

Adaptive Behavior and Development in CHARGE Syndrome: Results of a Longitudinal Study

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Individuals diagnosed with CHARGE syndrome have been described in medical literature as having severely delayed development. The results of this longitudinal study reveal that adaptive behavior scores for this sample appear to split equally between 1) moderate to severe impairment and 2) low average to average developmental abilities.

Scores on the Adaptive Behavior Evaluation Scale over time show good test-retest reliability ($r = .68, .74, .84, p < .01$), and good stability, which increases as participants get nearer to adult age. Correlations between the ABES and other survey items reveal that those who walked and were toilet trained at an earlier age tend to score higher on the ABES. Significant relationships were also found with the ABES for number of friendships and degree of reading ability, including reading comprehension.

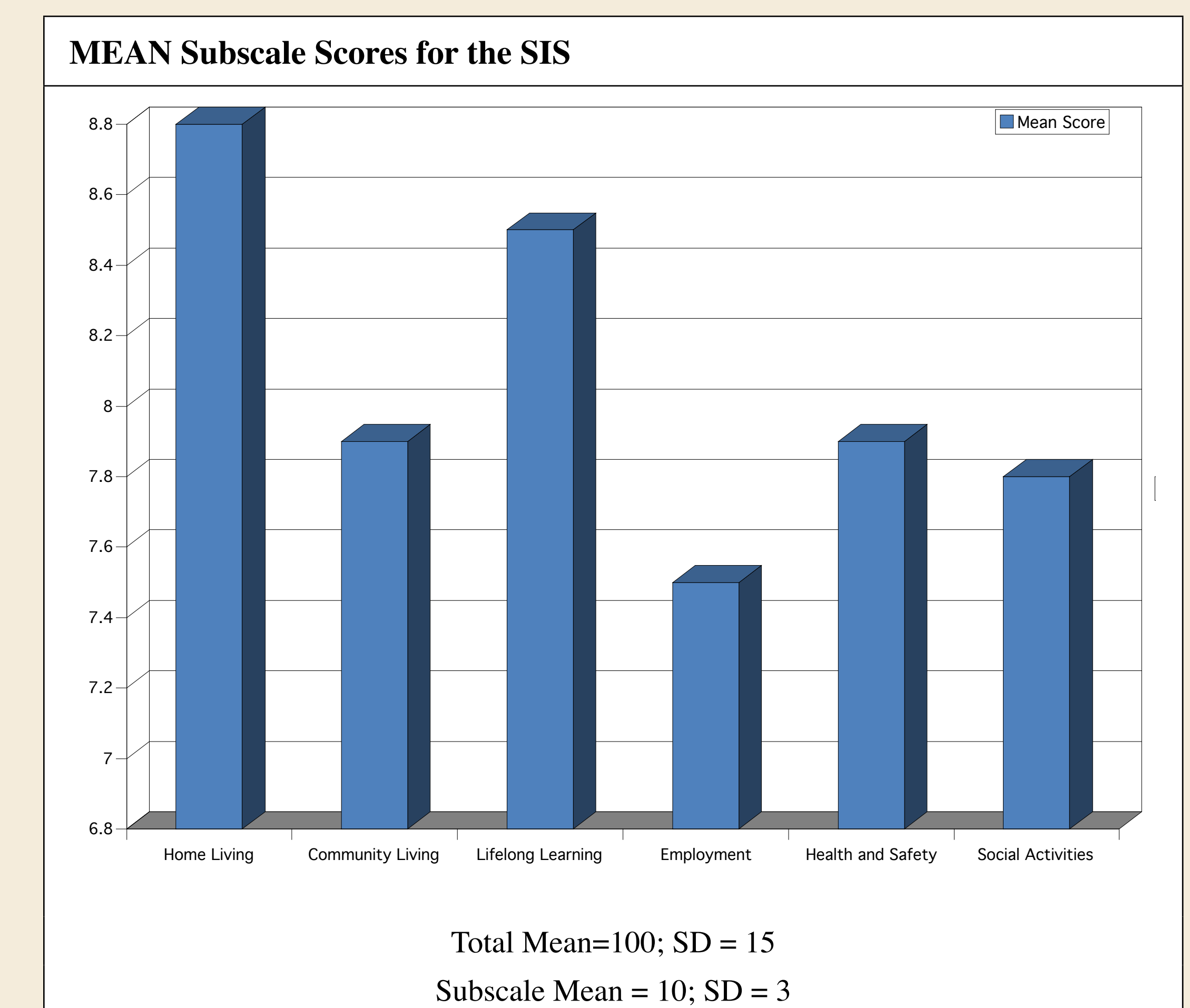
The Supports Intensity Scale (SIS) was administered during Time 3 to those of adult age ($N = 15$). The SIS is designed to measure the amount of support an individual with developmental disabilities needs. Mean scores for these participants for total and individual subscale scores clustered around “intermittent” and “limited” needs for supports (vs. “extensive” or “pervasive” needs). Adaptive behavior scores at Time 1 for these 15 participants were found to predict SIS scores in adulthood.

ABES Scores Over Time			
	N	Mean	SD
1999	100	74.1	13.6
2003	80	71.9	13.6
2006	51	72.6	13.4
ABES Mean = 100; SD = 15			

ABES correlation with Survey Items		
	r	N
Walking Age	-.44**	50
Reading Grade Level	.68**	50
Reading Comprehension	.48**	46
Independent Toileting Age (Urine)	-.37*	38
Independent Toileting Age (Bowel)	-.40*	32
Number of Friends	.33*	50
*Significant at the .05 level **Significant at the .01 level		

Selected Survey Items: Average Findings			
Item	Average	N	SD
Age at Walking	3-5 years	61	2.9
Reading Level	2nd-3rd grade	61	1.9
Comprehension	50% of what's read	56	1.5
Toileting (Urine)	Independent with reminders at age 6	45	1.2
Toileting (Bowel)	Independent with reminders at age 6	40	1.3
Friends	Friends with disabilities	61	1.1

Mean Supports Intensity Scale Score: 86.2 (N = 15)



Interpretation of Support Needed

- Total 84 or less; Subscale 6 or less = Intermittent
- Total 85-99; Subscale 7-9.9 = Limited
- Total 100-115; Subscale 10-13 = Extensive
- Total 116 or more; Subscale 14 or more = Pervasive

Early ABES Scores' Predictability of Adult Support Needs

	SIS	N
Time 1	$r = -.70^{**}$	15
Time 2	$r = -.86^{**}$	14
** $p < .01$		

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