

# Supplementary Material

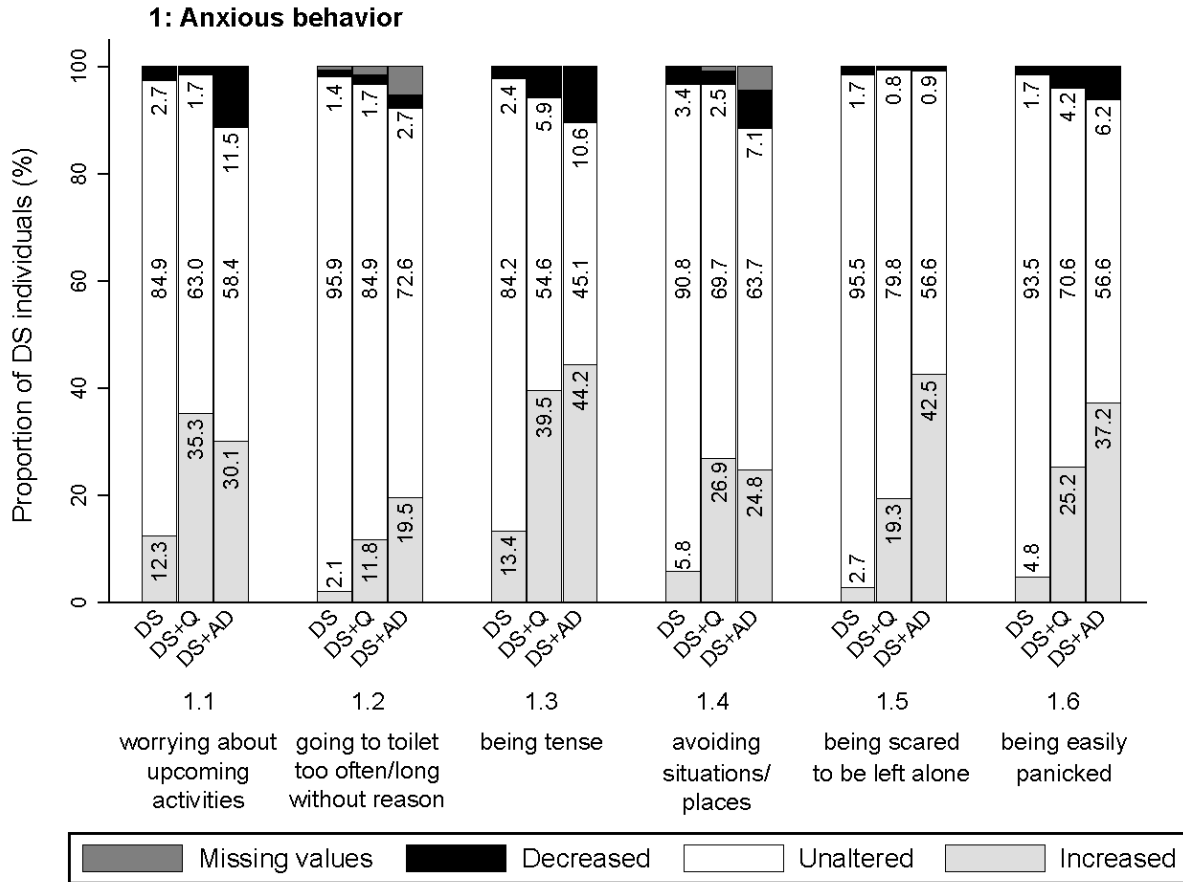
## The Behavioral and Psychological Symptoms of Dementia in Down Syndrome scale (BPSD-DS II): Optimization and Further Validation

**Supplementary Table 1. Interrater reliability, test-retest reliability and internal consistency per item and for the total scale**

