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Promising Practice

EIGHT STEPS TO SCHOOL-BASED EMPLOYMENT TRAINING FOR ADOLESCENTS WITH AUTISM SPECTRUM DISORDER AND INTELLECTUAL DISABILITY

Juliet E. Hart Barnett

Arizona State University

Robert Crippen

Arizona State University

Abstract: Despite the transition requirements mandated by IDEA, and a growing body of research supporting effective transition planning for learners with autism spectrum disorders and intellectual disability, current national surveys of transition from school to work document dismal employment outcomes for adults with significant disabilities who frequently are without employment or are under-employed. Enrollment in vocational or employment-related programs in high school improves post-secondary employment attainment for students with disabilities. Using a restaurant organized and delivered by students with ASD and ID at their local high school as a model, the following describes eight, research-based, practical steps for teachers seeking to develop and implement high-quality, inclusive employment training programs for their students with disabilities. Implementing these steps will assist teachers in preparing students to assume post-secondary, meaningful integrated employment opportunities that are associated with greater economic self-sufficiency, social and community inclusion, and overall personal life satisfaction.

Keywords: *autism; cognitive impairments; adolescence; self-determination; transition*

Introduction

Despite the transition requirements mandated by the Individuals with Disabilities Education Act (2004) and a growing body of research supporting effective transition planning for learners with autism spectrum disorder (ASD) and intellectual disability (ID) (Gerhardt, 2007), many adults with these significant disabilities are without employment or are under-employed (Migliore & Domin, 2011). Among youth with ASD, 76% of teenagers over the age of sixteen have never applied for a job and 79% percent of adults with ASD continue to live at home (Seltzer & Krauss, 2002). Similarly, a recent analysis of the National Longitudinal Transition Study-2 documented that only 26% of transition-aged youth with ID were working for compensation; even within this relatively small group, 43% were working in settings comprised almost exclusively of individuals with disabilities such as enclaves, mobile crews, or sheltered workshops for sub-minimum wage (Carter, Austin, & Trainor, 2012). Although adolescents with developmental disabilities such as ASD and ID typically remain in school longer than their peers and often are provided with costly long-term funded supports as adults, national surveys document discouraging employment outcomes for this group (Migliore & Butterworth, 2008). With limited employment prospects, they often live lives of isolation and dependence with restricted opportunities to improve their quality of life (Gerhardt, 2007).

However, researchers have cited meaningful integrated employment as a critical goal for youth with developmental disabilities as it is associated with greater social and community inclusion, economic self-sufficiency, and overall personal life satisfaction (Carter et al., 2012; Migliore & Domin, 2011). Research has also stressed the importance of accurately documenting those factors that influence the post secondary attainment of direct hire jobs that pay above minimum wage for individuals with significant disabilities (Moon, Simonsen, & Neubert, 2011). One factor found to improve the post secondary employment attainment for students with disabilities is enrollment in vocational education or employment-related programs in high school (Carter et al., 2012; Shandra & Hogan, 2008). Therefore, interventions and recommendations from the research which reconsider how such learners can be prepared for life beyond the classroom, in the community, and, as gainfully employed citizens, are most critical and timely. Professionals must plan carefully for transition into adulthood to ensure success (Howlin, Alcock, & Burkin, 2005; Turnbull, Turnbull, Wehmeyer, & Shogren, 2013). Based on a model restaurant organized and delivered by students with ASD and ID at their local high school, eight research-based, practical steps for teachers to develop and implement high-quality employment training programs for their students with multiple disabilities will be described (see Table 1).

Step 1: Observe other Programs and Collaborate with District Teachers

Collaboration is an essential element of developing effective employment training and overall quality transition programming for adolescents with disabilities (Shogren & Plotner, 2012). Ensuring that school personnel establish collaborative partnerships and network within and across other model school and community settings can greatly inform educators regarding best practices (Noonan, Morningstar, & Erikson, 2008). The first step in the design of a vocational program is to locate and observe other classrooms in the area and take into account the methods and strategies they employ to promote vocational instruction and job skills among their students

Table 1

Eight Steps to School-based Employment

Step 1: Observe other Programs and Collaborate with District Teachers

Step 2: Align your Program with State Standards

Step 3: Involve Students in the Planning Process in a Meaningful Way

Step 4: Connect the Program to Real-world Experiences

Step 5: Create Training Materials and Pre-vocational Tasks that Mimic Real-world Processes

Step 6: Use Research-based Training Methods

Step 7: Integrate your Program within the School Community

Step 8: Use Authentic “Real-world” Reinforcement

with disabilities. Many schools have a transition coordinator whose job it is to build interagency collaborations, provide technical assistance, conduct needs assessments, and engage in communication to support student transition needs among stakeholders (Noonan et al., 2008). This professional can also link teachers to other model school and community-based programs through the establishment of community of practice groups that can share best practices and support implementation of long term goals and policy recommendations related to effective transition. In a practical way, these collaborations can help teachers interface with others in their school districts and analyze the programs that have been successful in vocational training such as copy centers, mail delivery, and recycling. Such communities of practice can also enable participation in continuous training on transition needs and resources available in the community and state.

