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# Research in Developmental Disabilities



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



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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

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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

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