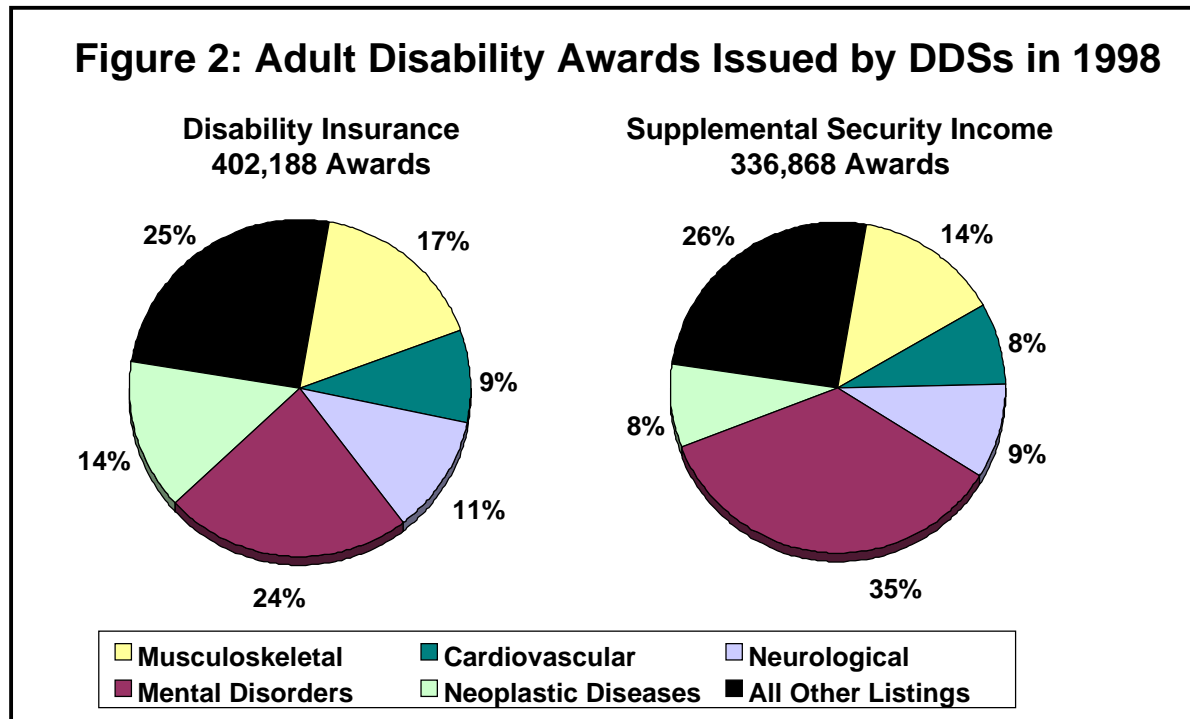
A final factor impacting the updates can be traced to the lack of adequate research on disability criteria to support medical listing updates. OD staff stated that because of the staffing and time constraints noted above, they could not do the necessary research. Also, the SSAB observed that SSA had not conducted enough research on disability issues. For example, in its January 1998 report, the SSAB noted that SSA first needed to increase its disability research capacity before making any significant changes in the way claims based on disability are processed. SSA staff acknowledged that during the 1990s they did not always have the necessary research in place to support proposing revisions to the medical listings or other disability projects. However, SSA has taken steps to correct the problems and is currently conducting both kinds of research.

STATUS OF THE MENTAL DISORDERS LISTINGS

SSA's last comprehensive update of the adult mental disorders listings was in 1985.¹² The adult mental disorders listings are the most frequently used medical listings for

¹² In 1990, SSA made a technical change to the adult mental disorders listings to ensure consistency with the childhood mental disorders listings.

disabled adults. Further, since 1985, there has been a gradual increase in the number of awards based on mental impairments. Our review of SSA's disability data for calendar year 1998 shows that of all medical listings, initial claims based on mental disorders accounted for the highest percentage of new awards. For example, during calendar year 1998 approximately 24 percent of the adults awarded benefits under the DI program and 35 percent under the SSI program were based on mental impairments.



By comparison, only 20 percent of DI awards in 1985 were based on mental impairments.