Step 2: Align your Program with Core Academic State Standards

Compliance with federal law requires that transition goals, including those associated with employment, be linked to specific academic experiences (Johnson, Stodden, Emanuel, Luecking, & Mack, 2002). In addition, academic instruction in vocational education must be functional and outcomes oriented in order to be successful (Turnbull et al., 2013). For a vocational program such as a classroom restaurant, teachers can look at the common core standards for academic achievement and align the instruction with these standards. For example, high school language arts common core standards require students to be able to understand the meaning of words (this includes technical text) from a variety of sources in order to solve a problem (see <http://www.corestandards.org>). The comprehension of informational text and the corresponding skills that the standard requires are demonstrated by the students in a vocational restaurant setting (e.g., comprehending menus, using order forms), a copy center (e.g., retrieving meaning from order forms and following the process to complete the order) or when delivering mail (e.g., comprehending the names on the envelopes, navigating maps of the campus in order to deliver).

Step 3: Involve Your Students in the Planning Process in a Meaningful Way

Career and vocational development begins with the student. Utilizing a student-directed approach requires consideration of student preferences and interests (Turnbull et al., 2013). Determining students' interests and providing them the autonomy and responsibility to decide on, design and evaluate their work empowers them to connect with the content and promotes self-determination. By giving students the opportunity to meaningfully participate in the curriculum, teachers can develop in their students the skills necessary to be proactive and self-determined members of society (Wehmeyer & Palmer, 2003). Incorporating meaningful participation in vocational programs by securing student input in job choices, services offered, and outcome-related rewards may increase student "buy-in." This buy-in will consequently increase student motivation and engagement, which are related to improved achievement (Guthrie & Wingfield, 2000). If student preferences, interests, and strengths do not significantly influence decisions in the planning process, students may be less likely to employ the skills they have acquired (Turnbull et al., 2013).

The preparation and planning for a classroom restaurant requires menus, decorations, finance decisions and a host of other responsibilities. Including the students in the process of creating the menus based on their favorite meals and snacks and determining prices not only connects to the common core standards but also contributes to increased student motivation. Giving the students artistic design in the creation of the restaurant space is another way to increase the sense of self-determination and emphasize choice in the development process of the vocational program.

Step 4: Connect the Program to Real-World Experiences

The overall goal of any inclusive vocational program is to teach job skills in a realistic vocational setting that will transfer to a supported, integrated employment setting in the community (Billstedt, Gillberg, & Gillberg, 2005; Migliore & Domin, 2011). A critical step in any vocational training program is to give students with ASD and ID the opportunity to gain experience that will logically lead to jobs after high school in a variety of settings. Although the most directly translatable option would be community-based instruction, many barriers exist that can make it impossible for schools to implement such programs such as funding, transportation, personnel, and location in proximity to possible job placements (Kim & Dymond, 2010). Despite these barriers, the school can offer many realistic, instructional job opportunities.

In a school community, a vocational restaurant program is an environment that incorporates key vocational skills for long-term success. We identified these key skills through a review of the literature and through consultation with local community businesses where students might someday work and/or become customers. Important skills such as money management, vocational communication (e.g., greeting customers, taking orders, accepting direction, and inter-staff communication), self-determination, and performance of routine job functions such as cleaning and uniform/hygiene maintenance (Snell & Brown, 2011) were identified for instruction. Included beyond the vocational skills, the restaurant setting was designed as a results-oriented context to increase the requisite, underlying academic skills necessary to participate in the general education curriculum and community beyond the classroom. Academic skills included: writing (e.g., orders, receipts, and menus), reading (e.g., menu items, orders coming in/going out

of the kitchen, and order forms for inventory), and mathematics (e.g., adding bill totals including tip, calculating change, totaling receipts after closing, and depositing money into store account).

Many self-contained classrooms have facilities that allow for life skills and employment-related instruction. These may include an oven or stove as well as a basic kitchenette that allows for food storage. Classrooms with these items can easily be converted into a restaurant setting (see Figure 1). Although community-based instructional environments are considered ideal, researchers have also spent decades documenting the impact of classroom instruction in simulated settings and their positive impact on skills such as ordering meals, (Pol, Iwata, Ivancic, Page, Neef, & Whitley, 1981), shopping for groceries (McDonnell, Horner, & Williams, 1984), using public transportation (Mechling & O'Brien, 2010; Neef, Iwata, & Page, 1978), as well as domestic and vocational skills (Bates, Cuvo, Miner, & Korabek, 2001) among adolescents and adults with disabilities. Through collaboration with local community businesses and integration of an inclusive vocational program as part of the school community, the classroom can be transformed into one that capitalizes on many of the beneficial components that community-based instruction offers.