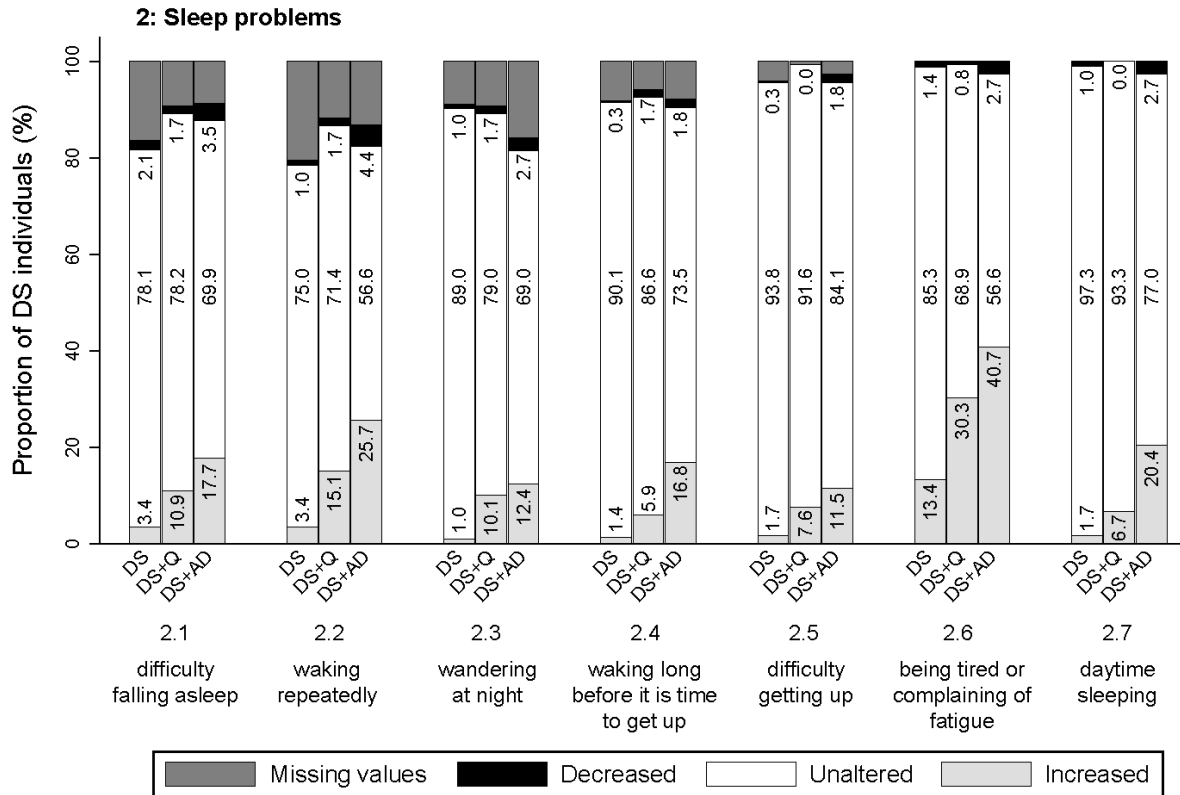
Section	Item	IRR (% agreement)		TRR (% agreement)		Internal consistency (alpha)	
		Frequency change	Severity change	Frequency change	Severity change	Frequency change	Severity change
1) Anxious behavior	1.1	96.3	97.6	80.0	84.0	0.843	0.795
	1.2	97.6	97.6	88.0	86.0	0.842	0.791
	1.3	95.1	97.6	76.0	76.0	0.841	0.794
	1.4	93.9	96.3	92.0	92.0	0.842	0.792
	1.5	97.6	95.1	92.0	90.0	0.841	0.796
	1.6	93.9	97.6	90.0	92.0	0.841	0.795
2) Sleeping problems	2.1	93.9	93.9	82.0	80.0	0.847	0.801
	2.2	92.7	93.9	78.0	78.0	0.847	0.800
	2.3	98.8	98.8	92.0	90.0	0.843	0.788
	2.4	97.6	96.3	84.0	92.0	0.844	0.794
	2.5	98.8	98.8	92.0	98.0	0.845	0.794
	2.6	97.6	97.6	72.0	82.0	0.843	0.796
	2.7	97.6	98.8	80.0	92.0	0.843	0.798
3) Irritable behavior	3.1	96.3	98.8	70.0	82.0	0.839	0.793
	3.2	97.6	98.8	86.0	88.0	0.842	0.794
	3.3	98.8	96.3	90.0	84.0	0.841	0.791
4) Obstinate behavior	4.1	98.8	98.8	86.0	86.0	0.844	0.795
	4.2	98.8	97.6	80.0	80.0	0.843	0.796
	4.3	97.6	98.8	76.0	86.0	0.844	0.796
	4.4	98.8	98.8	80.0	86.0	0.841	0.796
5) Restless & stereotypic behavior	5.1	100.0	100.0	92.0	92.0	0.842	0.795
	5.2	98.8	100.0	88.0	90.0	0.841	0.792
	5.3	100.0	98.8	94.0	94.0	0.843	0.795
