

# **FAMILY INVOLVEMENT IN SCHOOL-BASED DYSPHAGIA MANAGEMENT**

MAUREEN E. ANGELL

RITA L. BAILEY

JOANNA K. NICHOLSON

JULIA B. STONER

*Illinois State University*

## **ABSTRACT**

This article provides a practitioner-friendly synthesis of existing literature on family involvement in the management of dysphagia for school-age children. Research reviewed includes family perspectives on programs, therapists, and characteristics that comprise effective family involvement in school-based dysphagia management programs. Also included are pragmatic instructional approaches and techniques that are applicable for school personnel who work with students with dysphagia. Recommendations are based on themes that emerged during the authors' interviews with family members raising children with dysphagia. According to research findings, success of children's school-based dysphagia management programs was determined by the following factors: a sense of partnership between school and home, the frequency and quality of communication, the training that both families and school personnel received on dysphagia management, the consistent use of effective interventions, and the quality of Individualized Education Plan (IEP) processes and products.

## **WHAT IS DYSPHAGIA?**

Simply defined, dysphagia involves difficulties with eating and/or swallowing. These difficulties can include problems with "placement of food in the mouth, manipulation of food in the oral cavity prior to the initiation of the swallow, including mastication if necessary, and the oral stage of the swallow when the bolus is propelled backward by the tongue" (Logemann, 1998, p. 3). Individuals with dysphagia often have difficulty with mastication (chewing)

and/or swallowing. These problems can cause them to be at increased risk for aspiration and choking. Aspiration occurs when foods or liquids enter the airway and travel past the level of the vocal cords. Aspiration can lead to development of upper respiratory infections and even pneumonia. Individuals with dysphagia often experience nutritional deficits. These, and other dysphagia-related problems, may lead to poor growth and may negatively impact overall health (Gisel, Birnbaum, & Schwartz, 1998; Schindler, Ginocchio, & Ruoppolo, 2008).

#### WHAT CAUSES DYSPHAGIA?

There is no universal onset or etiology of dysphagia. "Any condition that weakens or damages the muscles and nerves used for swallowing may cause dysphagia" (National Institute on Deafness and Other Communication Disorders [NIDCD], 1998, Causes Section, para. 1). When dysphagia occurs in childhood, conditions such as respiratory distress syndrome (RDS), cardiac dysfunction, and neurological disorders such as cerebral palsy are frequent causes (Hawdon, Beauregard, Slattery, & Kennedy, 2001). Children born prematurely often experience early feeding and swallowing difficulties which can be transient or chronic in nature. Adult-onset dysphagia often co-occurs with conditions such as Parkinson's disease, stroke, and/or head/neck cancers.

#### WHAT ARE THE MEDICAL RISKS ASSOCIATED WITH DYSPHAGIA?

Regardless of the onset, individuals with dysphagia frequently experience similar health risks associated with their feeding/swallowing difficulties. Sometimes, these individuals are unable to effectively cough or clear foreign materials from their airways. Many individuals with dysphagia have impaired oral-motor and/or oral-sensory skills. Some are unable to initiate a timely swallow or swallow in a safe and efficient manner. As a result, material can spill into the airway prior to the swallow or remain in the oral cavity or pharynx after the swallow. Weak or impaired pharyngeal muscles can also cause food to be misdirected into the airway, which can lead to upper respiratory infection and/or pneumonia. Because the process of food intake and subsequent swallowing requires increased effort, many individuals with dysphagia do not have a daily caloric food intake that allows for adequate nutrition and the sustainability of a healthy weight (Schindler et al., 2008).

### HOW DOES A DYSPHAGIA DIAGNOSIS AFFECT EDUCATIONAL PROGRAMMING?

The Individuals with Disabilities Education Act (IDEA, 1997) guarantees the delivery of a free and appropriate public education to all eligible children from birth to age 22. Students are eligible for special education services when they have disabilities that have adverse effects on the students' educational performance, and when the need for special education and related services to address these adverse effects is present and documented (Individuals with Disabilities Education Improvement Act [IDEIA], 2004). Children with feeding and swallowing problems are known to have more nutritional and growth deficits and other health complications than their peers without disabilities (Bartz & Deubler, 1990; Boddy, Skuse, & Andrews, 2000; Drewett & Wright, 1999; Kovar, 1997). Additionally, they are at higher risk for learning problems (Heffer & Kelley, 1994). While no direct studies of children have been conducted, investigations of adults with dysphagia have reported a profound social/emotional impact of dysphagia on those who have this impairment (Ekberg, Hamdy, Woisard, Wuttge-Hannig, & Ortega, 2002; Farri, Accornero, & Burdese, 2007).

When students do not qualify for dysphagia services for educational reasons related directly to dysphagia's adverse effect(s), the IDEIA (2004) states that students with disabilities who are eligible for special education may receive related services, including supplementary aides and services (Power de Fur & Alley, 2008). Related services include transportation and such developmental, corrective, and other supportive services as may be required to assist children with disabilities to benefit from special education (IDEIA, 2004, 34 CFR §. 300.34[a]). These include services provided by professionals such as those in school health services, speech-language pathology, and physical and occupational therapies. The IDEIA (2004) provides a definition of school health services stating,

School health services and school nurse services mean health services that are designed to enable a child with a disability to receive a free and appropriate education (FAPE) as described in the child's individual education plan (IEP). School nurse services are provided by a qualified school nurse. School health services are services that may be provided by either a qualified school nurse or other qualified person" (34 CFR §. 300.34.[c].[15]).