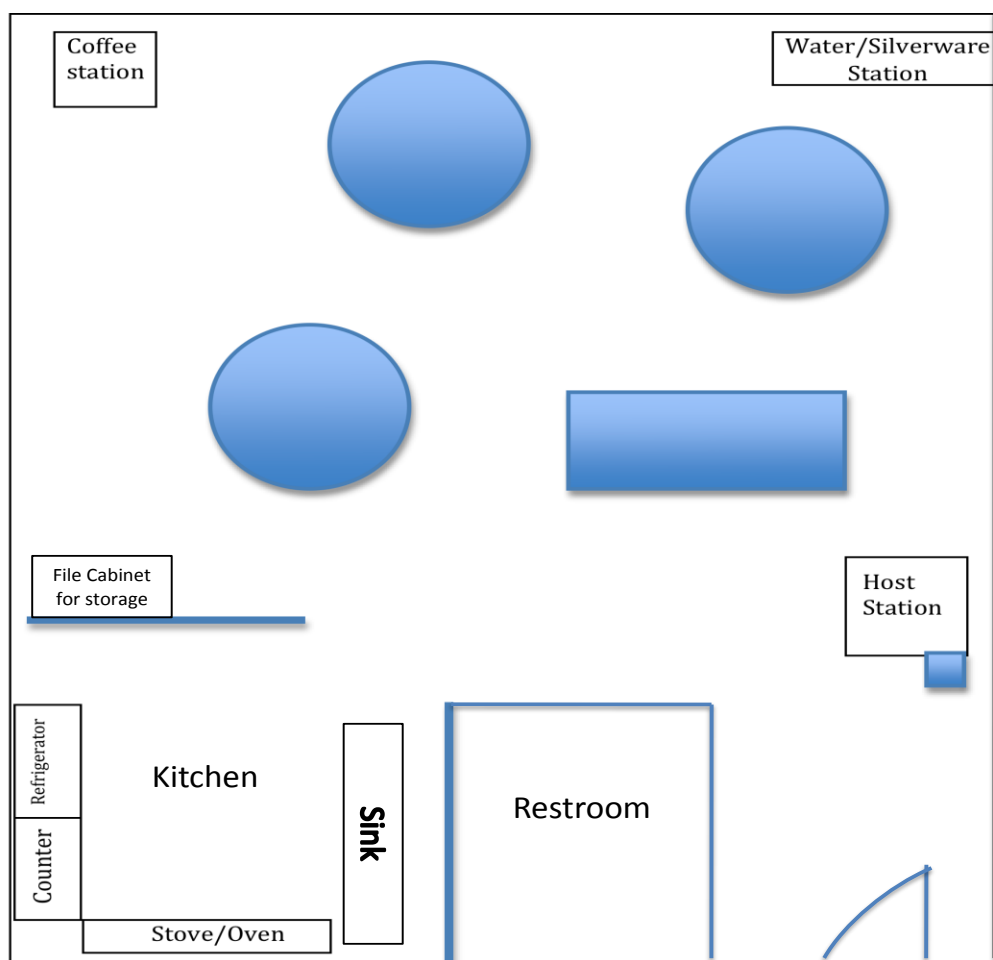


Figure 1. Example of self-contained classroom reorganized into a restaurant layout.

Step 5: Create Training Materials and Pre-vocational Tasks that Mimic Real-world Processes













In order to achieve an authentic connection to community job settings, teachers and staff must treat the vocational training setting as the equivalent of a community job placement. Part of this process includes creating the training materials necessary for a vocational setting and ensuring that the process is as realistic as possible. It is important to develop training materials such as employee manuals that can be used when the students begin their job placements within the school. These training materials should also be based on scientifically validated practices (No Child Left Behind Act, 2001). For students with ASD and other developmental disabilities, visual supports have been found to be particularly helpful (Arthur-Kelly, Sigafos, Green, Mathisen, & Arthur-Kelly, 2009).

Prior to participating in our restaurant vocational program, students were required to take and pass the state food safety exam, just as they would be required for this type of employment position in the community. Students then applied to the restaurant for desired positions using applications created in a word processing document by the teacher. We collected applications from restaurants familiar to the students in order to engage and introduce the content to the students. Based on this discussion and the application forms used by local businesses, we were able to modify the application as necessary depending on the students' abilities (see Figure 2). For learners that required more differentiation, pictures were added to the application to guide responses. Students that demonstrated difficulty with writing used adaptive materials such as name stamps and pictures affixed with Velcro to add them to a laminated application, or used voice to text technology to fill out the form. To further increase the authenticity of the program, we conducted job interviews with the students and, based on their performance, preferences, and skills match, chose to hire the applicants. The students, now considered restaurant staff, were assisted in their daily activities by laminated checklists that they used to track their progress and evaluate their task completion. By linking evidence-based strategies to real-world employment expectations in the creation of our materials, our student staff members were trained to become self-reliant and able to self-prompt their way through the day's work.

Step 6: Use Research-Based Training Methods

Since the No Child Left Behind Act (2001) was enacted, the curriculum and instructional methods used within both the special and general education settings must be derived from scientifically based strategies. The goal is to ensure each student's academic success and applies equally to students with and without disabilities. For students with significant disabilities at the transition stage, it is critical that these research-based approaches be applied to the development of their vocational skills in a functionally relevant way. Teachers must investigate evidence-based and scientifically validated practices and apply these in their training programs.

Bear Café Employment Application

Personal Information														
Name										Date of Birth 				
Address (Where do you live?) 														
City 										State 				
Phone () <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> - <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>														
Student ID number <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>							State 							
Have you ever been convicted of a felony?										Yes <input type="checkbox"/>		No <input type="checkbox"/>		
Are you a citizen of the United States?										Yes <input type="checkbox"/>		No <input type="checkbox"/>		
Position Applying for?														
Have you applied for this position before?										Yes <input type="checkbox"/>		No <input type="checkbox"/>		
Education														
High School 										From <input type="text"/> <input type="text"/>		To <input type="text"/> <input type="text"/>		
Address														
City 										State 				
Employment Experience														
Employer										From <input type="text"/> <input type="text"/>		To <input type="text"/> <input type="text"/>		
Address														
City 										State 				
Job Title										Pay \$ <input type="text"/> /hour				
Reference														
Please provide one reference we can talk to about your job performance														
Name										 (<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> - <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>)				

I certify that my answers are true and complete to the best of my knowledge.