	5.4	98.8	98.8	92.0	94.0	0.844	0.793
	5.5	98.8	100.0	84.0	96.0	0.844	0.795
	5.6	98.8	98.8	84.0	84.0	0.845	0.796
6) Aggressive behavior	6.1	98.8	97.6	84.0	88.0	0.842	0.789
	6.2	97.6	98.8	84.0	90.0	0.843	0.796
	6.3	100.0	98.8	80.0	88.0	0.844	0.796
7) Apathetic behavior	7.1	97.6	98.8	86.0	86.0	0.840	0.795
	7.2	98.8	100.0	96.0	98.0	0.841	0.796
	7.3	96.3	100.0	82.0	90.0	0.842	0.795
	7.4	100.0	95.1	78.0	80.0	0.839	0.794
	7.5	97.6	100.0	92.0	98.0	0.842	0.796
	7.6	98.8	98.8	84.0	86.0	0.845	0.796
	7.7	100.0	100.0	92.0	98.0	0.845	0.798
	7.8	100.0	98.8	90.0	94.0	0.843	0.798
8) Depressive behavior	8.1	100.0	97.6	92.0	86.0	0.839	0.794
	8.2	98.8	100.0	76.0	78.0	0.841	0.795
	8.3	100.0	98.8	88.0	90.0	0.843	0.794
	8.4	97.6	98.8	94.0	96.0	0.844	0.798
	8.5	97.6	100.0	82.0	86.0	0.840	0.795
9) Psychotic behavior	9.1	98.8	100.0	96.0	96.0	0.844	0.796
	9.2	100.0	100.0	98.0	98.0	0.844	0.798
10) Disinhibited behavior	10.1	100.0	100.0	92.0	94.0	0.845	0.798
	10.2	100.0	100.0	96.0	98.0	0.846	0.796
	10.3	100.0	95.1	90.0	96.0	0.843	0.797
11) Eating & drinking behavior	11.1	98.8	100.0	88.0	96.0	0.842	0.796
	11.2	98.8	98.8	96.0	98.0	0.843	0.798
	11.3	98.8	98.8	96.0	96.0	0.842	0.797
	11.4	98.8	98.8	90.0	94.0	0.844	0.797

