



# A Comprehensive Revision of the Incapacity Status Scale: ISS-2

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## Abstract

➤ **Purpose:** The Incapacity Status Scale (ISS), while psychometrically sound, possesses shortcomings that have limited its use in research. Present research will adapt the ISS to a patient-reported outcome (PRO) format. Changes have been made through alterations in order and scoring to reduce unclear ratings, updates to grammar, phrasing, and terminology, and adjustments that more clearly delineate levels of dysfunction. Additionally, infrequently used items have been revised or replaced with more relevant items. Finally, the original sexual dysfunction supplement has been replaced with the well-validated Multiple Sclerosis Intimacy and Sexuality Questionnaire (MSISQ-15).

➤ **Method:** The ISS-2, like the original scale, consists of 16 zero-to-four ordinal items, with a primary score that sums all items. A newly introduced secondary scoring method will evaluate the items according to functional systems (FSS) criteria, where the highest disability level in each cluster generates the score. The scale will be normalized against scores on the Patient Determined Disease Steps (PDDS) and selected abbreviated scales from the Multiple Sclerosis Quality of Life Inventory (MSQLI), and compared to the Expanded Disability Status Scale (EDSS). Item analysis will evaluate weighting of primary scale scores and FSS clusters, both internally and compared to existing scales.

## Background

- Attempts to standardize dysfunction have led researchers to use the EDSS as a catch-all scale, though it more strictly measures impairment and disease severity than disability.
- Scales of living disability in MS, including the ISS, have had limitations that have prevented their widespread use.
- Literature has called for a disability scale that can be related conceptually and statistically to measures like the EDSS.
- The original ISS is well validated, but it under-reports disability in certain functional domains.
- Patient reports of many types of living disability in MS show good consistency with clinician evaluations.
- Statistical examination reveals room for improvement on the original ISS in the content of certain types of disability items.

## Aims

- **Revise the format from a structured interview to a PRO.** The PRO format will save clinicians time, and may lead to more accurate reports on emotionally sensitive items like sexual dysfunction.
- **Remove ambiguity in the scoring of items.** The sequencing of questions within items caused uncertainty about how to score specific levels of disability.
- **Update and simplify language.** In the PRO format, language is simpler and more patient-friendly.
- **Replace infrequently used items.** Poor internal consistency, low inter-rater reliability, and low scale relevance caused several items to be frequently omitted.
- **Improve psychometrics, and relate scores to other measures.** A new secondary scoring system, based on FSS scores, will reduce the problems with item weighting that diminish the influence of certain systems, and allow ISS-2 scores to be conceptualized in relation to the EDSS.
- **Validate revisions.** Analyses will be conducted to ensure that the new scale is an effective, reliable, and valid measure of disability in MS.

## Key Updates to ISS Items

- **“Medical Problems”** was frequently omitted by researchers using the ISS. It has shown very low inter-rater reliability, and differs conceptually from other disability items. It has been replaced with a new item assessing diminished sensation.
- **“Fatigability”** now queries both physical and cognitive fatigue.
- **“Vision”** scoring has been altered to assess the multiple types of visual impairment found in MS.
- **“Mood and Thought Disturbances”** was frequently omitted from research. It has shown modest inter-rater reliability, and has been revised to reduce subjectivity in scoring.

Primary Scoring (Disability Items)	Equivalent ISS-1 ITC <sup>7,8</sup>	Secondary Scoring (Functional Systems)	Equivalent ISS-1 Mean <sup>7</sup>
1) Stair Climbing	.82–.83	Pyramidal	2.4
2) Ambulation	.83–.86		
3) Transfer	.86–.87		
4) Bowel	.52–.64	Bowel and Bladder	1.7
5) Bladder	.61–.62		
6) Bathing	.85–.89	Cerebellar	1.6
7) Dressing	.84–.86		
8) Grooming	.71–.73		
9) Feeding	.68–.72	Brainstem	0.9
10) Speech/Hearing	.36–.43		
11) Vision	.43–.47	Visual	1.0
12) Sensation	--	Sensory	--
13) Mood/Thought Disturbances	.33–.41	Cerebral/Mental	0.9
14) Cognition/Mentation	.33–.41		
15) Fatigability	.30–.56		
16) Sexual Function	.53–.57		
(Range: 0–64)		(Range: 0–28)	

## Statistical analyses

- Internal consistency and item analyses will be conducted for the 16 items, and 7 secondary scores. Expected Cronbach’s  $\alpha$  is greater than .80, while corrected item-total correlations (ITC) are expected to range no lower than .50 for primary scores and .65 for secondary scores; most are expected to exceed .70. This will provide a preliminary estimate of both scoring systems’ reliability, and begin to indicate the construct validity of the functional systems clusters in the ISS-2.
- Spearman rank-order correlations will compare primary and secondary score totals to the PDDS, a previously validated Likert scale of dysfunction, to assess criterion validity. Expected correlation to the PDDS is strong ( $\rho > .50$ ).
- Spearman correlations with selected self-report scales from the MSQLI will assess the concurrent validity of analogous ISS-2 items on fatigability (Modified Fatigue Impact Scale), bowel function (Bowel Control Scale), bladder function (Bladder Control Scale), vision (Impact of Visual Impairment Scale), and cognition (Perceived Deficits Questionnaire).
- Ordinal regression will be used to further evaluate the relationship between secondary scores and EDSS scores; as ISS-2 secondary scores are analogous with the FSS scores used to generate EDSS, there is a reasonable assumption of content validity in this comparison.

## References

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