If this application leads to employment, I understand that false or misleading information in my application or interview may result in my release.

Figure 2. Modified job application.

Social scripts. In a restaurant setting, the servers in the restaurant were trained using social scripts (see Figure 3 for an example). Social scripts are used to teach a variety of social and conversational skills such as asking for items, initiating, and turn taking (Charlop-Christy & Kelso, 2003; Ganz, Kaylor, Bourgeois & Hadden, 2008; Howlet, Sidener, Progar, & Sidener, 2011; Sarokoff, Taylor & Poulson, 2001). The script mirrored the requisite language needed to function in the server role. The script training included reviewing the script with the student server and using role-play to ensure independence of the serving skills. The script was faded as the student begins to show mastery of the content.

The server walks up to the customers sitting at the table

- “Welcome to the Bear Café
- “What would you like to drink?”

The server gets the drink for the customer and brings it to the table.

- “What would you like to eat?”

The server places a check mark on the order form next to what the customer orders.

The server gives the order form to the cook.

When the order is finished, the cook puts the food on the tray.

The server takes the food to the customer

- “Can I get you anything else?”
- “Enjoy your meal!”

The server keeps the glass full of the drinks.

Figure 3. Sample server training script.

Video modeling. The kitchen staff was trained using video modeling. Video modeling has been shown to increase a variety of skills such as social skills (MacDonald, Clark, Garrigan, & Vangala, 2005), vocational skills (Kellems & Morningstar, 2012), play skills (Shipley-Benamou, Lutzker, & Taubman, 2002) and participation in the academic curriculum (Hart & Whalon, 2012). Video modeling has also been demonstrated to teach domestic skills such as coffee preparation (Bidwell & Rehfeldt, 2004), a major component of the restaurant. Video was taken using an iPad from the preparers’ point of view for each step in the preparation of the menu items. Using video editing software (iMovie), short videos were streamed together to make a step-by-step video on how to make each menu item. Preparation of each menu item was not longer than five steps and the video model could be paused, rewound, and fast-forwarded if necessary for review and reinforcement.

Step 7: Integrate Your Program within the School Community

Another goal of vocational programs should be to encourage meaningful interaction among students such that students and staff in self-contained classrooms are a vital part of the school community. Connecting students to the school community via a simulated community environment offers real world challenges similar to a typical employment context. Moreover, communicating with school personnel in a business setting has many potential benefits. First, students in self-contained settings often become accustomed to communicating only with other students and staff in their own classroom (Carter, Hughes, Guth & Copeland, 2005). By expanding the program to personnel outside of the self-contained setting, atypical school communication was encouraged and expansion of students' language use and abilities was facilitated. Second, providing a service that is not only tangible but is also visible within the school setting provides natural reinforcers that a contrived setting is simply unable to offer effectively. Third, school-wide recognition of the students' efforts creates a sense of responsibility and identification that increases the students' sense of self-worth and self-esteem.

As part of the classroom restaurant, a Keurig coffee machine was used to create a coffee delivery service. Teachers in the school were given student-created menus (see Figure 4) and were encouraged to place their order with the students for the next school day. The students then created the order and delivered the coffee to the teachers in their classrooms. The service fee was \$1.25 that was paid to the students. The total sales for the day were summed after the closing of the restaurant and added to the classroom account. The popularity of the coffee delivery service quickly increased the visibility of the students as members of the school community.

Step 8: Use Authentic “Real-world” Reinforcement

People go to work for a variety of reasons (Amabile & Kramer, 2010). Those that stay at their jobs and perform to the best of their ability do so partly due to a level of pride and purpose they experience in their work. This level of satisfaction should be no different for students working in an inclusive vocational setting. Naturally occurring reinforcers such as social praise from a job well done can increase generalization of learned skills (Aspy & Grossman, 2011). The increase in self-determination can be established easily in a vocational setting. Increases in self-determination have been correlated with enhanced “social capital” or connection with those in the surrounding community, greater choice and control, as well as enhanced health and economic success (Bacon, Walker, Schwartz, O'Hara, Calkins, & Wehmeyer, 2011).

Following these steps from beginning to end with the students' participation and input creates a sense of ownership that will drive them to continue and to further develop their skills. Establishing a vocational setting with natural maintaining contingencies such as payment and evaluation systems similar to those used in everyday work settings can reinforce appropriate work ethics and behavior (Schloss & Smith, 1998). Developing a “paycheck” system to reward employees for their efforts aligned with a reward system such as a classroom store motivates students the same way we are all motivated to get up each day and go to work.

Bear Cafe

Daily Specials



Donut Shop: Medium Roast		<input type="checkbox"/>
Breakfast Blend Light Roast Coffee		<input type="checkbox"/>
Hawaiian Blend Medium Roast, Extra Bold		<input type="checkbox"/>
Dark Magic Dark Roast, Extra Bold		<input type="checkbox"/>
<i>Hot chocolate</i>		<input type="checkbox"/>
<i>Apple Cider</i>		<input type="checkbox"/>

Flavor shots:

French Vanilla ____ Caramel Macchiato ____

Half & Half ____ Sugar ____

Name: _____

Room Number: _____

Only
\$1.25!