		11.5	100.0	100.0	98.0	100.0	0.846	0.799
Total scale	all items						0.845	0.799
- perfect agreement	all items	70.7	65.9	12.0	26.0			
- margin -1 to +1	all items	82.9	81.7	34.0	38.0			
- margin -2 to +2	all items	84.2	87.8	40.0	56.0			
- margin -3 to +3	all items	86.6	89.0	54.0	66.0			

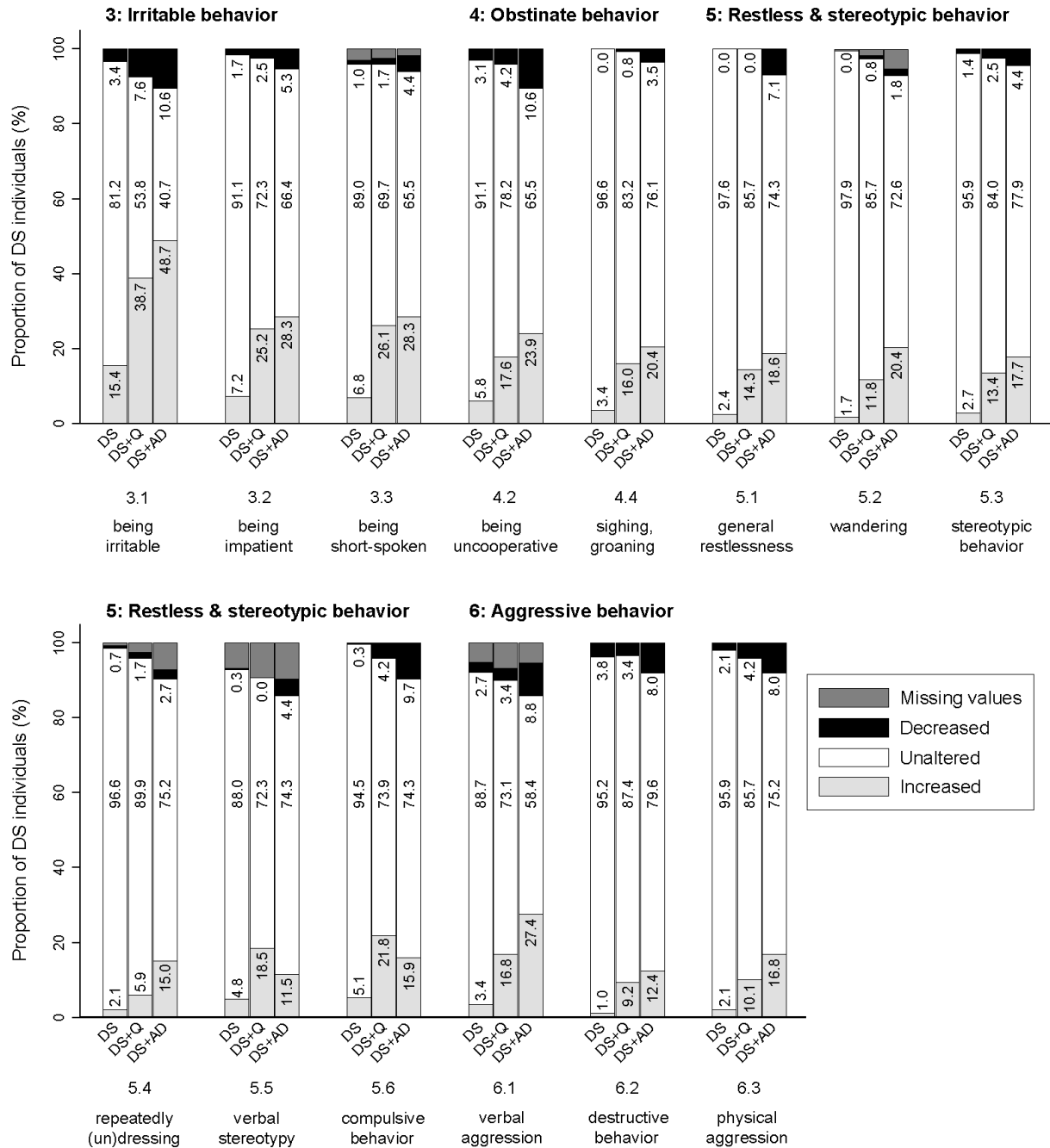
Interrater reliability (IRR) and test-retest reliability (TRR) for frequency change and severity change are provided as percent agreement per item and for the total scale (all items). Internal consistency is provided as Cronbah's alphas per item and for the total scale. DS, Down syndrome without dementia; DS+Q, Down syndrome with questionable dementia; DS+AD, Down syndrome with diagnosed AD dementia.



