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The Dysphagia Disorder Survey: Validation of an assessment for swallowing and feeding function in developmental disability



Justine Joan Sheppard^{a,*}, Roberta Hochman^{b,1},Carolynn Baer^{c,2}

^a Teachers College, Columbia University, Box 180, 525W. 120 Street, New York, NY 10027, USA

^b Woodbridge Developmental Center, Department of Speech and Hearing, PO Box 189, Woodbridge, NJ 07095, USA

^c Northern Virginia Training Center, 9901 Braddock Road, Fairfax, VA 22032-1941, USA

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ABSTRACT

Swallowing and feeding disorder (dysphagia) have high incidence and prevalence in children and adults with developmental disability. Standardized screening and clinical assessments are needed to identify and describe the disorder. The aim of this study was to describe the psychometric properties of the *Dysphagia Disorder Survey (DDS)*, a screening and clinical assessment of swallowing and feeding function for eating and drinking developed specifically for this population. The statistical analysis was performed on a sample of 654 individuals (age range 8–82) with intellectual and developmental disability living in two residential settings in the United States that served somewhat different populations. The two samples had similar factor structures. Internal consistency of the DDS and subscales was confirmed using Chronbach's coefficient alpha. The DDS demonstrated convergent validity when compared to judgments of swallowing and feeding disorder severity made by clinical swallowing specialists. Discriminative validity for severity of disorder was tested by comparing the two samples. The results of the study suggest that the *DDS* is a reliable and valid test for identifying and describing swallowing and feeding disorder in children and adults with developmental disability.

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1. Introduction

Estimates of prevalence and incidence of dysphagia in children and adults with developmental disability (DD) suggest that 80–90% of the population will have dysphagia during their life-time. Onset of the disorder occurs typically in infancy or early childhood during the development of swallowing and feeding skills. The functional deficits may resolve, may persist throughout the life of the individual or onset later in life (Lefton-Greif and Sheppard, 2005; Sheppard, 2002b). Its presentation may be complicated by medical co-morbidities and psychiatric, cognitive, speech, language and behavioral problems (Sheppard, 2010). Dysphagia in this population presents variably as a combination of developmental, physiological and behavioral problems. As a consequence a modification in terminology has occurred in which swallowing and feeding

* Corresponding author at: 111 Chincopce Road, Lake Hopatcong, NJ 07849, USA. Tel.: +1 973 663 3630; fax: +1 973 663 4108.

E-mail addresses: jjsheppard38@gmail.com, jjs74@tc.columbia.edu (J.J. Sheppard).

¹ Present address: 2103 Conrad Way, Somersett, NJ 08873, USA.

² Present address: 4605 Marshall Hall Lane, Fairfax, VA 22033-3718, USA.

disorder in developmental disability (SFD-DD) is used to refer to both ‘dysphagia’, i.e. abnormal function in one or more phases of swallowing, and “feeding disorder”, i.e. problems in eating activities that, in this population, may be physiologic or psychological signs and symptoms of dysphagia (Arvedson, 2008). Defining competent swallowing and feeding in DD populations requires special considerations, as well. It is not unusual to see idiosyncratic behaviors and oral-facial movement patterns that are not seen in the neuro-typical population but, nevertheless, are competent, functional solutions in swallowing and feeding.

1.1. Assessments for swallowing and feeding disorder

The assessment of dysphagia includes a clinical dysphagia screening (CDS) to identify probable dysphagia, a clinical dysphagia evaluation (CDE) to diagnose dysphagia and, in some cases, fluoroscopy, endoscopy or other instrumental examinations of swallowing to view components of swallowing that cannot be appreciated by clinical observation alone (Arvedson, 2008; Delaney and Arvedson, 2008; Kuhn and Matson, 2004; McCullough and Martino, 2013; Sheppard, 1995).

1.1.1. Standardized clinical assessments

Development, standardization and validation of testing tools for CDS and CDE have been population specific, for children or adult populations and for specific etiologies. *The Screening Tool of Feeding Problems (STEP)*, a CDS developed for adults with DD and subsequently validated for children with DD as *The Screening Tool of Feeding Problems applied to children (STEP-CHILD)*, contains signs of behavioral and skill based deficiencies that were associated in the literature with SFD-DD (Kuhn and Matson, 2002; Seiverling, Hendy and Williams, 2011). A number of standardized CDEs have been developed for pediatric DD populations. Benfer et al., 2012a published a systematic review in which they found nine assessments that met their criteria for standardized administration and scoring and had published psychometric properties (Benfer et al., 2012b). In their review the *Dysphagia Disorder Survey*, the subject of this article, was found to be one of the two most clinically useful. These existing tests were limited and/or unsuitable with respect to age range, focus on specific etiologies, testing time and/or scoring complexity.

The purpose of this paper is to describe the development, phase 1, and the psychometric testing, phase 2, of the *Dysphagia Disorder Survey (DDS)*, a quantitative observation tool with capability for discriminating swallowing and feeding pathology from functionally competent patterns and providing an objective description of the clinical presentation of SFD-DD.

2. Method

This study was approved by the Teachers College, Columbia University Institutional Review Board and by the sites at which the data were collected. The test was adopted into the care plan for residents at the two centers and administered under a general consent signed by their guardians that allowed for clinical evaluations and treatments.

2.1. Development of the assessment and preliminary statistical analysis

Development of the *Dysphagia Disorder Survey* began in response to the need for an efficient, objective, reliable and valid means, (a) to screen for SFD-DD in children and adults with DD, (b) to describe the clinical characteristics of the disorder while differentiating disorder characteristics from functionally competent movement patterns and eating behaviors and (c) to provide a measure of the individual’s relative, functional, swallowing and feeding competency within the population. Our goal, therefore, was to have an assessment that would function both as a CDS and as the feeding observation component of a CDE to identify, evaluate and re-evaluate SFD-DD.

A database search was conducted to find an instrument that would identify SFD-DD and provide a quantitative measure of eating in children and adults with DD that could describe functional competencies and the deficiencies caused by developmental delay, behavioral disorder and neuro-motor dysfunction. The databases included MEDLINE and PsycInfo. Search terms included dysphagia, deglutition, deglutition disorder, pediatric, adult and developmental disorder.

Test development was conducted at three residential centers for children and adults with DD beginning in 1979. During this phase there were interdisciplinary, focus groups with stake holders including speech-language pathologists, occupational and physical therapists, dieticians, nurses, physicians and special educators at all three sites and preliminary versions of the *DDS* were trialed (Sheppard, 1991; Sheppard, Berman and Kratchman, 1984; Sheppard, Berman, Kvietok and Kratchman, 1987; Sheppard and Hochman, 1988b; Sheppard and Hochman, 1989; Sheppard, Hochman and Dioso, 1998; Sheppard, Liou, Hochman, Laroia and Langlois, 1988). The validation studies were conducted subsequently at two of these sites.

