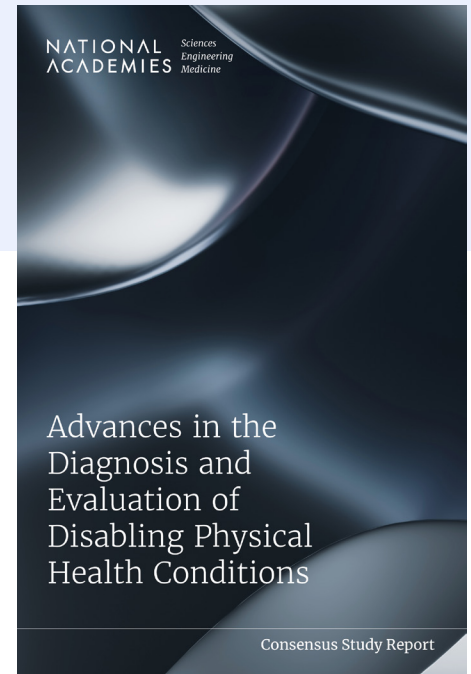


# Advances in the Diagnosis and Evaluation of Disabling Physical Health Conditions

## OVERVIEW

The United States Social Security Administration (SSA) provides benefits to adults and children who meet the eligibility requirements for a disability described in Title II and Title XVI of the Social Security Act. SSA requested the National Academies of Sciences, Engineering, and Medicine (the National Academies) assemble a committee to review new or improved diagnostic or evaluative techniques that have become generally available within the past 30 years for assessing physical conditions in five body systems: cardiovascular, neurological, respiratory, hematological, and digestive. A focus of the request is to ascertain whether more accurate or precise techniques exist for determining if a previously evaluated physical impairment was either more or less severe.

The final report of the Committee on Identifying New or Improved Diagnostic or Evaluative Techniques presents a summary of the evidence and information around selected techniques. The committee selected a subset of techniques that span diagnostic and biophysical tests, and, to a lesser extent, functional assessments, by turning to a recent National Academies' publication on the topic. *Functional Assessment for Adults with Disabilities* (NASEM, 2019), also sponsored by SSA, presented a comprehensive review of the literature pertaining to the functional assessment of physical and mental health abilities relevant to work requirements. This new report should be reviewed in conjunction with the 2019 report, as they share many themes. It is important to note that given the broad scope of the Statement of Task, this report does not encompass an exhaustive review of all of the possible techniques available within the five health fields.



## THE IMPORTANCE OF FUNCTIONAL ASSESSMENT

*Advances in the Diagnosis and Evaluation of Disabling Physical Health Conditions* underscores the importance of using evaluative information from functional assessments in disability determination. In conjunction with the medical interview and other tests, standardized measures of functioning can help quantify and track symptoms or outcomes. In the realm of functional assessment, capacity is what a person can do; performance is what a person actually does in their environment. Developing an accurate assessment of individual functioning requires measures of both capacity and performance. Data on capacity are often measured by exercise-based performance tests, and measures of capacity use standardized protocols in a controlled setting.

A wide range of functional outcomes can be measured using patient-reported instruments, including return to work, physical function, cognitive function, emotional function, support network, and social supports. Like performance-based functional measures and unlike capacity measures, patient-reported assessments evaluate what a person does in everyday settings. Patient-reported measures are valid and reliable indicators of the effects of disabling disease and impairments; importantly, these measures can identify factors contributing as barriers or facilitators to a person's ability to perform tasks.

Reviewing the full range of new and improved functional assessments goes beyond the committee's task; however, information and resources for a range of functional assessment measures are included in this report.

## THE ROLE OF SOCIAL DETERMINANTS OF HEALTH

In an assessment carried out in a controlled setting, the impacts of the environmental, social, and personal factors are obscured or minimized. While two individuals may be diagnosed with the same health condition, they may experience vastly different social determinants of health and circumstances; as such, their associated disabilities may be markedly different. This is especially true when the individuals have co-occurring health conditions.

Literature searches conducted for this study revealed few research studies examining whether diagnostic and evaluative tests perform differently across racial/ethnic groups, by age of the participants, or by other sociodemographic characteristics. While there is a lack of data in this regard, there is ample compelling evidence that there are disparities in access to new and improved diagnostic and evaluative techniques.

## THE ROLE OF TECHNOLOGICAL ADVANCES

Medical assessment and treatment have been steadily transforming. These advances are generating more detailed diagnostic information to help clinicians diagnose disease or determine how well a particular therapy is working.

Newer diagnostic techniques that focus on individualized molecular diagnoses and targeted therapeutics will continue to revolutionize the diagnosis and treatment of many diseases and conditions. However, the assessment of the functional status of an individual, including the possibility of disability, is not dependent on any single test. Instead, a holistic approach integrated across organ systems and the individual's environment is required.

## CONCLUSIONS

The committee offers eight conclusions with relevance to SSA's evaluation of an individual's severity of disability and appropriateness for benefits.