### WHAT IS THE ROLE OF SCHOOL PERSONNEL IN DYSPHAGIA MANAGEMENT?

Over the years, students with moderate to severe cognitive and/or multiple disabilities have been steadily moving from educational placements in clustered schools to home school placements. Students' home schools are where they would attend if they were not disabled (Brown et al., 1989). Many of these

students have disabilities that affect their feeding and swallowing abilities. It is now commonplace for children with feeding tubes, ventilators, and other health care needs associated with dysphagia to attend a wide variety of schools in their own communities. Because of this move from clustered schools to home school placements for students with disabilities, management of students with dysphagia in school settings is becoming an area of significant need. A recent American Speech-Language-Hearing Association (ASHA) 2008 survey of school-based speech-language pathologists (SLPs) found that 9% provided dysphagia services in elementary and secondary schools on a regular basis.

When working with students who have dysphagia, school personnel must be qualified to implement appropriate evidence-based feeding and swallowing evaluation and management methods. This often requires additional professional development programming that focuses on management of dysphagia in school-age children and youth (Power-de Fur, 2000; Silliman, 2000). SLPs often serve as case managers and/or dysphagia team leaders in educational settings (ASHA, 1994; Bailey & Angell, 2004; Homer, 2003) although “no single discipline can adequately address the needs of these children” (Arvedson, 2000, p. 28). SLPs are bound by a code of ethics developed by ASHA (2003) which provides principles related to professional and ethical commitments. According to the code of ethics, ASHA-certified SLPs should “engage only in those aspects of the profession that are within the scope of their competence, considering their level of training, education, and experience” (p. 14).

A team approach is important for comprehensive management of students with dysphagia. Several teaming models for dysphagia management have been described (Bailey & Angell, 2003, 2007; Homer, Bickerton, Hill, Parham, & Taylor, 2000; Lefton-Greif & Arvedson, 1997). Although team membership and operation may vary across schools, it is important that all members of dysphagia management teams acquire extensive knowledge about evidence-based practices related to appropriate evaluation and management of dysphagia. Information about areas affected by dysphagia such as nutrition and health, behavior, communication, and physical disabilities is also necessary (Bailey & Angell, 2007). School-based teams often include professionals such as SLPs, occupational therapists, social workers, physical therapists, dieticians, nurses or other medical personnel, special education teachers, and behavior specialists (Bailey & Angell, 2003; Homer et al., 2000).

#### WHY INVOLVE FAMILY MEMBERS ON DYSPHAGIA MANAGEMENT TEAMS?

Most people would agree that parents know their children best. Raising a child with dysphagia can affect an entire family structure—routines are altered, mealtimes are more complicated, and other daily activities are, at

times, complicated. Working with students who have dysphagia can certainly be difficult, but understanding families' perspectives can prove not only helpful, but, in many instances, crucial to developing and implementing effective programming. The IDEA granted parents/guardians the right to participate in all educational decisions including participation in the development of their children's IEPs (Fiedler & Swanger, 2000). Within the framework of the IDEA, parents are considered valued members of multidisciplinary teams (Ruddy & Sapienze, 2004; Turnbull, Turnbull, Erwin, & Soodak, 2006). Many children require specialized assistance or supports to maximize feeding/swallowing safety and efficiency in all settings where food or liquids are consumed. Therefore, it is important to include parents/guardians for generalization of effective strategies to home environments.

#### FAMILIES' PERSPECTIVES ON EFFECTIVE SCHOOL-BASED DYSPHAGIA MANAGEMENT

Recent research has provided the teaching community with insight into the perspectives of families of children diagnosed with dysphagia (Angell, Bailey, & Stoner, 2008; Stoner, Bailey, Angell, Robbins, & Polewski, 2006). Stoner et al. (2006) conducted interviews with the parents or grandparents of 8 children aged 2 through 11 who had been diagnosed with dysphagia. These primary caregivers were asked to describe their experiences related to school-based dysphagia management programs and to describe their interactions with education professionals who had been involved with their children's feeding/swallowing issues. Qualitative methodology was used to analyze the data into themes, which were confirmed through triangulation from participants and reviews of the students' IEPs.

Interviews with family members revealed factors that parents and guardians perceive as facilitators or inhibitors of effective school-based management of students with dysphagia (Stoner et al., 2006). The specific needs of students with dysphagia typically vary, but common themes were found across interviews. For example, the need for partnership with school-based teams, shared understanding of the focus children, and communication between school and home seem to be universal requirements.