There were general criteria that were considered to be essential for a practical and objective examination for this population and in the various settings in which the population might be examined. Although SFD-DD includes patients who are nil-by-mouth, and those who have deficiencies in saliva control and in swallowing for oral medications, the proposed tool was restricted to evaluating eating and drinking in those individuals that were receiving their nutrition and/or hydration totally or partially by mouth. The lower age limitations would be 2-years old, when a typically developing child had achieved the milestone skills for mature eating. The eating conditions would be as close to the usual for the individual with respect to foods, utensils, care giver routine and feeding strategies, thus a low level of demand for the individual and their care givers. The item targets were to be readily observable during these typical eating contexts or require only commonly available

information about the individual. To avoid ceiling and floor effects, the items and the scoring protocols would be formulated to describe the full range of capability from no SFD-DD to marked oral-pharyngeal or esophageal SFD-DD for which tube feeding was needed. The observation model would be sensitive to the signs and symptoms of the full range of contributing causes and presentations seen in the population, and would differentiate those functionally competent but idiosyncratic abilities that were not SFD-DD. Standardized administration and scoring procedures would be compatible with the interdisciplinary models and trans-disciplinary staffing that are typical in management of this population. Tester qualifications would allow use by a variety of allied health and educational professionals who could be trained to satisfactory intra- and inter-rater reliability in a training workshop. The qualifications were (a) licensed professional and (b) familiar with standardized testing procedures. The administration time would be limited to 10–15 min for the experienced user. These constraints shaped decisions about scoring modality and procedures, number of items and the model for observing function.

2.2. Test structure and scoring for Part 1. Related Factors

It was determined that the test would have two parts. Part 1, Related Factors (RF), was modeled as a screening observation with descriptive items for individual characteristics and compensatory management strategies. Scores were weighted for levels of severity or compensation in each item. The related factors were body mass index, independence in eating, body-postural control during eating, dietary consistency restrictions, adaptive utensils used to accommodate SFD-DD, special feeding techniques and seating supports and alignment during eating. Definitions of items in Part 1 are provided in Table 1. The criteria for selecting these items were, in order of importance, (a) associated with severity of swallowing and feeding disorder in children and adults with DD, (b) readily apparent on observation in an actual or sample meal, and (c) readily available information in the various settings in which the test might be used. Consensus was achieved in the focus groups for the seven factors selected for this section. See Fig. 1 for an illustration of Part 1 items.

2.3. Test structure and scoring for Part 2. Feeding and Swallowing Competency

Part 2, Feeding and Swallowing Competency (FSC) was modeled as an observation of eating for the food types that were typically included in the individual's diet. The observation was structured as a task analysis in which the sensory motor components of the phases of swallowing were represented in eight items: orienting, reception, containment, oral transport, chewing, oral-pharyngeal swallow, post swallow and gastro-esophageal function. Definitions for items in Part 2, are provided in Table 1.

The three food types that are seen in the development of mature eating skills to require distinctly different skill sets were selected for scoring. These were non-chewable solid foods, chewable solid foods and liquids (Delaney and Arvedson, 2008; Gisel, 2008; Sheppard, 1995). Non chewable solid food and liquid were scored on all items except chewing. Chewable solid food was scored on each of the 8 items. See Fig. 2 for an illustration of Part 2 items.

The binary scoring system (0 for competent, 1 for deficient), used to score performance for each task component and each food-type, accommodated omissions of items because of refusal or inability and deficiencies caused by delayed or dysfunctional skill acquisition, eating motivation and eating pragmatics and physiologic limitations in sensory-motor function. Test trials were conducted to find the minimum number of task repetitions needed for sample validity. It was hypothesized that a sample size of a minimum of five tokens, e.g. bites, spoonful, sips, etc., of each food provided during the observation was sufficient. In order to minimize false negative scores in this small sample, the deficient token(s) in each sample set of five or more tokens determined the score for the set.

Table 1
Definitions of items in Parts 1 and 2 of the *Dysphagia Disorder Survey*.

Item	Definition
Part 1. Related factors	
Body Mass Index	A weight for height ratio scored for low levels.
Independence	Ability to feed one-self.
Body postural control	Ability to stabilize head-neck and thorax for sitting during eating.
Diet consistency	Texture and viscosity restrictions in diet.
Adaptive utensils	Use of utensils to facilitate better oral management during eating.
Special feeding techniques	Use of compensatory techniques during eating.
Seating supports/alignments	Use of supports to maintain upright sitting or eating in reclining.
Part 2. Feeding and Swallowing Competency	
Orienting	Alert to, and postural adjustment for, the approaching bolus.
Reception	Removing liquid or solid food from utensil or biting off bolus.
Containment	Maintaining food in mouth during oral transport and processing.
Oral transport	Moving food in mouth and clearing oral residuals on swallowing.
Chewing	Adequate strength and duration of chewing to reduce bolus to swallow-ready consistency.
Oral-pharyngeal swallow	Prompt swallow initiation and pharyngeal clearance Sequential sip-swallow . Absent clinical signs of disorder.
Post swallow	Clearance of residuals from upper airway. Absent clinical signs of disorder.
Esophageal swallow	Effective transport of bolus to, and retention in, stomach. Absent clinical signs of disorder.

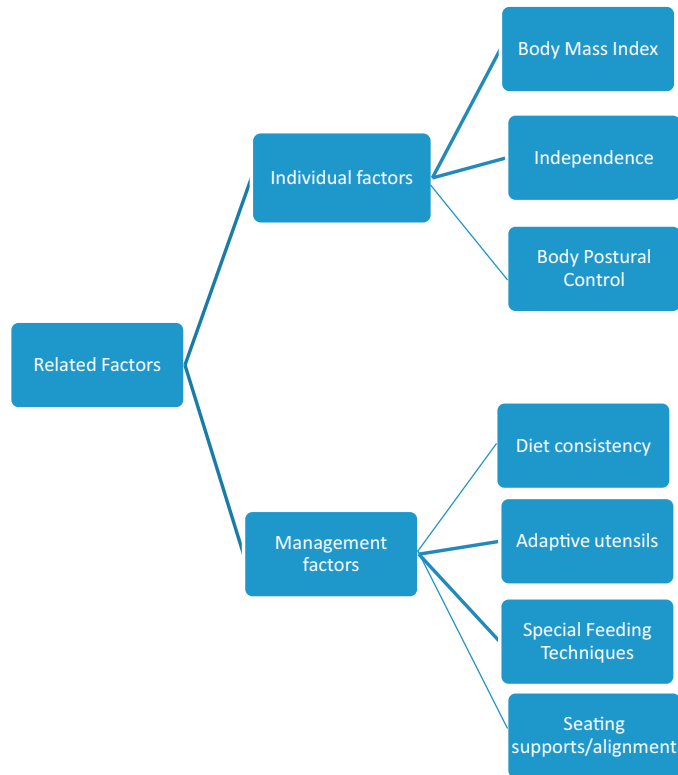


Fig. 1. Dysphagia Disorder Survey Part 1 Related Factors.

It was hypothesized that the Part 2 analysis would identify SFD-DD and the Part 1 score would load for severity. That is, the sensory-motor task analysis plus the management modifications and related individual characteristics would increase test validity for identifying SFD-DD and increase discriminative validity for severity of SFD-DD than would either of the parts individually.

2.4. Preliminary validation

The preliminary trial was conducted at two of the residential centers, referred to as Site A and Site B. Training modules for test administration were developed and piloted on an interdisciplinary group of allied health professionals that included swallowing and feeding specialists (SFSs), nurses and educators who were currently engaged with the population.