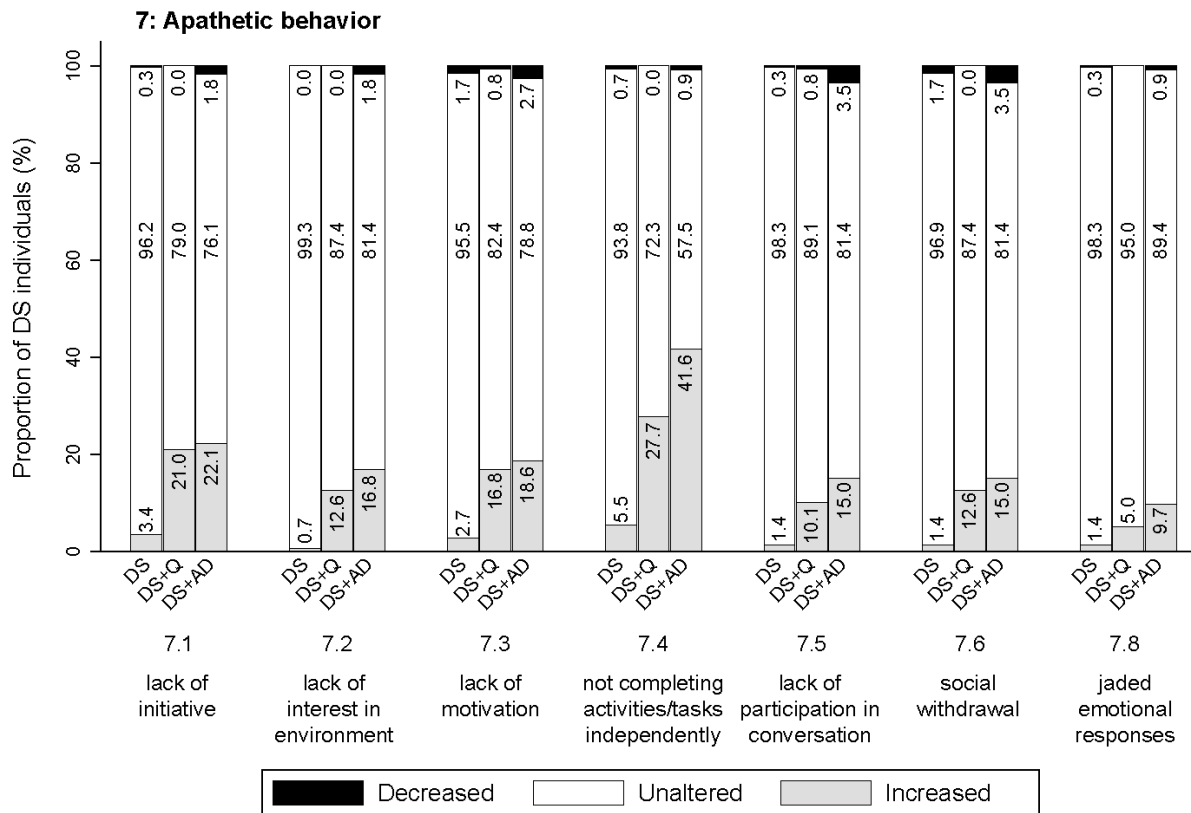
**Supplementary Figure 1.** Significant severity changes for items in section 1 (anxious behavior). Underlying severity change scores are depicted in a simplified way: the proportion of individuals (%) per group showing any decreased, unaltered or any increased severity comparing the last sixth months to the typical/characteristic behavior in the past. Proportions of individuals (%) with missing values is depicted in dark grey, but not in numbers. Item descriptions and p-values (Kruskal-Wallis) are provided in the text. DS, Down syndrome without dementia; DS+Q, Down syndrome with questionable dementia; DS+AD, Down syndrome with diagnosed AD dementia.