(Cash only please, payment upon request.) Thank you for your order!!

Figure 4. Student-created menu for coffee delivery service.

The Importance of Promoting Generalization

Foundational to implementing these steps to effective employment training is a focus on generalization. Children and youth with ASD and other developmental disabilities experience difficulty generalizing newly learned skills to other settings, situations, people, and environments (Hart & Whalon, 2008). As such, a critical component of any employment skills program is to

develop a sound plan for transfer of skills across settings, persons, contexts, and time (Bellini, Benner, & Peters-Myszak, 2010). The goal of any training program is behavioral change; that is, if the students are not impacted in a positive way across most aspects of life, the change cannot be considered very meaningful. Bellini et al. (2010) recommended the following techniques to facilitate generalization:

- a) train with multiple persons and across multiple settings,
- b) ensure the presence and delivery of natural reinforcers for the performance of social skills,
- c) practice the skill in the natural environment,
- d) fade prompts as quickly as is feasible,
- e) provide multiple exemplars for social rules and concepts,
- f) train skills loosely (e.g., vary instructions, directives, and prompts), and
- g) teach self-monitoring strategies.

As part of a sound plan for promoting students' ability to generalize the skills learned and noted above, it is important to choose functional skills and to teach them using many examples, across many people, and with multiple instructions. It is also especially important to inform and train other school personnel who have contact with students to reflect these instructional techniques as part of a wrap-around approach (Hart & Whalon, 2011).

The classroom restaurant described herein embedded numerous opportunities for students to practice highly functional skills with a variety of people and across naturalistic contexts. The skills students developed were directly transferrable to outside employment in the community such as cafes, grocery stores, and clerical positions. Connection with community-based instruction sites such as coffee shops, bakeries, and cafes in surrounding areas, in collaboration with rehabilitation/transition specialists, can further facilitate the seamless transition from school programs to competitive, outside employment for students completing a similar school-based, vocational training. Preliminary findings from research with a sample of our students suggested positive impact on target social communication skills (Authors, under development).

Conclusion

Although significant strides have been made over the last two decades in ensuring that students with disabilities enter post-secondary education or are gainfully employed (Newman, Wagner, Cameto, Knokey, & Shaver, 2010), true economic self-sufficiency, life satisfaction, and overall community integration are still distal goals for many adolescents and adults with disabilities (National Organization on Disability, 2010). Programs employing the steps described in this article can create opportunities for individuals with ASD and ID that may have otherwise been nonexistent and open doors that were previously closed for students educated in more segregated special education settings. Using a collaborative approach with other key school professionals; integrating students' skill sets, preferences, and interests as part of the planning process; and application of evidence-based training materials and methods can result in employment opportunities that promote positive, long-term results for students.

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Article

SCHOOL EXPERIENCES OF AN ADOLESCENT WITH MEDICAL COMPLEXITIES INVOLVING INCONTINENCE

Hollie Gabler Filce

The University of Southern Mississippi

John B. Bishop

The University of Southern Mississippi

Abstract: The educational implications of chronic illnesses which involve incontinence are not well represented in the literature. The experiences of an adolescent with multiple complex illnesses, including incontinence, were explored via an intrinsic case study. Data were gathered from the adolescent, her mother, and teachers through interviews, email correspondence and school documentation over four months. Analytic memo writing was used to promote reflexivity and address researcher subjectivity. Three prominent themes emerged. There were excessive absences from school which were not always due to the physical implications of the student's incontinence. Some absences were attributed to fear of accidents at school or even fabricated by the student to avoid attendance. Next, an incomplete and inconsistent support and communication system was found which contributed to academic underachievement. Finally, the persona presented by the student led to inaccurate assumptions by school personnel and sometimes her mother regarding her ability to cope with her condition.

Keywords: *qualitative; chronic illness; adolescents; incontinence*

Introduction

It has been estimated that over 11 million children (15.1%) in the United States have special healthcare needs (U.S. Department of Health and Human Services, 2013). Multiple, complex medical diagnoses make it difficult for professionals to adequately understand each condition, to determine how each condition impacts the child individually and collectively, or to identify how to best support the child across environments (Cohen et al., 2011). The needs of children with medical complexities, including those with rare disorders, are often underrepresented in the research due to the difficulty in attaining large enough sample sizes. These children are diverse in their specific diagnoses, and require study and understanding of their functional limitations across settings (Cohen et al., 2011).

VACTERL association is a medically complex, rare condition occurring in 1:10,000- 40,000 live births (Solomon, 2011). By definition, those with VACTERL association have at least three congenital malformations from among the following seven major body systems: vertebral defects (V), absence or abnormal narrowing of the anal systems (anal atresia, A), cardiac defects (C), abnormal openings in the trachea or esophagus (tracheo-esophageal fistula, TE), renal anomalies (R), and limb abnormalities (L). Individuals with VACTERL association do not typically have concurrent cognitive or neurological impairments (Solomon, 2011). It is estimated that anywhere between 55 and 90% of individuals with VACTERL association have anal atresia, which impacts bowel continence, and 50-80% have renal anomalies, which impacts urinary continence (Botto, 1997; Rittler, Paz, & Castilla, 1996; Solomon et al., 2010; Solomon, 2011; Weaver, Mapstone, & Yu, 1986). As with any congenital condition, the level of impairment varies widely from individual to individual, and functional limitations are difficult to predict on the basis of diagnosis alone.