##### *Theme #1: Partnership through Open, Honest, Communication*

Partnerships between family members and school personnel are invaluable in the education of all students. Those partnerships are an essential component of effective school-based dysphagia management programs. Angell and colleagues (2008) found that family members indicated a willingness to

accept school practitioners' lack of knowledge about dysphagia programs and therapies, but were not tolerant of practitioners' unwillingness to learn about dysphagia and dysphagia management. In essence, families tolerated a lack of dysphagia experience or expertise, but were unhappy when practitioners exhibited or expressed unwillingness to seek guidance and training to compensate for their lack of knowledge. Interviewees also expressed a need for genuine concern, social support, and congruence between home and school goals. These family members acknowledged that school personnel may not have all of the answers needed to initially work with students diagnosed with dysphagia, but they felt that education professionals' willingness to learn and work collaboratively with families was a requirement for effective dysphagia management.

Caregivers expressed that communication between school personnel and families serves as a primary catalyst when striving to implement effective school-based dysphagia management programs (Angell et al., 2008). Recognizing that the viability of home-school partnerships is often contingent on ongoing communication, families have provided specific recommendations to facilitate effective communication. Stoner et al.'s (2006) interviewees consistently cited the need for open, honest, and frequent communication between school and home as a determinant factor in the success of dysphagia management programs for their children. Throughout these interviews, caregivers did not talk about communication in nebulous terms; they delineated specific techniques that facilitated home-school communication such as notebooks that were exchanged between home and school on a daily basis, phone calls, and conferences. These methods were perceived as a fundamental means for facilitating effective school-family partnerships.

While face-to-face meetings provide a forum for problem-solving, issues such as time constraints, logistics, and competing responsibilities prevent them from occurring as regularly as most school personnel and family members would like. Daily updates can be given through other mediums to keep communication lines open between meetings. According to Diane, a parent interviewed by Stoner et al. (2006), a daily notebook containing information about her daughter's feeding/swallowing activities and perceived characteristics was sent home each night and provided important information about "what her daily feedings are, how she does, how she does drinking and everything . . . they are all like a team that they work with us, with her" (p. 344). To help educators understand the specific needs of students with dysphagia, families need to provide information to school personnel as well. This can be achieved through a reciprocal communication notebook, similar to a daily agenda, which the child transports between home and school, describing daily feeding and swallowing observations. These daily

interactions via communication notebooks can, at minimum, keep key individuals informed of children's feeding/swallowing-related behaviors and needs. Phone calls and consistently sent e-mail messages can serve as another viable means of communication, accommodating some individuals' communication preferences. See Table 1 for a list of benefits and drawbacks of several home-school communication approaches.

Although caregivers expressed an appreciation for and understanding of the IEP process, they did not perceive annual meetings as a sufficient means of communication (Stoner et al., 2006). They expressed a comfort in regularly scheduled meetings with members of their children's or grandchildren's IEP teams, but not just for the purposes of reporting on and updating IEP objectives. Meeting with IEP teams on a regular basis was most beneficial, according to caregivers, when the intent of those meetings was to collectively identify feeding/swallowing techniques that had been perceived as most effective. During the interviews, family members acknowledged that open communication is a two-way street, and that both school personnel and family members must take the initiative to keep communication lines open. Honest, open, and frequent communication between school personnel and family members is vital for effective educational programming for students with dysphagia. However, engagement in meaningful communication on a regular basis requires planning by and commitment from all individuals who work with students. Partnerships and communication are essential, yet both families and school personnel must be educated about dysphagia to ensure effective school-based dysphagia management programs for students with feeding/swallowing issues.

### *Theme #2: School and Family Education*

While feeding and swallowing processes are reflexive, innate behaviors for most people, understanding these processes and behaviors is anything but reflexive or innate—it must be learned. Both school personnel and families must be formally trained in the biological and anatomical functions that underpin the feeding/swallowing process and in established methods used to enable that process (Arvedson & Brodsky, 2002). The need for education and training was a reoccurring theme during caregiver interviews Stoner et al. (2006) conducted. In fact, training was cited as a need for both family members and school personnel. Caregivers provided several suggestions including the need for attendance at workshops that provide practical strategies for working with children with dysphagia and the need for reciprocal instruction and information sharing between school personnel and family members.

School personnel must receive up-to-date and practical staff development programming if they aspire to understand the feeding/swallowing issues of

Table 1.