Updates to the Mental Disorders Listings

In 1985, in compliance with the Social Security Disability Benefits Reform Act of 1984 (Public Law 98-460), SSA revised the mental disorders listings to reflect changes made to the process of evaluating mental impairments and to reflect medical advancements in the treatment and diagnosis of such impairments. Also, the revision updated the terminology in the mental disorders listings to conform to terminology used in the Diagnostic and Statistical Manual of Mental Disorders (DSM),¹³ third edition, which was published in 1980.

¹³ The DSM, published by the American Psychiatric Association, is widely used by mental health professionals. It provides disability examiners and adjudicators with a common basis for communication to evaluate medical reports used in determining disability.

Recognizing that periodic review and revision was needed to keep abreast of developments in the diagnosis, evaluation and treatment of mental impairments, SSA made the 1985 revision effective for only 3 years. During this 3-year period, SSA

planned to monitor and evaluate the regulation's impact on the disability programs. When the effective period expired, the regulation would be extended, or revised and promulgated again.

For example, one change in the 1985 revision addressed a major area of criticism and deficiency of the prior mental disorders listings. Specifically, SSA recognized that impairments in an individual with a mental disorder, such as chronic schizophrenia, could be lessened by treatment, but the individual still could not work because side effects produced by the medications add to his or her work-related limitations. SSA added new evaluation considerations to the listing for schizophrenic, paranoid and other psychotic disorders to address this prior deficiency in the listings. Under this 1985 change, a chronic schizophrenic individual who meets the severity of the revised listing could be found disabled.

Prior to the August 1988 expiration date for the adult mental disorders listings, SSA extended the effective period by 3 years to provide additional time to continue evaluating the 1985 rules. During this period, the adult and childhood parts of the mental disorders listings were being reviewed and updated separately. By December 1990, the update to the childhood listings¹⁴ had been finalized, while the adult listings were still under review.

Proposed Rule for Adult Mental Disorders

In 1991, SSA proposed a rule to amend the adult mental disorders listings. The revisions reflected advances in medical knowledge, treatment, and methods of evaluating mental disorders, and provided up-to-date criteria for evaluating disability in initial claims. The revision also made the diagnostic terminology for adult mental disorders criteria consistent with the criteria in the 1990 revised childhood mental disorders listings, as appropriate. If the 1991 proposed rule had been finalized, the diagnostic terminology for the adult mental disorders listings would have been standardized (like the 1990 childhood mental disorders listings), using the revised third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III-R) published in 1987 as the guide.

Two points in the DSM-III-R drew the most criticism from mental health organizations. These were SSA's proposal to amend the special procedure¹⁵ used to evaluate mental impairments and the use of psychological testing. Concerns regarding the special technique related to the scale points and the examples SSA proposed to illustrate the level of functional loss associated with them. The issue regarding psychological testing

¹⁴ The proposed rule was published at 54 FR 33238, "Disability Insurance and Supplemental Security Income; Mental Disorders in Children," in August 1989.

¹⁵ The special procedure used to evaluate mental impairments under these rules is found in 20 CFR 404.1520a and 20 CFR 416.920a.

involved the use of certain types of tests and whether they were useful. Under the proposed rule, such psychological testing would have been limited to those situations

where the required documentation of a mental impairment could not be obtained from other sources. The proposed rule noted that:

- the individual usually can best describe his or her own functional limitations; and
- the presence of a mental impairment does not automatically rule out the individual as a reliable source of such information.

Under the 1985 medical listings, SSA placed greater reliance on such examinations and tests, as well as third-party information, in determining disability.

A further revision addressed the issue of fairness in the functional criteria requirement for the various categories of mental impairments. Under the 1985 mental disorders listings, six listings required an applicant to satisfy two criteria of the functional group to be considered disabled, while two other listings required an applicant to satisfy three criteria from the same functional group to be considered disabled. The 1991 proposed rule would make the number required consistent at two such criteria for all categories of mental impairments having this same set of functional criteria.

Nonetheless, the 1991 proposed rule to update the adult mental disorders listings was never finalized. As a result, the mental disorders listings has remained basically unchanged for the last 15 years, or 5 times longer than SSA originally intended. (See Appendix A for the timeline of updates to the mental disorders listings since 1985.)

In addition, mental health organizations and medical experts have advocated updates to the adult mental disorders listings in their publications and public pronouncements since the late 1980s. They expressed their concerns that limitations in the current mental disorders listings can and do cause problems in the interpretation and application of the listings in the disability evaluation process.