1. *Tremendous progress has occurred in the development of new—and the improvement of existing—diagnostic and evaluative tests used in clinical practice over the past 30 years.*

The committee reviewed evidence on many selected diagnostic and evaluative tests that demonstrates increased accuracy over previously generally available tests or that fulfill functions for which tests were previously unavailable. In many cases these important advances are helping improve the ability to diagnose conditions in the pre-symptomatic phase of disease (such as genetic testing for neurodegenerative conditions) or at the early stages, when the disease may be less severe. Earlier diagnosis allows earlier treatment

initiation, which may help reduce the risks and disabling consequences of severe disease.

2. *Despite displaying new or improved diagnostic capabilities, new diagnostic tests are limited in their ability to provide information regarding the presence or severity of disability.*

Diagnostic accuracy is not always sufficient, and even medical tests that make possible the precise measurement of disease characteristics may not provide accurate or useful information about the degree of an individual's functional limitations. In the context of continuing disability review, new or improved diagnostic tests will often yield little or no information on the functional consequences of previously identified health conditions.

3. *Evaluative tests can measure functioning and disability. There is insufficient evidence to conclude that any new or improved evaluative test could demonstrate that an individual is more or less disabled than had been previously found in the disability determination process.*

The committee's review did not reveal sufficient evidence from high-quality comparative evaluations between various evaluative tests to demonstrate that any particular evaluative test is more precise or accurate than other tests to the point that an individual evaluated using that test should be deemed more or less disabled than the person was when previously evaluated. Furthermore, focusing solely on the accuracy or precision of any one evaluative test to understand whether an individual may be more or less disabled oversimplifies the dynamic nature of, and contextual influences on, disability.

4. *Measuring functional limitations accurately requires gathering multiple sources of information as no single source can reliably and definitively determine a person's ability to engage in substantial gainful activity.*

It is essential to interpret the results of evaluative tests in the context of an individual's history, findings on physical examination, and other relevant testing (e.g., functional testing in a real work or school environment) in assessing disability. A test of a person's capacity (e.g., 6-minute walk test) cannot provide a comprehensive

understanding of the consequences of an individual's functional limitations in real-world settings. Contextual factors (physical and social environment) and personal factors (such as motivation) that influence a person's performance in everyday settings are critical in the assessment and interpretation of disability.

The committee found that SSA's current process for examining residual functional capacity would likely benefit from improvements in the systematic collection of information from multiple sources, increased objectivity in the process, and more comprehensive examination of all aspects of whole person function.

5. *There are barriers to the widespread use of diagnostic and evaluative medical technologies.*

Studies show that people unable to access timely, appropriate care are less likely to be diagnosed with early-stage disease, are more likely to have co-morbid conditions, and are more likely to experience poorer health outcomes overall, including disabling consequences. If an individual does not have access to diagnostic and evaluative tests, it limits the clinician's ability to determine the nature and severity of the person's condition with increased specificity. The variable distribution and availability of diagnostic and evaluative resources can be a barrier to the integration of these resources into routine clinical practice in some areas of the United States.

6. *Functional assessments using patient-reported measures are valid and reliable indicators that deserve greater attention by SSA.*

The use of patient-reported measures in functional assessments can provide an enhanced understanding of the effects of disease on health, functioning, and quality of life, and thus these are important tools in monitoring disease progression across a wide spectrum of diseases. There are hundreds of validated patient-reported measures relating to nearly all body regions and conditions that are used clinically to assess a range of functional outcomes, such as return to work, physical function, cognitive function, emotional function, support network, and social supports.

7. *There are important gaps in the literature and in knowledge for each of the body systems regarding how diagnostic and evaluative tests perform differently across subpopulations and in comparison with other tests.*

The committee found important gaps in the existing research literature regarding how various diagnostic and evaluative tests may perform differently across racial or ethnic groups, by age of the participants, or by other sociodemographic characteristics. The committee notes that some diagnostic or evaluative tests may not be culturally or linguistically sensitive and results may not be reliable when compared between subpopulations. Research focused on determining the validity of generally available diagnostic and evaluative tests across the full range of developmental, demographic, cultural, linguistic, and socioeconomic groups would enhance SSA's ability to make disability determinations.

8. *Advances in health care are constantly occurring, which makes staying abreast of new and improved diagnostic and evaluative tests important for assessment and care.*

Frequent updates to SSA program guidance performed in a timely manner would help ensure that the disability evaluation process consistently reflects the best current practice in clinical diagnosis and in the evaluation of disability.

#### **LOOKING FORWARD**

There has been great progress in the development of new—and the improvement of existing—diagnostic and evaluative tests used in clinical practice. However, in the context of disability review, no single diagnostic or evaluative test can reliably and definitively determine a person's ability to engage in substantial gainful activity. By considering the committee's conclusions, SSA will be better equipped to conduct accurate, holistic, and equitable disability diagnoses and evaluations.

#### **REFERENCE**

NASEM (National Academies of Sciences, Engineering, and Medicine). 2019. *Functional assessment for adults with disabilities*. Washington, DC: The National Academies Press.

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