*Benefits and Drawbacks of Several Home-School Communication Approaches.*

Partnerships through Communication: Engage in frequent, honest, and open communication with parents to enable congruence between home and school feeding behaviors		
Approaches	Benefits	Drawbacks
<ul style="list-style-type: none"> <li>• Communication Notebooks</li> </ul>	<ul style="list-style-type: none"> <li>• Provides a holistic account of student behavior over the course of a day</li> </ul>	<ul style="list-style-type: none"> <li>• Does not lend itself to the identification of feeding patterns</li> </ul>
<ul style="list-style-type: none"> <li>• Daily Agendas</li> </ul>	<ul style="list-style-type: none"> <li>• Disaggregates feeding/swallowing behavior by time and event and is helpful when identifying patterns of behavior</li> </ul>	<ul style="list-style-type: none"> <li>• Time-consuming and may not adequately reflect the totality of feeding behavior</li> </ul>
<ul style="list-style-type: none"> <li>• Phone calls</li> </ul>	<ul style="list-style-type: none"> <li>• Time-efficient and often perceived as more personal</li> </ul>	<ul style="list-style-type: none"> <li>• May lack essential information and the absence of documentation may result in reliance on anecdotal records as the means of data-reporting may suffer due to human error</li> </ul>
<ul style="list-style-type: none"> <li>• Email exchanges</li> </ul>	<ul style="list-style-type: none"> <li>• Time-efficient and convenient</li> </ul>	<ul style="list-style-type: none"> <li>• Email messages tend to lack emotional and/or contextual content, which may negatively affect how the message is given and/or received.</li> </ul>
<ul style="list-style-type: none"> <li>• Classroom newsletters</li> </ul>	<ul style="list-style-type: none"> <li>• Contain general information about feeding and swallowing issues for all families of students in class</li> </ul>	<ul style="list-style-type: none"> <li>• Information provided is general, rather than pertaining to a specific individual or individuals</li> </ul>



students with dysphagia and to learn how to manage these needs accordingly. School districts must not only allocate resources for this training; education personnel must understand the importance of training and attendance at these staff development programs. Unfortunately, a wide variety of staff development programs focusing on evaluation and management of school-age students with dysphagia is not common in many school districts (Krueger & Conlon, 2006).

Teachers and SLPs often experience enormous pressure when working with students who have feeding/swallowing issues. Professional development programming aimed at providing practitioners with specific dysphagia management techniques has been reported as an unequivocal need. Targeting necessary dysphagia management training for SLPs, Stoner et al. (2006) concluded:

More preservice and inservice experience in feeding clinics and workshops should be considered an integral part of SLPs' professional development. In addition, the effectiveness of SLP training programs and intervention programs for the improvement of feeding/swallowing skills needs to be more closely monitored. As results of such testing become clear, administrators and higher education professionals need to make data-based decisions to enhance the effectiveness of these programs (p. 350).

The importance of understanding the needs of students with dysphagia is multi-faceted; no one person or entity is expected to have all the answers. Students' needs vary, as do levels of training required to meet those needs. Because feeding and swallowing issues transcend typical academic and behavioral objectives that were formally taught in degree-seeking programs, school personnel may often have to seek training on their own initiative. Angell et al. (2008) described the complexities of working with children who have feeding/swallowing issues: "Team members must also be familiar with the use of adaptive equipment, instructional strategies appropriate to meet the needs of diverse learners, positive behavior management methods, and models for facilitating mealtime communication in children with severe communication impairments" (p. 7). Specific training in dysphagia management is needed to gain this familiarity and to implement these techniques so that the educational experiences and outcomes of students with dysphagia can be maximized.

Stoner and colleagues' (2006) caregiver interviewees said they relied on school personnel as a resource for managing their children's feeding and swallowing issues. While caregivers expressed a desire to learn from the expertise of school personnel, they stated a resounding preference for in-home training, perceived as occurring in relaxed and natural settings. In addition to in-home training, parents and grandparents also indicated a need, not just for traditional

instruction but also for therapists to model and demonstrate feeding techniques. Stoner et al. concluded that caregivers “expressed appreciation for professionals who listened to their concerns, recognized and valued their parental expertise, and met parents’ need for problem-solving behavior by providing parents with effective intervention methods through one-on-one instruction and demonstration” (p. 347). While most practitioners do not typically have home visits built into their schedules, this may be a feasible accommodation during days allocated for school improvement or professional development. It is recommended that teachers and SLPs discuss the utility and feasibility of this accommodation with their administrators.

### *Theme #3: Effective Interventions*

There is no single intervention that can meet the needs of all individuals with dysphagia; the effectiveness of any intervention is inextricably tied to the specific feeding/swallowing needs of a particular child. While the replication of specific techniques proven effective for some students with dysphagia may not meet the needs of others, some interventions have more generalized applicability across students and settings than others. Some effective techniques are based on the timing and nature of the interventions, in general, while others are situation-specific. Parents and school personnel must exercise caution in using these techniques, as their application is determined by the needs of individual children. There is no universal methodology that can address the needs of all students.

Raising a child with dysphagia can be stressful for parents and the entire family unit (Sullivan, Lambert, Rose, Ford-Adams, Johnson, & Griffiths, 2000), but in a study conducted by Brown and Bhavnagri (1996), families reported that they perceived less stress when their children participated in early intervention programs as opposed to higher stress levels indicated by families who did not participate in similar programs. Stoner et al. (2006) also found that families were generally more pleased with dysphagia programs offered as part of early intervention programming than with traditional school-based programs that typically begin when children start school. These findings indicate that early intervention programs may reduce family stress and that timing of interventions is crucial to the perceived effectiveness of dysphagia management programs.

Families who have raised children with dysphagia have reported that mere acknowledgement by practitioners of the stress they endure helps reduce their stress-level (Stoner et al., 2006). They want communication and support from school personnel; they want school personnel to acknowledge the demands of raising medically fragile children, even if service providers do not have all the answers (Franklin & Rodger, 2003). In essence, families have expressed a

Table 2.