In addition to physical well-being, we are also concerned with the educational well-being of children with chronic illness. School attendance is a strong predictor of academic achievement for students in general (Balfanz & Byrnes, 2012; Carroll, 2010) and for students with chronic illnesses in particular (Caldwell et al., 1997; Sato et al., 2007; Wodrich & Cunningham, 2008). When a child has a chronic illness that manifests in incontinence, the physical impact of illness often necessitates absences from school for hospitalizations, treatments, therapies, and recovery time. While studies have shown students with chronic illness miss school more frequently than their peers (Caldwell et al., 1997; Sato et al., 2007; Shapiro et al., 1995; Wodrich & Cunningham, 2008), little has been reported regarding absenteeism for children with incontinence related to VACTERL association. Filce and LaVergne's study (2011) showed a significantly higher absenteeism rate for children with bowel and/or bladder dysfunction (22.5% missed more than 11 days per year) as compared to the general population (6%) (Bloom, Cohen, & Freeman, 2011).

While all students with chronic illnesses are eligible for educational accommodations under Section 504 of the Rehabilitation Act of 1973, the impact of their illness sometimes makes them also eligible for special education services under the Individuals with Disabilities Education Act (IDEA, 1997). Both of these laws require schools to develop educational plans (504 Plans or Individualized Education Plans [IEP]) to address the needs of these students during the school day. Additionally, professional organizations recommend the development of an Individualized Healthcare Plan (IHP) to specifically address the medical needs of students with chronic illnesses

(American School Health Association, 2002; National Association of School Nurses, 2013). Despite these mandates, many students with chronic illnesses impacting continence often do not have formal structures of support in place during the school day. Filce and LaVergne (2011) studied educational plans specifically for this population and noted that, despite their medical complexity, almost a third (31.4%) had never had any type of educational support plan. Additionally, despite their medical needs, only 8.8% had ever had an IHP as a standalone document or as a part of a 504 Plan or IEP.

To further complicate the school experience for students with chronic illnesses, psychological and emotional factors are often inextricable from an adolescent's illness and physical conditions. Anxiety in various forms is linked to school attendance among children with chronic illness (Fereday, Kimpton, & Oster, 2011; Lundblad, Berg, & Hellström, 2007; Weaver & Dobson, 2008; Williams, Chambers, Logan, & Robinson, 1996). For children with incontinence, a negative social stigma is reported to increase anxiety (Boyt, 2005; Butler & Swithinbank, 2007; Dowbiggin, 2009; Gray, Blackinton, & White, 2006; Lundblad et al., 2007; Lundblad, Hellström, & Berg, 2010; Sureshkumar, Bower, Craig, & Knight, 2003; Weaver & Dobson, 2008; Williams et al., 1996). Moreover, fears related to embarrassment, bullying, and need for privacy contribute to school attendance, often preventing children with incontinence and parents from telling teachers about the child's condition (Best, 2005; Fereday et al., 2011; Lopez, Mullins, Wolfe-Christensen, & Bourdeau, 2008; Lundblad et al., 2007; Lundblad et al., 2010).

While some literature is available discussing overall quality of life for children with incontinence due to a chronic illness (Bai et al., 2000; Baker-Towell & Towell, 2003; Brandt et al., 2007; Fasten, 2000; Nisell, Öjmyr-Joelsson, Frenckner, Rydelius, & Christensson, 2008; Funakosi et al., 2005; Grano, Aminoff, Lucidi, & Violani, 2012; Luscombe, 2000; Mills, 2007; Mukherjee, McCauley, Hanford, Aalsma, & Anderson, 2007; Yi et al., 2009), there is less available focusing on the needs of these children at school (Butler & Swithinbank, 2007; Fereday et al., 2011; Filce & LaVergne, 2011; Lundblad et al., 2007; Weaver & Dobson, 2008; Williams et al., 1996; Lundblad, Hellström, & Berg, 2010). Still, school professionals are charged with understanding complex medical, emotional, and academic needs of these children in order to provide appropriate accommodations and supports.

This intrinsic case study explored the educational experiences of an adolescent girl, Emily (pseudonym), with VACTERL association and incontinence. Emily's experience was significant, as the unique and complex nature of her conditions challenged the typical processes of schools as professional service providers sought to provide educational services. Making the case even more interesting was the sensitive nature of Emily's incontinence, which challenged Emily not only physically but emotionally. Emily's willingness to share openly provided detailed and honest descriptions of her school experiences as well as valuable insight to our primary research question: *How does an adolescent with a medically complex condition involving incontinence navigate her school experience?* Our research had two purposes: (1) to provide a detailed account of Emily's schooling from multiple data sources, and (2) to generate a depth of understanding about this individual case that may lead to insight and empathy for other students who have chronic illnesses including incontinence.

Methods

Participants

Emily, a 15-year-old Caucasian female diagnosed with VACTERL association at birth, was a sophomore at a public high school in a rural, Southeastern town. Of the seven body systems affected by VACTERL association which were described earlier, Emily had defects with four. She had vertebral defects (V); specifically, tissues in her spinal column had become attached to her spinal vertebrae which prevented her spinal cord from moving within her vertebrae normally. This tethering of the spinal cord restricts movement and can cause neurological and motor impairments. Her spinal cord had been surgically released in the past, but some motor deficits remained. Emily also was born with anal atresia (A), specifically cloacal exstrophy in which she was born with her bowel, bladder, and reproductive organs on the outside of her abdomen. These systems were moved into her abdominal cavity at birth. Emily's renal anomalies (R) included a solitary left kidney. Finally, her limb abnormalities (L) were a webbed right leg which was amputated during the fall of her freshman year in high school. Her cloacal exstrophy and solitary left kidney resulted in a lack of continence for both urine and stool. Emily had a Mitrofanoff, which is an opening surgically created using the appendix to create a conduit between the surface of the abdomen and the bladder through which a catheter can be inserted to empty urine.