The *DDS* was administered by trained professionals as part of the regular patient care protocols. Training consisted of a 5-hour workshop followed by practice administering the *DDS* to six individuals. The validity of the *DDS* was tested against CDEs administered by the dysphagia specialists at the sites all of whom were trained in dysphagia and SFD-DD and were experienced in conducting full CDEs on this population. These SFSs who conducted the CDEs were blinded to the results of the *DDS* testing. They judged whether or not the individual had SFD-DD and, if so, its severity with reference to the range of eating competency seen in the population. In order to increase the inter-rater reliability for judging severity an ordinal scale was devised to guide the decisions. The SFSs were trained to the standards for using the ordinal scale prior to evaluating the subjects (Ss). The variables contained in the scale were presence/absence of signs of SFD-DD, number of compensatory strategies needed to support swallowing and eating during meals and health outcomes judged by presence/absence of nutritional failure, dehydration and/or diagnosed aspiration related pneumonia within the past year (Sheppard, 1991, 1995; Sheppard et al., 1998). These variables were selected as sensitive indicators of presence and functional adequacy of SFD-DD that could be rated by observation or by readily available information. The scale was titled the *Dysphagia Management Staging Scale (DMSS)*. See Table 2 for description of DMSS levels.

2.5. Preliminary statistical analysis, inter-rater reliability and internal consistency

Preliminary statistical analyses were conducted using Chronbach's Alpha for inter-item reliability. Pearson Correlation coefficients were used to test the relationship between Parts 1 and 2 and between the *DDS* results and SFS ratings of presence and severity of SFD-DD. Multiple regression analysis was applied to determine strength of relationships between individual test items and severity of SFD-DD (Sheppard and Hochman, 1988a, 1988b). As a result of the analysis two items were deleted,

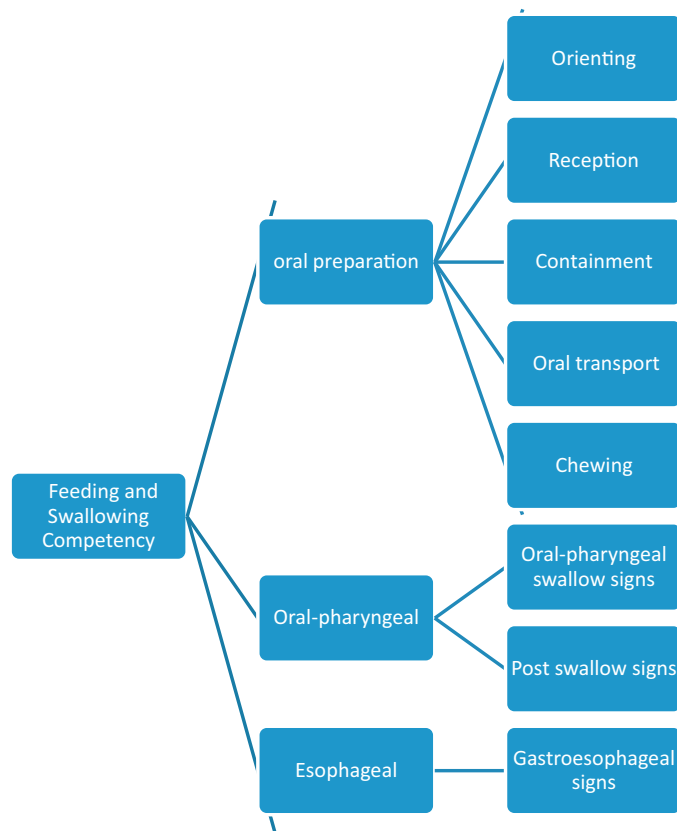


Fig. 2. Dysphagia Disorder Survey. Part 2. Feeding and Swallowing Competency.

Table 2
Dysphagia Management Staging Scale ordinal levels.

Level of Swallowing and feeding disorder	Definition
Level 1. No disorder	No signs or symptoms of swallowing and feeding disorder in oral preparation, oral-pharyngeal or esophageal stages of swallowing. Swallowing capabilities are functional for all bolus types. No symptoms of related unsafe or anorectic behaviors. May be dependent for eating.
Level 2. Mild disorder	Swallowing and feeding disorder and unsafe or anorectic behaviors can be managed with a single strategy type: adaptive utensils, diet restrictions, seating, adaptive feeding/swallowing strategies or medications. Person maintains satisfactory health with reference to nutrition, hydration and respiratory function.
Level 3. Moderate disorder	Swallowing and feeding disorder and unsafe or anorectic behaviors can be managed with a combination of two or more strategy types including adaptive utensils, diet restrictions, seating, adaptive feeding/swallowing strategies and/or medications. Person maintains satisfactory health with reference to nutrition, hydration and respiratory function.
Level 4. Severe disorder	Management of swallowing and feeding disorder and unsafe or anorectic behaviors includes a combination of two or more strategy types including adaptive utensils, diet restrictions, seating, adaptive feeding/swallowing strategies and/or medications. Related nutritional, hydration or respiratory problems persist in spite of the management program.
Level 5. Profound disorder	Disorder is managed with non-oral feeding for supplemental or total nourishment. Related nutritional, hydration and/or respiratory problems may persist or condition may be satisfactory.

two items found to be correlated with swallowing competency in the population were added (Sheppard et al., 1988), an item was added to Part 2 to better represent clinical signs for the oral-pharyngeal phase of swallowing and scoring was adjusted to increase sensitivity for individuals fed by gastrostomy tube.

Inter-rater reliability was tested by three pairs of professionals who had administered this revised version of the DDS. Each pair tested seven children and adults that they had not tested previously. They were blinded to the results of any previous testing. There were 8 disagreements in 336 pairs of judgments on the DDS or a 97% rate of agreement.

The revised DDS was used in Phase 2 of the validation study. Phase 2 data collection was conducted at the same sites. The statistical analysis was repeated for the revised DDS and that version was distributed for use (Sheppard, 2002a).

Table 3
Frequencies and distributions for Site A and Site B samples on background variables.

Variable	Sample					
	Site A		Site B		Total	
	N	%	N	%	N	%
Gender						
Male	134	62.3	238	54.2	372	56.9
Female	77	35.8	199	45.3	276	42.2
Missing	4	1.9	2	.5	6	.9
Ambulation						
Nonambulatory	59	27.4	311	7.8	370	56.6
Assisted	42	19.5	29	6.6	71	1.9
Independent	97	45.1	86	19.6	183	28.0
Missing	17	7.9	13	3.0	30	4.6
Age						
<11	0	.0	5	1.1	5	.8
11–20	10	4.7	42	9.6	52	8.0
21–30	51	23.7	107	24.4	158	24.2
31–40	53	24.7	147	33.5	200	3.6
41–50	19	8.8	55	12.5	74	11.3
51–60	14	6.5	12	2.7	26	4.0
61+	3	1.4	8	1.8	11	1.7
Missing	65	3.2	63	14.4	128	19.6
Total	215	32.9	439	67.1	654	100.0

The *DDS* statistical analysis was repeated and updated in 2013 using the original raw data. The purpose of this study was to further determine the test and item characteristics for identifying dysphagia in SFD-DD and to determine its suitability for making objective clinical determinations of presence and severity of the disorder. This updated analysis is reported here.