*General Techniques for School-Based Management of Dysphagia.*

• Attend dysphagia management training to learn research-based practices that foster the development of adaptive mealtime behaviors of students with dysphagia
• Develop strong, collaborative partnerships with SLPs, school nurses, and OTs
• Learn from <i>all</i> team members
• Invite parents to demonstrate how they manage dysphagia in the home
• Demonstrate effective dysphagia management techniques to parents and school personnel
• Employ research-based techniques that are proven effective for students
• Actively engage parents in the IEP process and specifically document feeding/swallowing protocol in students' IEPs

desire for school personnel to not just understand the needs of their students but to also exhibit sensitivity to the pressures and concerns of individual families. While early intervention services and an understanding of the complex needs of families may serve as programmatic tools when developing dysphagia management programs, there are specific techniques that may help guide efforts to effectively accommodate families and their children with feeding/swallowing challenges.

Knowledge of “tried and true” techniques may prove useful when fostering adaptive feeding/swallowing behaviors. Specific techniques can be disaggregated by members of the dysphagia team; school personnel can modify mealtime environments and/or provide specific therapies and/or cuing to facilitate a safer and more efficient mealtime. Individually adapted direct and indirect swallowing therapies, encouragement of self-feeding when feasible per individual students’ abilities, positioning, use of adaptive equipment, environmental modification, dietary modifications, and specific feeding strategies have been described elsewhere for use in school environments (e.g., Bailey & Angell, 2005a, 2005b, 2008). While no technique is applicable to every child, an appropriately selected therapeutic feeding program can be taught to involved family members to encourage generalization of techniques in all environments where children consume food. See Table 2 for some general techniques for school-based management of dysphagia.

Environmental modifications may ease feeding/swallowing strain for individuals with dysphagia. Lowman and Murphy (1999) cited environmental

distracters as one factor that can negatively or positively affect mealtime behaviors of students with feeding/swallowing difficulties, particularly for students with difficulty remaining focused on the task of eating. Family members and researchers have suggested that environmental modifications such as dimming the lights, providing meals away from the distraction of classmates, and playing soft, rhythmical music may facilitate the expediency and efficiency of mealtime behavior (Angell et al., 2008; Lowman & Murphy, 1999; Morris & Klein, 1987). Limiting mealtime distractions is not location-specific and could prove beneficial across settings.

Nourishment is a critical means of livelihood for all living things, as eating sustains energy. While eating is necessary to sustain vitality, it is more than just a rote motion. For many, mealtime behaviors are as much about socialization, choices, and self-determination as they are about physical replenishment. According to Bailey and Angell (2003), "mealtimes offer many naturalistic opportunities to give children experiences with choice-making" (p. 28). In tandem, Angell et al. (2008) stated, "practicing early self-determination skills within naturalistic settings such as meals may foster or reinforce the development of self-determination skills in other settings" (p. 28). Given the research base on the needs and mealtime behaviors of students with dysphagia, it is plausible that student empowerment in the process of food selection, timing, and environmental preference plays a tangential, if not instrumental, role in facilitating the entire feeding process. Effective interventions should guide daily programming and that effectiveness should also be documented. To ensure accountability and delineate responsibilities for those who work with, care for, or instruct children with dysphagia, specific protocols for mealtime programming for students with dysphagia must be included in every applicable student's IEP.

#### *Theme #4: IEP Protocol*

Family concerns related to dysphagia management have repeatedly focused on relationships, training, and effective interventions (Angell et al., 2008; Stoner et al., 2006). In addition, families have expressed their belief that the effectiveness and consistency of their children's dysphagia management programs are closely linked to the IEP process and to the specification of feeding/swallowing techniques in IEP documents. They have also asserted that factors such as team composition, parental participation, and specific IEP objectives addressing the particular components of dysphagia management programs are instrumental in the perceived effectiveness of the IEP process (Stoner et al., 2006).

Angell et al. (2008) advocated for a comprehensive IEP team composition at IEP meetings for students with dysphagia, including all related service

personnel/therapists, medical personnel (e.g., nurses and dieticians), teachers, and, certainly, families. While an increase in the number of service providers attending an IEP meeting may lengthen the duration of the meeting, the accuracy of the information provided is directly proportional to the representation of all individuals who have insight into a student's feeding/swallowing behaviors and patterns. Ample time should be allocated for these meetings, and arrangements should be made in advance to ensure that all participants can attend. If meetings are held during the school day, team members may have to alter their schedules; teachers may require substitutes during their absence(s) from the classroom.

IEP meetings provide a forum for all team members to provide and seek knowledge about students' specific needs. To facilitate efficiency and maximize thoroughness, all team members should be fully prepared prior to the initiation of these IEP meetings. Participants should attend IEP meetings with data supporting student dysphagia symptoms, mealtime behavior, and responses to interventions, including effective and ineffective practices. They should be ready with questions for other team members. Although IEPs are developed by teams, advanced preparation for IEP development meetings is crucial. Families have also expressed increased comfort when the feeding/swallowing techniques teams used were detailed in their children's IEP documents (Stoner et al., 2006). School-based SLPs have supported the belief that consistency across school personnel is enhanced when feeding/swallowing protocols are clearly articulated, and advanced preparation can enhance the specificity and comprehensiveness of final IEP documents (Bailey, Stoner, Angell, & Fetzer, 2008).