When Emily was younger, her fecal incontinence was managed through the use of a Malone Antegrade Continence Enema (or MACE), which is an opening from the abdomen to the colon through which a solution is injected into the top of the colon flushing stool out through the anus. However, Emily's MACE was removed after a bowel obstruction and she used rectal enemas to empty her bowels daily at the time of data collection. During the bowel obstruction, Emily reacted negatively to an antibiotic, causing permanent, bi-lateral hearing loss. She wore hearing aids in both ears.

Emily lived with her mother, stepfather and three step-siblings, all aged four and under. She attended public school until the middle of her fourth grade year. During that time, Emily received accommodations via a 504 Plan which included nursing services to assist her with toileting issues. However, because of what Emily's mother described both as a lack of support at school and her personal desire for homeschool, she began homeschooling Emily midway through fourth grade. Emily had no diagnosed intellectual or learning disability, nor was she considered behind academically. This proved an important contextual piece to Emily's overall academic history and no evidence was found that Emily struggled intellectually with school.

After four and a half years of homeschooling, and at Emily's request, she returned to public school to begin her freshman year of high school. A 504 Plan was developed and included accommodations such as a flexible restroom schedule, limited physical education requirements, preferential seating, written directions for all assignments, extended time for testing (with breaks), an extra set of textbooks at home, use of elevators, and the use of crutches. Both her mother and teachers indicated Emily received "flexible homebound instruction" as an accommodation, but her 504 Plan did not refer to this in any written form. According to both her mother and teachers, "flexible homebound" referred to Emily's option to miss school "whenever

needed” without being subject to truancy regulations. Emily had never received special education services.

Intrinsic Single-Case Study Design

A single-case study (Merriam, 1998; Stake, 1995) allowed us in-depth, descriptive research processes (Miles, Huberman, & Saldaña, 2014; Yin, 2014) that guided our methodology towards understanding as much as possible about the particularities of Emily’s schooling within her real-life context. Variation as to what defines a case study exists across a spectrum of theoretical and methodological conceptualizations (Baxter & Jack, 2008; Creswell, 2013; Hancock & Algozzine, 2011; Stake, 1995). However, one distinguishing feature of all case study research involves “bounding” the case by both a specific temporal reference indicating the beginning and ending of the investigation along with a predefined contextual boundary. This case study was designed as an intrinsic case study, exploring a particular case because of the interesting nature of the case itself (Stake, 1995). Data collection began in September 2013 with face-to-face interviews, follow-up emails, and a final follow-up telephone interview four months later. This timeframe did not include our research design, participant recruitment, or related work after data collection. The timeframe was selected to mirror a contemporary high school semester and was a meaningful length for our defined contexts of school settings and experiences.

Researcher Reflexivity

As the parent of a child who shares some of Emily’s medical conditions, our lead researcher was personally and professionally invested in understanding school experiences of students with incontinence. As a research team, we noted both the benefits and challenges this experiential knowledge presented for our research. We gained insight from this researcher’s experience with parent-to-parent support groups for children with congenital anorectal malformations, consultation for affected children and their families regarding school accommodations, work as a special educator in public school, and scholarship as a university faculty member engaged in research regarding students with medically complex conditions. Though our case study was designed to be exploratory and descriptive, our research process was informed by academic assertions and personal understandings. For example, we chose to include a modified process of pattern matching (Yin, 2014), analyzing data against both existing theories in scholarly literature and direct experiential knowledge. Throughout the data collection period, we engaged in analytic memo writing to check for researcher subjectivity. The process of interviewing was coupled with frequent co-researcher data discussion meetings. The two perspectives represented on the research team (one with experience with the given conditions and one without) proved invaluable, providing increased capacity for seeking divergent information during data analysis.

Data Collection

In-depth interviews. We conducted in-depth interviews (Hancock & Algozzine, 2011; Lichtman, 2013; Seidman, 2011; Yin, 2014) using open-ended questions intended to maximize our participants’ perspectives. Interviews were conducted with Emily, her mother, and her teachers face-to-face in September and by phone in December. Each initial interview lasted approximately 60-90 minutes, with subsequent phone interviews lasting 30-60 minutes. The style

of interviews varied between conversational (as relevant researcher experiences and motives were made transparent) and phenomenological (with efforts to place maximum value on the participant's words). This was done to maximize the distinct language and personal stories of the primary participant's experiences. Ultimately, the inherently collaborative role the researcher plays in data production during interviews (Fontana & Frey, 2008) was heightened in the process through shared empathy, mainly with Emily's mother. As such, it is important to note that the lead researcher conducted all interviews and gained "insider" status with Emily and her mother. Listening with empathetic insight to a wide range of feelings and experiences provided ways to explore topics during interviews with more opportunities for elaboration. However, this furthered the methodological need to use multiple data sources and give explicit attention to ways interview data were co-constructed and analyzed.