3. Results

3.1. Sample population

In order to validate the *DDS*, data were taken from the two sample sites. Frequencies and distributions for the two samples on demographic background variables are presented in Table 3. The Site A sample contained 134 (62.3%) males and 77 (35.8%) females; Site B sample contained 238 (54.2%) males and 199 (45.3%) females. The gender makeup of the two samples was significantly different ($\chi^2 = 4.76$, 1 df, $p < .05$). Site A sample contained 97 (45.1%) ambulatory patients, 42 (19.5%) assisted ambulatory patients, and 59 (27.4%) non-ambulatory patients; Site B sample contained 86 (19.6%) ambulatory, 29 (6.6%) assisted, and 311 (70.8%) non-ambulatory patients. The Site B sample was significantly more impaired on ambulation ($\gamma = .63$, $p < .01$). Distributions by age are also reported in Table 3. Differences were assessed using an independent samples *t*-test. No significant differences were found between the two samples on age.

3.2. Construct validity

The first test of validity was to assess Part 1, Related Factors (RF) sub-scale, Part 2, Feeding and Swallowing Competency (FSC) sub-scale and the total *DDS* scale for factorial consistency using factor analysis with principal components extraction. Analyses were conducted for the RF and FSC independently and then combined as the *DDS*. In all cases the Kaiser–Meyer–Olkin measure of sampling adequacy was above .90, which is considered “superior,” suggesting that within the valuable set there is little error variance. Table 4 contains the eigenvalues of the initial factor loadings using the independent samples (Site A and Site B) and the combined sample. It also contains the factor loadings for the independent and combined samples on the 15 items comprising the *DDS*.

The data in Table 4 indicate that with the exception of BMI and GE function, all variables load highly on Factor 1 with factor scores between .50 and .85, whether on the Site A, Site B, or combined samples. Second, with the Site A sample, all variables that loaded on Factors 2, 3, and 4 also loaded highly on Factor 1, again with the exceptions of BMI and GE function. In the Site B sample, BMI loads weakly on both Factor 1 and 2; GE function loaded strongly on Factor 2. These findings suggest that, at least statistically, with the exception of GE function, the remaining items constitute a single scale.

In the analysis of factor statistics, factor analysis of the RF (items 1–7) on the Site A sample revealed two factors, with the first factor having an eigenvalue of 3.50 and accounting for virtually 50% of the variance, with a second factor achieving the minimum eigenvalue for inclusion as a factor of 1.00, accounting for an additional 14.35% of the variance, with the two factors explaining 64.29% of the total variance. On the Site B sample, only one factor was found with an eigenvalue of 4.56, accounting for 65.09% of total variance. When the two samples were combined, again only one factor revealed itself with an eigenvalue of 4.18, accounting for 59.77% of the variance.

Table 4
Factor scores and factors for Site A, Site B and combined samples on RF, FSC and DDS.

	Sample						
	Site A				Site B		Combined
	Factor				Factor		Factor
	1	2	3	4	1	2	1
1. BMI ^a				-.69	.42	.45	.42
2. DIET	.84				.86		.85
3. INDEP	.78				.83		.82
4. ADAPUT	.75				.85		.81
5. POSITION	.50	.70			.74		.66
6. POSTURE	.63	.58			.84		.79
7. FEEDING	.63				.82		.77
8. ORIENTING	.75				.85		.82
9. RECEPTION	.54		-.49		.84		.74
10. CONTAINMENT	.73				.82		.78
11. ORAL TRANS	.76				.85		.82
12. CHEWING	.67				.73		.71
13. O-P SWALLOW	.77				.79		.78
14. PST SWALLOW	.55				.62		.60
15. GE FUNCTION			.44	.60		.74	
Factor Statistics							
RFS (1–7)							
Eigenvalue	3.50	1.00			4.56		4.18
% of Variance	49.94	14.35			65.09		59.77
Cumulative %	49.94	64.29			65.09		59.77
FSCS (8–15)							
Eigenvalue	3.77				4.72		4.39
% of Variance	47.06				59.02		54.92
Cumulative %	47.06				59.02		54.92
DSS (1–15)							
Eigenvalue	6.50	1.15	1.08	1.01	8.69	1.02	7.93
% of Variance	43.31	7.68	7.21	6.73	57.94	6.78	52.88
Cumulative %	43.31	5.99	58.2	64.93	57.94	64.72	52.88

Note: ^a Factor scores < 40 excluded for ease of viewing.

On the FSC sub-scale, the findings were more consistent, with all three samples having one strong factor: the Site A sample had an eigenvalue of 3.77 with the factor accounting for 47.06% of the variance; the Site B sample had an eigenvalue of 4.72, with the factor accounting for 59.02% of the variance; combined they had an eigenvalue of 4.39, with factor accounting for 54.92% of the variance.

Table 5
Factor scores and components for Site A, Site B and combined samples on RF and FSC sub-scales.

Variable	Sample				
	Site A		Site B		Combined
	Component		Component		Component
	1	2	1	2	1
RF					
BMI ^a	.48		.43		.46
DIET	.84		.85		.85
INDEP	.84		.87		.86
ADAPUT	.80		.88		.83
POSITION	.59	.66	.80		.73
POSTURE	.67	.53	.88		.82
FEEDING	.65		.84		.79
FSC					
ORIENTING	.72		.84		.80
RECEPTION	.62		.87		.79
CONTAINMENT	.75		.85		.82
ORAL TRANS	.82		.89		.87
CHEWING	.74		.77		.76
O-P SWALLOW	.79		.83		.82
PST SWALLOW	.55		.66		.63
GE FUNCTION					

Note: ^a Factor scores < 40 excluded for ease of viewing.

Table 6
Descriptive statistics on RF, FSC, DDS, BMI and GE function, combined samples.

Variable	N	N of Items	Min.	Max.	M	SD	α
RF	654	6	0	15	5.11	4.25	.89
FSC	644	7	0	19	8.05	6.05	.89
DDS	654	13	0	34	13.29	9.80	.93
BMI	651	1	0	2	.37	.59	
GE	633	1	0	3	.33	.92	

The DDS is the combination of the RF and the FSC sub-scales. The factor analysis on Site A revealed four factors with eigenvalues over 1.00: the first factor was by large the strongest with an eigenvalue of 6.50, accounting for 43.31% of the variance. The other three factors had eigenvalues between 1.15 and 1.01 and accounted for between 7 and 8% of the variance each. The total variance accounted for by the factors was 64.93%. The Site B sample evinced a very strong first factor with an eigenvalue of 8.69, accounting for 57.94% of the variance and a weak second factor with an eigenvalue 1.02, accounting for an additional 6.78 percent of the variance, totaling 64.72% of the variance. When the two samples were combined, only one factor emerged with an eigenvalue of 7.93, which accounted for 52.88% of variance.

The results of the factor analysis consistently show that regardless of the sample or the sub-scale, that there is a single factor that accounts for approximately 50% of the total variance among the 15 variables entered into the equation (seven items for the RF and eight items for the FSC). Table 5 provides a detailed analysis of the factor components for the RF and FSC for each sample and the combined samples.

On the RF sub-scale, two issues are immediately apparent: first, the BMI is the weakest factor for both samples and for the combined sample with factor scores between .43 and .48, whereas most other factor scores are in the .80 s; second, that for the Site A sample, the two variables that loaded on the second factor (position and posture) also score highly on the first factor. On the FSC sub-scale, the GE function does not load on any factor for the split samples or the combined sample. In summary, the factor analyses suggest that with the exceptions of the BMI and GE function variables, all variables load on a single factor. To confirm that observation, the RF, FSC, and DDS were analyzed for internal consistency reliability using coefficient alpha. The results are in Table 6.