The IEP process can be intimidating for many parents. Practitioners can ease the stress level that parents experience by engaging them as valuable members of IEP teams (Stoner et al., 2006). The roles of school personnel and families who work with or raise children with dysphagia are related, but it is unlikely that either partner fully understands the role of the other. For this reason, it is recommended that team meetings be viewed as opportunities to share, learn, improve, and refine practices, rather than solely to complete the paperwork necessary to fulfill a legal requirement. To ease the stress many families experience during IEP meetings, it is imperative that they be provided ample opportunities to contribute, that adjustments be made to help them feel both physically and emotionally comfortable, and that the focus of IEP meetings is to help address and meet their needs and the needs of their children.

Parents and guardians of children with dysphagia often rely on IEP meetings to get progress updates, understand educational placement, and engage in meaningful dialogue with practitioners who work with their children. During interviews that Stoner et al. (2006) conducted with family members of students with dysphagia, family members repeatedly expressed concern with the generalization of school-based dysphagia management techniques across settings.

While families certainly value their children's acquisition of adaptive feeding and swallowing behaviors, they also expressed concern about whether or not those skills would be generalized and maintained. Providing a summary of the requisite skills needed for generalization, Angell et al. (2008) stated, "since many children require specialized assistance or supports to maximize feeding/swallowing safety and efficiency in all feeding settings, it is important to include parents/guardians for generalization of effective strategies/methods" (p. 7).

## CONCLUSION

School personnel must adhere to state and school district standards and philosophies, as well as meet specific educational objectives for students with disabilities and dysphagia. Standards and philosophies alone do not, in isolation, directly parallel best management practices for students with dysphagia. In order to effectively construct, institute, and evaluate school-based dysphagia management programs, it is clear that family input is essential. Accordingly, this may require a shift in IEP development protocol that emphasizes speaking with families and encouraging their input, rather than speaking to them only to disseminate assessment results or have them sign a document into which they had very little opportunity to provide their input. Given the time constraints and the multitude of responsibilities placed on school personnel, finding the time to really listen to families is much harder than it sounds, but the rewards can be well worth the efforts. See Table 3 for a list of components of effective dysphagia management systems that might be useful to school-based dysphagia management teams as they develop, implement, and evaluate their programs.

According to family members, the most determinant factors for satisfaction with school-based dysphagia management programs include: family-school partnerships, communication, training, effective interventions, and use of effective and truly collaborative IEP protocols. While emerging themes have been discussed in direct relationship to the quality of dysphagia management programs, all themes are intertwined. For example, it is not possible to develop authentic partnerships with families without effective communication methods. Effective interventions are informed by training, communication, and family involvement. The management process must include appropriate staff development, assessment and intervention trials, and opportunities for education and training. Use of a truly collaborative process must be achieved through authentic home-school partnerships.

While this article is intended to inform the educational community of the perspectives of families who are raising children with dysphagia, the suggestions listed here are not intended to be exhaustive, diagnostic, or prescriptive. Rather, this article is intended to provide practitioners with insight into the

Table 3.

*Components of Effective Dysphagia Management Systems.*

Related to the IEP Protocol
• Practice effective teaming
• Allow ample time for IEP meetings
• Set individualized, specific dysphagia objectives on IEPs
• Identify necessary environmental modifications
• Set measurable behavior management objectives related to feeding
Effective Interventions for Students with Dysphagia
• Teach student self-relaxation and self-regulatory techniques—Use pauses between instances of food-consumption, talk to students about non-feeding parts of their day, encourage breaks from the feeding process if students exhibit physical or emotional stress.
• Obtain family consent to discuss feeding/swallowing concerns with knowledgeable medical practitioners. Learn about students' specific abilities, health and safety risks, and needs related to eating and swallowing.
• Modify the environment as needed—Dimming the lights or playing soft, rhythmic music may also improve attention to the task of eating and aid in the mealtime process.
• Avoid environmental distracters when needed, such as the presence of peers, loud noises, or excessive visual stimuli. However, when students are able to manage distractions of a typical lunchroom setting, include them with their peers in the lunchroom.
• Allow students as much medically sound control as possible, to establish their ownership over the feeding process—provide choices, opportunities for self-feeding, and a willingness to allow students to be the decision-makers during the mealtime process. Use individually chosen adaptive feeding equipment to encourage self-feeding when possible.
• View mealtimes as an opportunity for socialization. Engage students in conversation, ask for their opinions, simply talk to them and encourage responses. Use low-tech AAC systems as needed to encourage mealtime communication.
• Use structured and individually designed positive behavior management programs to improve mealtime behaviors.
• Consult dysphagia team members such as Speech-Language Pathologists, Occupational Therapists, Physical Therapists, behavior management specialists, and family members to develop specific dysphagia programming for students.

perspectives of these families gained through a review of recently published research. It is clear that effectively teaching and raising any child is not easily accomplished, when using even the most liberal of definitions. This article has identified processes and techniques that may help school-based dysphagia teams work effectively with families to meet the needs of students with feeding and/or swallowing issues.