STRATEGY FOR UPDATES SINCE 1998

In 1998, SSA initiated a plan to update the medical listings by requesting input on needed revisions from various SSA components, and establishing a strategy and goals to accomplish the revisions. To help carry out that commitment, SSA added 15 full-time policy analysts to OD's Division of Medical and Vocational Policy (the division responsible for updating the medical listings). Six of the new hires have advanced degrees, including a doctor of physical medicine and rehabilitation, and a speech analyst. The others include personnel transferred from other OD components and DDS medical examiners.

SSA is utilizing a 3-phase strategy in its plan to update the medical listings (see Table 2). In 1999, OD's Phase I accomplishments included:

- an update of the endocrine system listings that deleted obesity as a listing-level impairment;
- a Notice of Proposed Rulemaking (NPRM) for Adult Down Syndrome; and
- numerous Fiscal Year (FY) 1999 research activities.

Among OD's research activities were the awarding of two contracts to the National Research Council to establish committees to address: (1) measurement and evaluation of mental retardation; and (2) functional consequences of vision loss. Phases II and III relate to completion of work started in Phase I as well as proposing additional medical listing updates.

Table 2: SSA's Strategy to Become Current with the Medical Listings

Impairment	Phase One	Phase Two	Phase Three
Growth Impairment			NPRM
Musculoskeletal System	Final		
Special Senses and Speech			NPRM
Respiratory System		NPRM	Final
Cardiovascular System		NPRM	Final
Digestive System		NPRM	Final
Genito-urinary System			NPRM
Hemic and Lymphatic System		NPRM	Final
Skin (1)		NPRM	Final
Endocrine System		NPRM	Final
-- Obesity	Final		
Multiple Body Systems			NPRM
Neurological		NPRM	Final
Mental Disorders:			
-- Adult Down Syndrome	NPRM	Final	
-- Partial Mental Disorders	Final		
-- Final Portion of Mental Disorders (1)		NPRM	Final
Neoplastic Diseases		NPRM	Final
Immune System (1)			NPRM

Note: (1) Updates to these listings were not included in the original plan submitted to the Commissioner. During our review, OD staff provided this information regarding additional planned updates.

Mental Disorders Listings

During Phase I, SSA will finalize parts of the 1991 proposed rule for the adult mental disorders listings that require no further revisions or comments. Despite the length of time since the rule was first proposed, SSA staff have determined that finalizing such

parts of the update is allowable under the Administrative Procedure Act.¹⁶ Further, SSA staff have determined that DSM-III-R terminology used in the parts being finalized in Phase I is still appropriate for evaluating mental impairment(s). However, OD staff stated that the remaining parts of the 1991 proposed rule cannot be finalized as written because of limitations imposed by the Administrative Procedure Act.

SSA plans to issue a new proposed rule on the remaining portion of the adult mental disorders listings during Phase II. Updating the remaining parts requires additional review and research. SSA staff stated that additional work on the mental disorders listings has been initiated. However, SSA staff also stated that they are not restricting their investigations to just the remaining parts of the adult mental disorders listings. Further, some of the language in the 1991 adult mental disorders proposed rule was based on DSM-III-R which is outdated since another revision of the DSM has since been published. Revising the remaining adult mental disorders listings is needed not only to make technical corrections, but to make the listings current with the latest advances in medical treatment and technology.

On-Going Research Efforts

SSA has also committed to improving the disability determination process, which started with the Disability Redesign project in the early 1990s. In its FY 2000 Annual Performance Plan (APP), SSA set a strategic objective to:

"Promote policy changes, based on research, evaluation and analysis, that shape the disability program in a manner that increases self-sufficiency and takes account of changing needs, based on medical, technological, demographic, job market, and societal trends."

Some of the specific goals and indicators established under this objective include areas that could affect the medical listings, depending on the results of research projects. For example, three research projects underway are: (1) the Disability Evaluation Study; (2) the Disability Research Institute; and (3) development of techniques for validating a medical listing (see Figure 3 for a summary of these projects).