Table 6 contains the descriptive statistics and the alpha coefficients for the RF, FSC, and DDS. It also contains the descriptive data for the BMI and the GE function. Because they are single items, no reliability assessment was made. The six item RF (excluding the BMI) for the combined samples had a mean of 5.11 ($SD = 4.25$) and achieved the coefficient alpha of .89. The seven item FSC (excluding GE function) had a mean of 8.05 ($SD = 6.05$) and achieved a reliability coefficient of .89. The combined DDS, minus the BMI and GE function variables, contained 13 items and a mean of 13.29 ($SD = 9.80$), and a coefficient alpha .93. These findings suggest that the RF, FSC, and DDS have factorial consistency across samples and are internally consistent. However, the data also suggest that the three scales measure the same construct.

3.3. Convergent validity

To further explore the relationship among the scales, they were inter-correlated. The results are presented in Table 7.

Correlations were computed using Spearman rank correlations because the severity ratings, BMI, and GE function were ordinal. Intercorrelations of the RF, FSC, and DDS were conducted using Pearson correlations, which were virtually the same as the Spearman correlations. Therefore, only Spearman correlations are presented in the table. As can be seen in Table 7,

Table 7
Spearman intercorrelations of DDS, SFS severity ratings, BMI, and GE function.

	RF	FSC	DDS	BMI	GE FUNCTION
SFS Severity Ratings (DMSS)					
ρ	.88**	.91**	.93**	.49**	.32**
N	416	416	407	414	398
RF					
ρ		.85**	.94**	.36**	.20**
N		644	644	641	633
FSC					
ρ			.97**	.34**	.19**
N			644	641	633
DDS					
ρ				.36**	.20**
N				641	633
BMI					
ρ					.06
N					630

Dysphagia Disorder Survey (DDS); Related Factor Scale, Part 1, DDS (RF); Feeding and Swallowing Competency Scale, Part 2, DDS (FSC); Body Mass Index, Item 1, DDS (BMI); Gastro-esophageal Function, Item 15, DDS (GE Function).

** $p < .01$.

Table 8
Frequencies and distributions for Site A and Site B samples on SFS assessments of severity of dysphagia.

Severity	Sample					
	Site A		Site B		Total	
	N	%	N	%	N	%
None	52	24.3	74	36.6	126	30.3
Mild	55	25.7	27	13.4	82	19.7
Moderate	68	31.8	24	11.9	92	22.1
Severe	30	14.0	51	25.2	81	19.5
Profound	9	4.2	26	12.9	35	8.4
Total	214	100.0	202	100.0	416	100.0

correlations of the RF, FSC, and *DDS* with SFS severity ratings are all above .85. In addition, inter-correlations among the RF, FSC, and the *DDS* are also .85 and above. Correlation coefficients above .85 can be considered reliability coefficients, indicating that the correlated variables measure the same variable. Correlations with BMI tended to be moderate (ρ between .34 and .49). Correlations with the GE function were weak (ρ s between .19 and .32). The findings in Table 7 suggest that SFS severity ratings, RF, FSC, and *DDS* measured the same variable. It is possible that the BMI could be included in the RF and *DDS*, but analyses have shown that it drops internal consistency reliability by a point or two. The data also suggest that the GE function is a separate variable relatively independent of other indicators as dysphagia severity.

At this point in the analysis, the evidence suggests that the RF, FSC, and the *DDS* have factorial stability and are internally consistent. Correlations with SFS severity ratings indicate that they have convergent validity; that is, they correlate strongly with other clinical measures of dysphagia severity. However, additional issues need to be addressed: first, the inter-correlations of the RF, FSC, and *DDS* are extremely high, suggesting that they may be redundant measures of dysphagia severity. There is also a question of whether SFS severity ratings may be sufficiently valid to negate the necessity of the *DDS* and its subscales. These issues will be considered in the remainder of these analyses.

The correlation between the RF and the FSC is .85, the minimum criterion for a reliability coefficient. Correlations of the RF and FSC with the *DDS* are inflated because of contamination; the *DDS* is the summation of the two subscales. Both subscales correlate more highly with the SFS severity ratings than they do with each other. Therefore, there is some evidence that they can be treated separately. Next we have to look at the relative validity of the SFS assessments with the RF, FSC, and the *DDS*. Table 8 contains the SFS ratings for the Site A and the Site B samples.

3.4. Discriminative validity

Cross tabular analyses were conducted on the SFS severity ratings comparing the two samples. Although the chi-square statistic was significant ($\chi^2 = 47.84$, 4 df, $p < .01$), the Mann–Whitney *U* statistic, which assesses ordinal differences between two categories was not ($p = .41$); the gamma statistic, which measures ordinality was also not significant ($\gamma = .06$, $p = .43$). This was because the Site B sample had significantly more subjects who were dysphagia-free (36.6% to Site A = 24.3%) and also more who were severely (25.2–14.0%) and profoundly (12.9–4.2%) dysphagic. Even though the data do not meet the criteria for *t*-tests, for comparison with the *DDS* and its subscales, a *t*-test was run comparing the two samples on SFS severity ratings. Differences were not significant ($t = 1.25$, ns). These findings suggest the possibility that SFSs in different institutions may use different criteria for global ratings of severity. Given the data in Table 8, SFSs raters in the Site A sample may have had a bias toward middle categories, whereas SFS raters for the Site B sample may have had biases toward the extremes. However, this cannot be verified until we examine the *DDS* data (Table 9).

Table 9
Dysphagia severity ratings for the Site A and Site B samples for the RF, FSC, and *DDS* Scale Scores.

Dysphagia severity	Sample	
	Site A	Site B
RFS		
M	4.04	5.80
SD	3.79	4.25
N	215	439
FSCS		
M	6.86	8.62
SD	5.18	6.30
N	206	438
DSS		
M	10.88	14.42
SD	8.37	10.22
N	206	438

Table 10
Dysphagia severity for the Site A and Site B samples and gender for the RF, FSC, and DDS Scales.

Dysphagia severity/Gender	Sample								
	Site A			Site B			Total		
	N	M	SD	N	M	SD	N	M	SD
RF									
Male	116	4.28	3.61	229	5.49	4.23	345	5.09	4.07
Female	71	4.10	3.94	194	6.29	4.28	265	5.71	4.30
Total	187	4.21	3.73	423	5.86	4.27	610	5.36	4.18
FSC									
Male	116	7.20	5.01	229	8.18	6.23	345	7.85	5.86
Female	71	6.59	5.65	194	9.31	6.41	265	8.58	6.32
Total	187	6.97	5.26	423	8.70	6.33	610	8.17	6.07
DDS									
Male	116	11.48	8.01	229	13.68	10.09	345	12.94	9.49
Female	71	10.69	9.35	194	15.61	10.36	265	14.29	10.32
Total	187	11.18	8.53	423	14.56	10.25	610	13.53	9.87

Table 10 contains the means and standard deviations for the Site A and Site B samples subdivided by gender. On the RF, the Site A sample obtained a mean score of 4.21 ($SD = 3.73$). Male members of Site A had a mean of 4.28 ($SD = 3.61$); females had a mean of 4.10 ($SD = 3.94$). The Site B sample had a mean score of 5.86 ($SD = 4.27$), with males having a mean of 5.49 ($SD = 4.23$) and females, scoring a mean of 6.29 ($SD = 4.28$). On the FSC, the Site A sample had a mean of 6.97 ($SD = 5.26$), with males having a mean of 7.20 ($SD = 5.01$) and females having a mean score of 6.59 ($SD = 5.65$). The Site B sample had a mean of 8.70 ($SD = 6.33$), with males having a mean of 8.18 ($SD = 6.23$) and females having a mean of 9.31 ($SD = 6.41$). On the DDS, the Site A sample had a mean of 11.18 ($SD = 8.53$); males had a mean of 11.48 ($SD = 8.01$) and females had a mean of 10.69 ($SD = 9.35$). The Site B mean was 14.56 ($SD = 10.25$); males had a mean of 13.68 ($SD = 10.09$) and females had a mean of 15.61 ($SD = 10.36$).