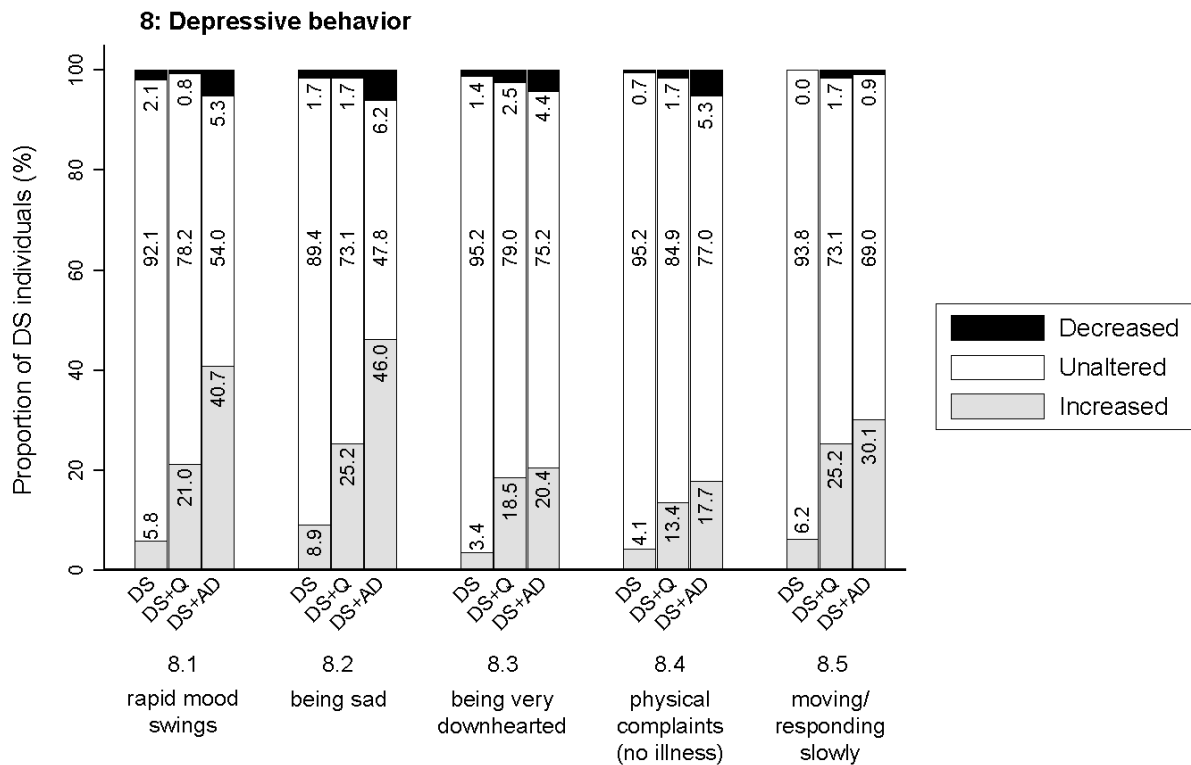
**Supplementary Figure 2.** Significant severity changes for items in section 2 (sleep problems). Underlying severity change scores are depicted in a simplified way: the proportion of individuals (%) per group showing any decreased, unaltered or any increased severity comparing the last sixth months to the typical/characteristic behavior in the past. Proportions of individuals (%) with missing values is depicted in dark grey, but not in numbers. Item descriptions and p-values (Kruskal-Wallis) are provided in the text. DS, Down syndrome without dementia; DS+Q, Down syndrome with questionable dementia; DS+AD, Down syndrome with diagnosed AD dementia.



**Supplementary Figure 3.** Significant severity changes for items in section 3 (irritable behavior), section 4 (obstinate behavior), section 5 (restlessness & stereotypic behavior) and section 6 (aggressive behavior). Underlying severity change scores are depicted in a simplified way: the proportion of individuals (%) per group showing any decreased, unaltered or any increased severity comparing the last sixth months to the typical/characteristic behavior in the past. Proportions of individuals (%) with missing values is depicted in dark grey, but not in numbers. Item descriptions and p-values (Kruskal-Wallis) are provided in the text. DS, Down syndrome without dementia; DS+Q, Down syndrome with questionable dementia; DS+AD, Down syndrome with diagnosed AD dementia.