SSA's regulations requiring the periodic review and update of the listings, as well as the current 3-phase approach for updating the medical listings, are consistent with the strategic objective noted above. However, as the mental disorders listings indicate, SSA has not been able to keep all the medical listings current. As we have noted in a past report,¹⁷ the value of an APP is increased if it includes performance goals to address mission-critical management problems.

¹⁶ SSA is required to follow rule-making procedures specified in the Administrative Procedure Act. The process from initial proposal to final regulation usually takes 1 to 2 years to complete. In the meantime, SSA uses existing criteria to determine disability at Step 3 of the sequential disability evaluation process.

¹⁷ SSA/OIG A-02-99-03007, "Review of the Social Security Administration's FY 2000 Annual Performance

Although SSA has identified the medical listings to be updated in each of the three phases, it has not established time frames for their completion. Setting the completion of each phase as a goal in the APP would not only show SSA's commitment to updating the medical listings, but would also show Congress that SSA is responding to past criticism and treats updating the listings as a priority.

Figure 3: SSA Research Projects

Disability Evaluation Study: This 4-year national disability study of the working-age population is in the pilot study phase through the end of 2000. The main study will begin in January 2001. This study will assess:

- the size of the disabled population;
- identify those factors that enable some individuals with disabilities to work gainfully in the economy; and
- determine the potential for long-term growth in the disability program.

Disability Research Institute: This project comprises one university-based, multi-disciplinary center that will use a network of scholars from a variety of institutions. The Institute will:

- conduct research in critical disability policy areas;
- disseminate important findings;
- provide a mechanism for training scholars in disability research; and
- assist in finding methods of sharing disability administrative data with researchers.

Validating Medical Listings: SSA plans to award a research design contract to develop a methodology to help SSA monitor and evaluate the listings. The purpose of this methodology is to:

- establish appropriate criteria by which SSA can assess the ability of a claimant to work;
- identify and adopt research protocols and statistical methods; and
- propose clinical or other testing methods to gather data.

CONCLUSIONS AND RECOMMENDATIONS

We commend SSA for making the medical listings a priority in 1998. Although SSA was slow to update some of the medical listings between 1985 and 1998, the Agency is now making progress in updating these listings. SSA's recently issued proposed and final rules, as well as their research efforts to better understand evolving medical and work-related environmental changes, are evidence of a commitment to move the process in the right direction. However, updating the rest of the mental disorders listings needs to remain a key concern for SSA given the current and potential number of claims based on this listing. In addition, SSA should provide a timetable indicating the planned start and completion dates for each section in its 3-phase plan, so that both SSA and the Congress have benchmarks for measuring the progress of the update process.

To ensure SSA remains focused on updating all the mental disorders listings, as well as enhance the usefulness of future APPs, we recommend that SSA establish a performance measure for its initiative to update the medical listings, with a specific timetable for each of the planned phases.

AGENCY COMMENTS

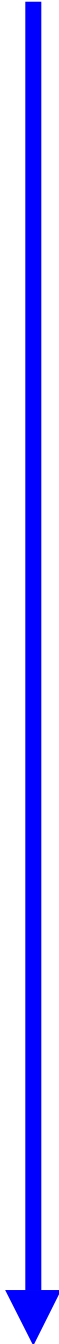
In response to our draft report, SSA stated that its entire strategy for maintaining the listings has changed. In the past, listings were revised and updated on the basis of an entire body system. The current strategy involves updating individual listings as needed, as well as, the parallel effort to bring entire body systems up to date. SSA agreed that updating the rest of the mental disorders listings needs to remain a key concern for the Agency and that SSA needs to keep a focus on updating the listings from a performance perspective. However, SSA did not agree to accomplish this through the establishment of a performance measure, with specific timetables for each of the phases.


OFFICE OF THE INSPECTOR GENERAL RESPONSE

The Government Performance and Results Act of 1993, Public Law 103-62, requires SSA to develop performance indicators that assess the relevant service levels and outcomes of each program activity. We believe that maintaining updated medical listings for assessing disability is a crucial function for the Agency in measuring its performance. Accordingly, we continue to believe that SSA should develop and report on a measure to assess the service level and outcomes of its listings update activities.