Because preliminary analyses indicated that the Site A and Site B samples were significantly different in gender composition and in ambulation, a MANOVA was computed with gender and sample as factors and ambulation as a covariate. The results are presented in Table 11.

An examination of Table 11 revealed that when ambulation and gender were controlled, differences between the two samples were not significant. However, ambulation accounted for 40% of the variance in the RFS ($F_{(1,605)} = 407.39, p < .001$),

Table 11
Summary of MANOVA for ambulation, sample, and gender for RF, FSC, and DDS.

Source/DV	SS	df	MS	F	Sig.	Partial η^2
Model						
RF	4529.48	4	1132.37	112.27	0.00	0.43
FSC	6436.08	4	1609.02	60.80	0.00	0.29
DDS	21,750.05	4	5437.51	87.46	0.00	0.37
Ambulation						
RF	4109.09	1	4109.09	407.39	0.00	0.40
FSC	5895.52	1	5895.52	222.78	0.00	0.27
DDS	19,848.43	1	19,848.43	319.25	0.00	0.35
Sample						
RF	22.96	1	22.96	2.28	0.13	0.00
FSC	58.78	1	58.78	2.22	0.14	0.00
DDS	155.22	1	155.22	2.50	0.11	0.00
Gender						
RF	18.37	1	18.37	1.82	0.18	0.00
FSC	39.75	1	39.75	1.50	0.22	0.00
DDS	112.16	1	112.16	1.80	0.18	0.00
Sample \times Gender						
RF	65.53	1	65.53	6.50	0.01	0.01
FSC	163.67	1	163.67	6.18	0.01	0.01
DDS	436.33	1	436.33	7.02	0.01	0.01
Error						
RF	6102.33	605	10.09			
FSC	16,010.19	605	26.46			
DDS	37,614.03	605	62.17			
Total						
RF	10,631.80	609				
FSC	22,446.27	609				
DDS	59,364.08	609				

Table 12
Sensitivity and specificity assessments of the DDS.

DSS factors	SLP Rankings		Total	Sensitivity	Specificity	PPV	NPV	κ
	Yes	No						
RFS				.88	.85	.61	.96	.63
Yes	279	49	328					
No	11	77	88					
FSCS				.94	.87	.67	.98	.71
Yes	285	42	327					
No	5	84	89					
DDS				1.00	.81	.44	1.00	.53
Yes	290	70	360					
No	0	56	56					
Total	290	126	416					

27% of the variance in the FSC ($F_{(1,605)} = 222.78, p < .001$), and 35% of the variance in the DDS ($F_{(1,605)} = 319.25, p < .001$). These data suggest that between-sample differences can be accounted for primarily by differences in ambulatory levels.

In addition, the MANOVA revealed a sample by gender interaction. Descriptive data indicate that on all three dysphagia severity variables, males in the Site A sample scored higher than the females, and within the Site B sample females scored higher on dysphagia severity ratings than the males. In each case, the interaction factor added 1% of the explained variance in the equation.

3.5. Sensitivity and specificity

The final assessment of the DDS and its subscales was to assess sensitivity, specificity, positive predictive value (PPV) and negative predictive value (NPV) in relation to SFS global ratings. Despite the possibility of bias in SFS rankings, it was expected that SFSs would be able to validly distinguish between those patients who have no evidence of dysphagia and those who did. Therefore, SFS global ratings, RF, FSC, and DDS ratings were dichotomized and the DDS subscale and total scale scores were compared to the SFS ratings, which were collapsed into no evidence of dysphagia (0) and evidence of dysphagia (mild-profound = 1). The results are presented in Table 12.

Table 12 presents the cross-tabulations of the DDS factors with SFS rankings. In addition to sensitivity, specificity, PPV and NPV, kappa (κ) coefficients are also reported. The kappa coefficient is an index of inter-rater agreement (Fleiss, 1981); the kappas in Table 12 are in the “good” range (.53–.71), with those over .75 described by Fleiss as “excellent.”

Sensitivity compares true positives with false negatives. Out of 290 cases rated by SFSs as positive for dysphagia, the RF scale identified 279, achieving a sensitivity ratio .88. Specificity compares true negatives with false positives; of the 126 patients rated by SFSs as negative for dysphagia, the RF scale identified 77 as negative, for a specificity ratio of .85. PPV assesses the ratio between false and true positives. As can be seen in Table 12, the RF was more likely to identify patients having symptoms of dysphagia, with a PPV = .61. Of the 88 patients scoring 0 on the RF, 77 were also indicated by SFS rankings as free from symptoms of dysphagia, generating a NPV of .96.

The FSC, which is more closely related to swallowing functions, obtained the highest sensitivity (.94), specificity (.87), PPV (.67), and NPV (.98) scores when compared to SFS global rankings. It also had the highest kappa coefficient (.71). The DDS scored the highest on sensitivity (1.00) and the lowest on specificity (.81). PPV is relatively low at .44, but negative predictive value was perfect (1.00) when compared to SFS rankings. Because it is a combination of the RF in the FSC, it is not surprising that is the most conservative measure, generating no false negatives and the greatest number of false positives.

3.6. Summary of results

In summary, the DDS and its RF and FSC subscales have shown to be factorially stable over two different samples and have demonstrated substantial internal consistency reliability. Convergent validity, correlating the DDS and its subscales with SFS severity ratings found extremely high relationships, essentially establishing themselves as equivalent to reliability coefficients ($\rho > .85$). The correlation of the RF and FSC was the lowest in that sector of the matrix ($r = .85$), which suggests that although they are strongly related, they may have different clinical functions. Correlations with the BMI were in the weak-to-moderate range ($\rho_s = .34-.36, ps < .01$), and GE function was weakly correlated ($\rho_s = .19-.20, ps < .01$). These findings collectively suggest that the DDS and its subscales are strongly related to SFS severity ratings and are not strongly related to BMI or GE function.

In a test of discriminant validity, the DMSS was quite powerful in relating dysphagia severity to ambulation, an indicator of overall severity of involvement. It was also able to identify an interaction between sample and gender on dysphagia severity.

In addition, the DDS and its subscales showed themselves to be superior indicators of SFD-DD severity than were the SFS global rankings. It appears from these results that by having SFSs use the DDS, observations were standardized on an objective scale and inter-rater bias was reduced. Global ratings have a subjective component in which one SFSs rating of

“moderate” may be another SFSs “severe”. This kind of bias is dramatically reduced by the *DDS*, which focuses on specific feeding requirements and symptoms of SFD-DD.