Like all students, those with dysphagia often require individualized instructional programming. However, unlike school-based programs for other students, programs for students with dysphagia encompass far more than concern with academic achievement, adaptive behavior, and a quarterly need for updating parents on their children's progress. Students diagnosed with dysphagia can experience serious health concerns if their feeding, swallowing, and/or nutritional needs are not met. To effectively educate students with dysphagia and meet their feeding/swallowing needs, frequent communication between school and home is essential. School and parent training on effective techniques can also be invaluable. The use of effective, individualized interventions focusing specifically on feeding/swallowing goals is important.

Working with, educating, and habilitating students with dysphagia is not an easy task. For these students, the education team's job is not just to manage students' mealtimes; it is also to work with their families. Understanding the perspectives of families and making educational decisions based on their input comprise a fundamentally sound approach to developing and implementing school-based dysphagia management programs.

## REFERENCES

- American Speech-Language-Hearing Association. (1994). *Professional liability and risk management for the audiology and speech-language pathology professions*. [Technical Report]. Rockville, MD: Author.
- American Speech-Language-Hearing Association. (2003). *Code of ethics* [Ethics]. Available from [www.asha.org/policy](http://www.asha.org/policy).
- American Speech-Language-Hearing Association. (2008). *2008 schools survey report: Caseload characteristics*. Rockville, MD: Author.
- Arvedson, J. C. (2000). Evaluation of children with feeding and swallowing problems. *Language, Speech, and Hearing Services in Schools, 31*, 28-41.
- Arvedson, J. C., & Brodsky, L. (2002). *Pediatric swallowing and feeding: Assessment and management* (2<sup>nd</sup> ed.). San Diego, CA: Singular.
- Angell, M. E., Bailey, R. L., & Stoner, J. B. (2008). Family perceptions of facilitators and inhibitors of effective school-based dysphagia management. *Language, Speech, and Hearing Services in Schools, 39*, 214-226.



- Bailey, R. L., & Angell, M. E. (2003). A model of collaborative school-based feeding teams. *ASHA Special Interest Division 16 Newsletter, Perspectives on School-Based Issues*, 4, 20-22.
- Bailey, R. L., & Angell, M. E. (2004). Critical components of school-based feeding improvement programs. *Physical Disabilities: Education and Related Services*, 23(1), 19-32.
- Bailey, R. L., & Angell, M. E. (2005a). Improving feeding skills and mealtime behaviors in children and youth with disabilities. *Education and Training in Developmental Disabilities*, 40(1), 80-96.
- Bailey, R. L., & Angell, M. E. (2005b). Service-learning in speech-language pathology: Results of a school-based feeding improvement project. *Contemporary Issues in Communication Science and Disorders*, 32, 126-133.
- Bailey, R. L., & Angell, M. E. (2007, October). A 'tried and true' collaborative school-based feeding team model. *Pediatric Feeding and Dysphagia Newsletter*, 9, 5-9.
- Bailey, R. L., & Angell, M. E. (2008, January). ABCs of dysphagia management in schools: An overview of practical strategies. *ASHA Leader*, 8-12.
- Bailey, R. L., Stoner, J. B., Angell, M. E., & Fetzer, A. (2008). School-based speech-language pathologists' perspectives on dysphagia management in the schools. *Language, Speech, and Hearing Services in Schools*, 39, 441-450.
- Bartz, A. H., & Deubler, D. C. (1990). Identification of feeding and nutrition problems in young children with neuromotor involvement: A self-assessment. *Journal of Pediatric and Perinatal Nutrition*, 2, 1-12.
- Boddy, J., Skuse, D., & Andrews, B. (2000). The developmental sequelae of nonorganic failure to thrive. *Journal of Child Psychology and Psychiatry*, 41, 1003-1014.
- Brown, N. L., & Bhavnagri, N. (1996). *Effects of an early intervention program on stress and teaching ability of single mothers of young multiply impaired children*. Michigan: U. S. Department of Education, Office of Educational Research and Improvement, Educational Resources Information Center. (ERIC Document Reproduction Service No. 398678).
- Brown, L., Long, E., Udvari-Solner, A., Schwarz, P., VanDeventer, P., Ahlgren, C., et al. (1989). Should students with severe intellectual disabilities be based in regular or in special education classrooms in home schools? *Journal of the Association of Persons with Severe Handicaps*, 14, 8-25.
- Drewett, R. F., Corbett, S. S., & Wright, C. M. (1999). Cognitive and educational attainments at school age of children who failed to thrive in infancy: A population-based study. *Journal of Child Psychology and Psychiatry*, 40, 551-561.