APPENDICES

MENTAL DISORDERS MEDICAL LISTINGS TIMELINE

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- **1968** Initial listings codified
 - **March 1977** *Part B* established - Childhood listings separated from adult listings (42 Federal Register (FR) 14705)
 - **March 1979** *Parts A and B* updated to reflect medical advances in treatment and diagnoses (44 FR 18170)
 - **1983** Expert Panel on adult mental disorders convened
 - **August 1985** *Parts A and B* updated to reflect medical advances in treatment and diagnoses (50 FR 35038)
 - **September 1987** *Parts A and B* established qualifications for psychiatrists who review cases (52 FR 33921)
 - **August 1988** *Part A* extended to August 1990 (53 FR 29878)
 - **October 1988** Public meeting for comments on revisions (53 FR 40135)
 - **August 1989** *Part B* proposed revision (54 FR 33238)
 - **August 1990** *Part A* extended to August 1991 (55 FR 35286)
 - **December 1990** *Part B* updated to reflect medical advances in treatments and diagnosis (55 FR 51208)
 - **July 1991** *Part A* rule proposed to revise listings, never made final (56 FR 33130)
 - **August 1991** *Part A* extended to August 1992 (56 FR 40780)
 - **August 1992** *Part A* extended to August 1993 (57 FR 24186)
 - **August 1993** *Part A* extended to August 1994 (58 FR 44444)

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- **August 1994** *Part A* extended to August 1995 (59 FR 41974)
 - **August 1995** *Part A* extended to August 1997 (60 FR 30746)
 - **December 1995** *Part B* extended to June 1997 (60 FR 62329)
 - **February 1997** *Part B* implemented rules for childhood disability provisions of Public Law 104-193 (62 FR 6408)
 - **June 1997** *Parts A and B* extended to August 1999 (62 FR 30746)
 - **June 1999** *Parts A and B* extended to July 2001 (64 FR 29787)

Note: Part A relates to adult medical listings. Part B relates to childhood medical listings.

AGENCY COMMENTS

COMMENTS ON THE OFFICE OF THE INSPECTOR GENERAL (OIG) DRAFT REPORT, “STATUS OF THE SOCIAL SECURITY ADMINISTRATION’S UPDATES TO THE MEDICAL LISTINGS” (A-01-99-21009)

Thank you for the opportunity to review and comment on this draft report.

The report presents a fairly clear history of SSA's efforts to keep the Medical Listings updated. However, in the discussion of our current efforts, the report does not reflect that SSA's entire strategy for maintaining the listings has changed. In the past, listings were revised and updated on the basis of an entire body system. The current strategy involves updating individual listings as needed - as well as the parallel effort to bring entire body systems up to date. We believe that this change of strategy should be clearly noted for accuracy and so that readers outside the Agency can be assured that every effort is being made to maintain the currency of the listings.

We agree that updating the rest of the mental disorders listings needs to remain a key concern for the Agency. As recognized on page 7 of your report, we have finalized the partial update of the adult mental disorders listings, and the final rule should be published shortly. We are currently in the process of developing proposed rules to address the remaining issues requiring revision in the mental disorders listings. In addition, we have finalized several other listings updates in the last few months.

Our response to the report recommendation follows, as well as several technical comments that we believe will improve the accuracy and content of the report.

Recommendation

Establish a performance measure for its initiative to update the medical listings, with a specific timetable for each of the planned phases.

Comment

We disagree. While we agree that we need to keep a focus on updating the Listings from a performance perspective, we do not believe that should be accomplished through the establishment of a performance measure, with specific timetables for each of the phases. Revisions to the medical listings are subject to several variables, some of which are not fully in our control. One variable concerns research upon which some listings rely. The outcome of such research can affect the timing of changes, and even whether any changes are necessary. A related variable is consultation with non-Agency experts on some of the body systems. The advice we receive from these experts may affect how we proceed. Third, changes to the listings are subject to the public-notice-and-comment procedures under the Administrative Procedure Act. The public comments we receive can affect the timing, as well as the content, of our planned revisions. In addition, as interests and priorities in different impairment areas arise in Congress, the Administration and advocacy groups, the timeframes and order of attention we give to different listings will change.

Nevertheless, because our listings generally are subject to 7 year sunset provisions, our Regulatory Agendas and our Regulatory Plans contain year-to-year information on what we plan to do to modify our listings. We have no reason to believe that this public notification process is not satisfying the needs of Congress.

OIG CONTACTS AND STAFF ACKNOWLEDGMENTS

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SSA ORGANIZATIONAL CHART