In conclusion, the RF, the FSC, and the *DDS* have met the criteria for construct validity using the multitrait-multimethod matrix (Fiske, 1982). They correlated highly with SFS ratings but not with BMI and GE function. They discriminated between two samples in which one had more serious symptoms of SFD-DD than the other. The data suggest that the three scales may have somewhat different functions. The RF is directed at dieting and feeding techniques that would be expected to be adapted to the severity of SFD-DD. As SFD-DD severity increases, the necessity to adapt feeding techniques increases. The FSC is a direct and objective measure of SFD-DD severity; it focuses on orientation, reception of food, mastication, and swallowing. Diagnostically for individual cases, a high discrepancy between scores on the RF and the FSC may indicate that patients may not be receiving proper feeding techniques given the severity of the SFD-DD. The *DDS*, because it is the combination of the two subscales is the most conservative indicator of the presence of SFD-DD. Therefore, it may be used as a diagnostic tool that produces very few false negatives. In the diagnosis of SFD-DD, it is much better to have false positives than false negatives because false negatives mean that pathology goes untreated. False positives can be remedied through further diagnosis.

4. Discussion

4.1. Overview of results

As a result of this study, the *DDS* has evidence of being a reliable and valid test for clinical presentation of dysphagia and related feeding disorder. It is able to discriminate SFD-DD from competent swallowing and feeding and to provide numerical scores that correlate significantly with ordinal levels of severity of disorder. These results support the use of the *DDS* in children and adults with developmental disability. The data indicate that the *DDS* has factorial stability and strong construct, convergent and discriminant validity. The analytics demonstrate that although the two parts of the *DDS*, RF and FSC, are closely related they are separate indicators and used together provide stronger correlation with presence and severity of SFD-DD.

4.2. Item analysis

The factor analysis provides convincing evidence that two items in the *DDS* are weakly related to the rest of the test items and weaken internal consistency. The first item is a weight for height ratio as expressed in a body mass index (BMI) for adults and percentiles for children. The second item, used as a sign of gastro-esophageal disorder, is the presence of regurgitation during the eating observation or the report of emesis or rumination occurring more than three times weekly. The weakness had been apparent from the preliminary statistical analysis in Phase 1. However, the rationale for including these items derived from the results of a study in which a group of adults with DD and a diagnosis of dysphagia disorder were compared to a group without the disorder. In that study persons with dysphagia had significantly lower BMI and higher occurrence of illnesses including vomiting (Sheppard et al., 1988). The items were considered, therefore, to be of clinical significance and as such were retained among the test items.

It remains for us to consider why these items fail to load on the same factors as the other measures of SFD-DD. With regard to BMI, deficient calorie nutrition has been found to be associated with dysphagia as well as other medical and management factors in children and adults (Dahl, Thomessen, Rasmussen and Selberg, 1996; Stewart, 2003). Calis, and colleagues (Calis et al., 2008) found that many children in their study of severe generalized cerebral palsy were under-weight, however, on statistical analysis they found that BMI increased with severity of dysphagia. They attributed this to the observation that many of the children with the most severe dysphagia had already been adequately treated with tube feeding, thus compensating for the disorder. It is possible that compensatory management in this population confounds the significance of the relationship between BMI and SFD-DD. In addition, it is noteworthy that securing accurate height measurements, a component of the BMI calculation, can be problematic in this population due to skeletal deformities, difficulties standing upright in non-ambulatory individuals and reduced cooperation during the procedure (Stevenson, 1996).

With regard to Gastroesophageal (GE) Function, the statistical analysis found that this item was scored as abnormal infrequently in the study population, although the literature indicated that gastroesophageal reflux with regurgitation and rumination have a high prevalence as compared with occurrence in the neuro-typical population (Altaf and Sood, 2008; Bohmer, Klinkenberg-Knol, Niezen-de Boer and Meuwissen, 2000; Sullivan, 2008). It had been our clinical observation that the presence of vomiting or rumination was associated with an increase in the severity of SFD-DD and was, therefore, a sign that should be considered on the test. It was apparent from the outset that this would be a difficult item for scoring. The five-token minimum sample for each food type observed reduced the probability that the sign would be seen. Furthermore, on interacting with care givers we found that their beliefs tended to minimize the importance of emesis and rumination, thereby confounding the collection of this data by report.

In summary, we found that both items, BMI and GE function, were difficult items to score and that, in addition, they were weakly related to the other test items. Both items were retained, however, for their apparent clinical importance with the accommodation that the *DDS* may be used for research and clinical practice with or without these two items. Their statistics are presented separately in Tables 6 and 7 to describe these weak relationships. Further study is needed to determine relationships between GE function, BMI and SFD-DD.

4.3. Uses of the DDS

This statistical analysis suggests the validity of the *DDS* (a) as a screening for presence or absence of SFD-DD in children and adults with a diagnosis of developmental disability, (b) as a means for obtaining an objective clinical description of SFD-DD that correlates with severity of the disorder and can be used in a CDE, and (c) in research to discriminate severity of SFD-DD among individuals and among groups of individuals.

The analytics compare the data samples from Site A and Site B to address the issue of whether or not SFS global ratings are sufficient for judging presence and severity of SFD-DD. This analysis suggests differences in SFS rating biases at the two sites, with the *DDS* having greater discriminative validity over the SFS global ratings. This result reaffirms the importance of the use of objective and valid tests to support clinical judgments. In this instance it was clear from the analysis that by having SFSs rate eating and swallowing function on individual factors on the *DDS*, bias and inter-rater differences were reduced.

Currently, the *DDS* is being used for clinical management in congregate residences, schools, group homes and family settings and for research (Benfer et al., 2012a, 2012b, 2013; Calis et al., 2008; Sheppard, 2002b). It has been translated into Dutch and Slovenian and appears to be a cross-culturally robust test for these cultures as well as for Australia, Canada and the United States, the primarily, English-speaking cultures in which it is being used.

4.4. Limitations

The *DDS* has inherent weaknesses. The task analysis model requires substantial training for users to develop the skills needed and maintain inter-rater reliability, thus limiting its use. It is limited to swallowing for eating activities and does not address swallowing in saliva control and swallowing for medications, both areas of concern for this population. It is a clinical measure with evaluative capabilities limited to signs and symptoms of dysphagia and without the discriminative value of videofluoroscopy and endoscopy for anatomical and physiologic abnormalities in swallowing. It lacks scoring considerations for age-appropriate immaturities in eating skills, limiting its use to children 2-years and older.

Limitations are apparent in the work that has been done on the *DDS* thus far. Although the *DDS* has been found to discriminate changes in function over time (Sheppard, 2002b, 2009), a statistical analysis for sensitivity to change would increase its usefulness. Better understanding of the relationship between clinical observation of SFD-DD using the *DDS* and instrumental observation using videofluoroscopy or endoscopy would be useful for understanding its use in predicting risk for aspiration and penetration. The standardization sample was taken face to face. For research it would be useful to have validity data for scoring from recorded samples, however, optimum recording strategies and scoring from recordings as compared to live observation have not been tested.

Conflict of interest

One of the authors, Justine Sheppard, is a member of Nutritional Management Associates, LLC the publisher and distributor of the Dysphagia Disorders Survey. At the time of the validation studies the three authors were employed at the testing sites.