**Supplementary Figure 4.** Significant severity changes for items in section 7 (apathetic behavior). Underlying severity change scores are depicted in a simplified way: the proportion of individuals (%) per group showing any decreased, unaltered or any increased severity comparing the last sixth months to the typical/characteristic behavior in the past. Item descriptions and p-values (Kruskal-Wallis) are provided in the text. DS, Down syndrome without dementia; DS+Q, Down syndrome with questionable dementia; DS+AD, Down syndrome with diagnosed AD dementia.

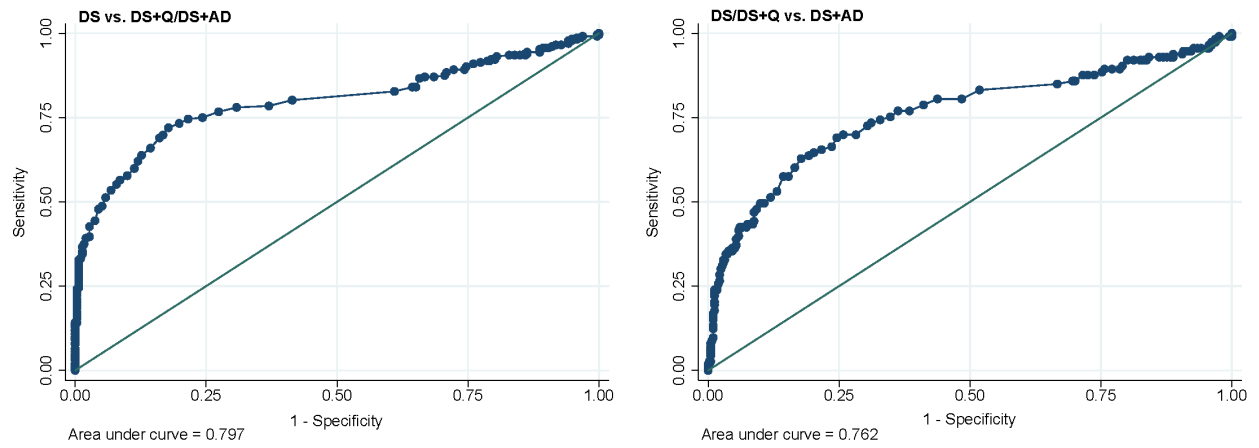


**Supplementary Figure 5.** Significant severity changes for items in section 8 (depressive behavior). Underlying severity change scores are depicted in a simplified way: the proportion of individuals (%) per group showing any decreased, unaltered or any increased severity comparing the last sixth months to the typical/characteristic behavior in the past. Item descriptions and p-values (Kruskal-Wallis) are provided in the text. DS, Down syndrome without dementia; DS+Q, Down syndrome with questionable dementia; DS+AD, Down syndrome with diagnosed AD dementia.



**Supplementary Figure 6.** Significant severity changes for items in section 9 (psychotic behavior) and section 11 (eating & drinking behavior). Underlying severity change scores are depicted in a simplified way: the proportion of individuals (%) per group showing any decreased, unaltered or any increased severity comparing the last sixth months to the typical/characteristic behavior in the past. Item descriptions and p-values (Kruskal-Wallis) are provided in the text. DS, Down syndrome without dementia; DS+Q, Down syndrome with questionable dementia; DS+AD, Down syndrome with diagnosed AD dementia.





**Supplementary Figure 7.** ROC curves for frequency change scores. To identify cut-off scores for the discrimination of DS versus DS+Q/DS+AD (cut-off score 1, left) and DS/DS+Q versus DS+AD (cut-off score 2, right), ROC analyses were performed using total scale frequency change scores.