- Ekberg, O., Hamdy, S., Woisard, V., Wuttge-Hannig, A., & Ortega, P. (2002). Social and psychological burden of dysphagia: Its impact on diagnosis and treatment. *Dysphagia*, *17*, 139-146.
- Farri, A., Accornero, A., & Burdese, C. (2007). Social importance of dysphagia: Its impact on diagnosis and therapy. *Acta Otorhinolaryngologica Italica*, *27*, 83-86.
- Fiedler, C. R., & Swanger, W. H. (2000). Empowering parents to participate: Advocacy and education. In M. J. Fine & R. L. Simpson (Eds.), *Collaboration with parents and families of children and youth with exceptionalities* (pp. 437-464). Austin, TX: PRO-ED.
- Franklin, L., & Rodger, S. (2003). Parents' perspectives on feeding medically compromised children: Implications for occupational therapy. *Australian Occupational Therapy Journal*, *50*, 137-147.
- Gisel, E. G., Birnbaum, R., & Schwartz, S. (1998). Feeding impairments in children: Diagnosis and effective intervention. *International Journal of Orofacial Myology*, *24*, 27-33.
- Hawdon, J. M., Beauregard, N., Slattery, J., & Kennedy, G. (2001). Identification of neonates at risk of developing feeding problems in infancy. *Intensive Care*, *14*, 40-45.
- Heffer, R. W., & Kelley, M. L. (1994). Nonorganic failure to thrive: Developmental outcomes and psychosocial assessment and intervention issues. *Research in Developmental Disabilities*, *15*, 247-268.
- Homer, E. M. (2003). An interdisciplinary team approach to providing dysphagia treatment in the schools. *Seminars in Speech and Language*, *24*(3), 215-227.
- Homer, E. M., Bickerton, C., Hill, S., Parham, L., & Taylor, D. (2000). Development of an interdisciplinary dysphagia team in the public schools. *Language, Speech, and Hearing Services in Schools*, *31*, 62-75.
- Individuals with Disabilities Education Act (IDEA)*. (1997). 20 U.S.C. 1411, Public Law 105-17.
- Individuals with Disabilities Education Improvement Act (IDEIA)*. (2004). 20 U.S.C. 1400, Public Law 108-446, 108<sup>th</sup> Congress.
- Kovar, A. J. (1997). Nutrition assessment and management in pediatric dysphagia. *Seminars in Speech and Language*, *18*, 39-49.
- Krueger, W., & Conlon, B. (2006, November). *Comparison of dysphagia competency procedures in medical and school settings*. Paper presented at the American Speech-Language-Hearing Association National Convention, Miami, FL.
- Lefton-Greif, M. A., & Arvedson, J. C. (1997). Ethical considerations in pediatric dysphagia. *Seminars in Speech and Language*, *18*, 79-86.

- Logemann, J. A. (1998). *Evaluation and treatment of swallowing disorders* (2<sup>nd</sup> ed.). Austin, TX: PRO-ED.
- Lowman, D. K., & Murphy, S. M. (1999). *The educator's guide to feeding children with disabilities*. Baltimore: Brookes.
- Morris, S., & Klein, M. (1987). *Pre-feeding skills: A comprehensive resource for feeding development*. Tucson, AZ: Therapy Skill Builders.
- National Institute on Deafness and Other Communication Disorders (1998, October). *Dysphagia*. Retrieved February 26, 2008, from <http://www.nidcd.nih.gov/health/voice/dysph.asp>
- Power-deFur, L. (2000). Serving students with dysphagia in the schools? Educational preparation is essential! *Language, Speech, and Hearing Services in Schools, 31*, 76-78.
- Power-deFur, L., & Alley, N. S. (2008). Legal and financial issues associated with providing services in schools to children with swallowing and feeding disorders. *Language, Speech, and Hearing Services in Schools, 39*, 160-166.
- Ruddy, B. H., & Sapienza, C. M. (2004). Treating voice disorders in the school-based setting: Working within the framework of the IDEA. *Language, Speech, and Hearing Services in Schools, 35*, 327-332.
- Schindler, A., Ginocchio, D., & Ruoppolo, G. (2008). What we don't know about dysphagia complications? *Revue de Laryngologie, Otologie, & Rhinologie, 129*, 75-78.
- Silliman, E. R. (2000). From the editor . . . *Language, Speech, and Hearing Services in Schools, 31*, 3.
- Stoner, J. B., Bailey, R. L., Angell, M. E., Robbins, R., & Polewski, K. (2006). Perspectives of parents/guardians of children with feeding/swallowing problems. *Journal of Developmental and Physical Disabilities, 18*(4), 333-353.
- Sullivan, P. B., Lambert, B., Rose, M., Ford-Adams, M., Johnson, A., & Griffiths, P. (2000). Prevalence and severity of feeding and nutritional problems in children with neurological impairment: Oxford feeding study. *Developmental Medicine & Child Neurology, 42*, 674-680.
- Turnbull, A., Turnbull, R., Erwin, E., & Soodak, L. (2006). *Families, professionals, and exceptionality: A special partnership* (5<sup>th</sup> ed.). Columbus, OH: Merrill.

---

Address correspondence to Dr. Maureen E. Angell, Illinois State University, Department of Special Education, Campus Box 5910, Normal, IL 61790-5910 [meangel@ilstu.edu](mailto:meangel@ilstu.edu)