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References

- Altam, M. A., & Sood, M. R. (2008). The nervous system and gastrointestinal function. *Developmental Disabilities Research Reviews*, 14, 87–95.
- Arvedson, J. C. (2008). Assessment of pediatric dysphagia and feeding disorders: Clinical and instrumental approaches. *Developmental Disabilities Research Reviews*, 14, 118–127.
- Benfer, K. A., Weir, K. A., Bell, K. L., Ware, R. S., Davies, P. S. W., & Boyd, R. N. (2012a). Longitudinal cohort protocol study of oropharyngeal dysphagia: Relationships to gross motor attainment, growth and nutritional status in preschool children with cerebral palsy. *BMJ Open*, 2(4), e001460.
- Benfer, K. A., Weir, K. A., Bell, K. L., Ware, R. S., Davies, P. S. W., & Boyd, R. N. (2013). Oropharyngeal dysphagia and gross motor skills in children with cerebral palsy. *Pediatrics*, 131(5), e1553–e1562.
- Benfer, K. A., Weir, K. A., & Boyd, R. N. (2012). Clinimetrics of measures of oropharyngeal dysphagia for preschool children with cerebral palsy and neurodevelopmental disabilities: A systematic review. *Developmental Medicine & Child Neurology*, 54(9), 784–795.
- Bohmer, C. J. M., Klinkenberg-Knol, E. C., Niezen-de Boer, M. C., & Meuwissen, S. G. M. (2000). Gastroesophageal reflux disease in intellectually disabled individuals: How often, how serious, how manageable? *American Journal of Gastroenterology*, 95(8), 1868–1872.
- Calis, E., Veugelers, R., Sheppard, J. J., Tibboel, D., Evenhuis, H. M., & Penning, C. (2008). Dysphagia in children with severe generalized cerebral palsy and intellectual disability. *Developmental Medicine & Child Neurology*, 50, 625–630.
- Dahl, M., Thomassen, M., Rasmussen, M., & Selberg, T. (1996). Feeding and nutritional characteristics in children with moderate or severe cerebral palsy. *Acta Paediatrica*, 85, 697–701.
- Delaney, A. L., & Arvedson, J. C. (2008). Development of swallowing and feeding: Prenatal through first year of life. *Developmental Disabilities Research Reviews*, 14, 105–117.
- Fiske, D. W. (1982). Convergent-discriminant validation in measurements and research strategies. *New Directions for Methodology of Social & Behavioral Science*, 12, 77–92.

- Fleiss, J. L. (1981). *Statistical methods for rates and proportions*. (2nd ed.). New York: John Wiley.
- Gisel, E. (2008). Effect of food texture on the development of chewing of children between six months and two years of age. *Developmental Medicine & Child Neurology*, 33(1), 69–79.
- Kuhn, D. E., & Matson, J. L. (2002). A validity study of the Screening Tool of Feeding Problems (STEP). *Journal of Intellectual and Developmental Disability*, 27(3), 161–167.
- Kuhn, D. E., & Matson, J. L. (2004). Assessment of feeding and mealtime behavior problems in persons with mental retardation. *Behavior Modification*, 28(5), 638–648.
- Lefton-Greif, M. A., & Sheppard, J. J. (2005). Swallowing dysfunction/dysphagia in adults and children. In W. M. Nehring (Ed.), *Health Promotion for Persons with Intellectual and/or Developmental Disabilities: State of the scientific evidence* (pp. 43–59). Washington, DC: American Association on Mental Retardation.
- McCullough, G. H., & Martino, R. (2013). Clinical evaluation of patients with dysphagia: importance of history taking and physical exam. In R. Shaker, C. Easterling, P. C. Belafsky, & G. N. Postma (Eds.), *Manual of diagnostic and therapeutic techniques for disorders of deglutition* (pp. 11–30). New York: Springer.
- Seiverling, L., Hendy, H. M., & Williams, K. (2011). The Screening Tool of Feeding Problems applied to children (STEP-CHILD): Psychometric characteristics and associations with child and parent variables. *Research in Developmental Disabilities*, 32(3), 1122–1129.
- Sheppard, J. J. (1991). Managing dysphagia in mentally retarded adults. *Dysphagia*, 6, 83–87.
- Sheppard, J. J. (1995). Clinical evaluation and treatment. In S. R. Rosenthal, J. J. Sheppard, & M. Lotze (Eds.), *Dysphagia and the Child with Developmental Disabilities, Medical, clinical and family interventions*. (pp. 37–76). San Diego: Singular Publishing Group.
- Sheppard, J. J. (2002a). *Dysphagia Disorder Survey and Dysphagia Management Staging Scale (Adult and Pediatric Applications), Users Manual, Assessment*, Lake Hopatcong.
- Sheppard, J. J. (2002b). Swallowing and feeding in older people with lifelong disability. *Advances in Speech-Language Pathology*, 4(2), 119–121.
- Sheppard, J. J. (2009). Intellectual and developmental disability. In H. N. Jones & J. C. Rosenbek (Eds.), *Dysphagia in rare conditions, An encyclopedia* (pp. 295–308). San Diego: Plural Publishing.
- Sheppard, J. J. (2010). Intellectual and developmental disability. In H. N. Jones & J. C. Rosenbek (Eds.), *Dysphagia in rare conditions, An encyclopedia* (pp. 295–308). San Diego: Plural Publishing.
- Sheppard, J. J., Berman, L., & Kratchman, R. (1984). Managing the developmentally disabled dysphagic. In Berg, J. M. (Ed.), *Perspectives and progress in mental retardation, Volume II – Biomedical aspects* (Vol. II). Baltimore: University Park Press.
- Sheppard, J. J., Berman, L., Kvietok, C. M., & Kratchman, R. (1987). A dysphagia program for the developmentally disabled. *New York Medical Quarterly*, 7, 19–23.
- J.J. Sheppard, R. Hochman. Dysphagia Disorders in a Large Residential Setting. Washington, D.C. 1988
- Sheppard, J. J., & Hochman, R. (1988b). Screening large residential populations for dysphagia Paper presented at the American academy for cerebral palsy and developmental medicine. *42nd Annual Meeting*.
- Sheppard, J. J., & Hochman, R. (1989). *Clinical symptoms of dysphagia in mentally retarded individuals*.
- Sheppard, J. J., Hochman, R., & Dioso, J. (1998). Natural history of dysphagia in developmental disability. *Paper presented at the dysphagia research society seventh annual international meeting*.
- Sheppard, J. J., Liou, J., Hochman, R., Laroia, S., & Langlois, D. (1988). Nutritional correlates of dysphagia in individuals institutionalized with mental retardation. *Dysphagia*, 3, 85–89.
- Stevenson, R. D. (1996). Measurement of growth in children with developmental disabilities. *Developmental Medicine & Child Neurology*, 3(9), 855–860.
- Stewart, L. (2003). Development of the Nutrition and Swallowing Checklist, a screening tool for nutrition risk and swallowing risk in people with intellectual disability. *Journal of Intellectual and Developmental Disability*, 28(2), 171–187.
- Sullivan, P. B. (2008). Gastrointestinal disorders in children with neurodevelopmental disabilities. *Developmental Disabilities Research Reviews*, 14, 128–136.