Follow-up emails. Email exchanges occurred at the end of September, October, and November. These email communications between the lead researcher and participants served to verify certain participant statements, and to gather more frequent attendance and academic progress data between the initial face-to-face interviews in September and the final phone interview in December. For example, the researcher used email to elicit information from participants about school absences and the communication between Emily, her mother and her teachers regarding those absences. While Emily's mother indicated during face-to-face interviews that teachers would call or send emails about makeup work, this communication did not occur according to the follow-up email exchanges. When asking about missed work being made up, Emily once indicated in an email that no work was sent home. The same week, teachers reported that Emily did not ask for missed work upon returning to school. This prompted the researcher to ask Emily, her mother, and her teachers whose "job" it was to make sure Emily knew what she missed in class. Both Emily and her mother responded, "Teachers," while all three teachers responded, "Emily." This exchange illustrates a lack of common understanding of the expectations and processes for ensuring content and work missed were addressed.

In addition, email was utilized to clarify certain interview statements. Emily's mother, for instance, stated she believed Emily sometimes "pretended" to need to stay home because she (the mother) was sick. When asked to elaborate, Emily's mother wrote, "I mainly felt that Emily wanted to take care of me because she would tell me to rest and she would take care of the little kids." The email data supplemented face-to-face interviews by providing further insight to existing data, in this case raising important questions about absenteeism and Emily's role at home.

Analytic memos. Writing analytic memos provided a means to be both reflective about the data collection and analysis methods, as well as more systematic in our observations of the nature of Emily's contexts and experiences. Researcher reflections regarding things reported by the various adults interviewed augmented the interview transcripts. Initially, pattern matching against existing propositions focused our initial coding choices. Our work with memo writing, however, evolved with more exploratory depth, particularly as we saw connections between contextual factors and behaviors Emily used to make her way through this high school year. Analytic memo writing aided in the discovery of "little conceptual epiphanies" (Miles et al., 2014) and simultaneously challenged the stated experiences of the various participants when examined through our own beliefs and values.

School documents. Much like the weekly email exchanges, school documents were reviewed to accompany and provide further insight to existing interview data. Specifically, accommodation plans, school report cards, and absentee records helped establish a more holistic view of the data. Emily's 504 Plan brought to our attention the absence of school documented information, specifically records addressing Emily's incontinence. Coupled with teacher interviews and email exchanges, Emily's 504 Plan documents raised questions about the school's understanding of Emily's medical conditions. Absentee records and report cards were also used to establish a more comprehensive view of Emily's attendance patterns and academic history.

Data Analysis

We individually coded interview transcripts through a variety of analytic lenses that focused on data holistically, emotionally, through actions, and through the "in vivo" language of participants (Saldaña, 2013). We then congregated salient codes into categorical groups and met to discuss coding and grouping decisions and the differences in our responses. Other analysis tasks were distinctively separate; one of us traveled via plane for participant and school data collection visitations and conducted all interviews while the other examined the interview process raising questions about reflexivity and interactions and their impact on data. Links, including prominent chains of evidence across data sources, and noteworthy diverging or contradicting data were examined and discussed collaboratively using interview categorization as foundational reference points. Beyond discussion, visually organizing and displaying data graphically (Merriam, 1998; Miles et al., 2014) helped move corroborating categorical evidence toward thematic development.

Thematic Results

Three themes emerged from the data and were broadly classified as excessive absenteeism, unclear and inconsistent support, and incongruent outward and actual coping with the physical and emotional ramifications of the illness. Multiple sources showed Emily missed an inordinate amount of school on a regular basis. Moreover, there was a lack of understanding by the teachers as to the reasons for those absences. Finally, decision-making as to if Emily should miss school was confounded by the unpredictable nature of Emily's incontinence, fears associated with potential accidents at school, and reported instances of Emily sometimes taking advantage of her condition to avoid school. A second theme centered on the lack of specificity and inconsistent support provided by school personnel. This included the presence, nature, and execution of formal support plans and communication systems at school. The ways Emily and those around her perceived that she handled the implications of her condition at school emerged as a final theme. Inconsistent expectations and actions were reported, further illustrating the complexities imposed by chronic illness on adolescents at school.

There were excessive absences from school which were not always due to the physical implications of Emily's incontinence. Some absences were attributed to fear of accidents at school or even fabricated by the student to avoid attendance. The literature suggests that children with chronic illness miss more school than do their peers without illnesses (Caldwell et al., 1997; Sato et al., 2007; Shapiro et al., 1995; Wodrich & Cunningham, 2008). During initial interviews, Emily and her mother reported that Emily might miss anywhere from 1-3 days of school each week if she was not feeling well. However, during the four months during which attendance data

were collected, there were at least two weeks where Emily missed every day, and no week passed in which she missed fewer than two days of school. Teachers reported absences from school ranging from a couple of days to weeks at a time. All five data sources converged highlighting Emily's absenteeism.

While absenteeism due to chronic illness is well supported in the literature, the degree of absenteeism for Emily was significantly higher than suggested by this literature and was not always reported to be a direct function of her illnesses or incontinence. Many times both Emily and her mother reported absences were based in a feeling that Emily would have an accident that day. Sometimes these feelings were shown to be justified and sometimes they were not. When asked why Emily missed school, her mother stated, "If we don't get a good cleanout...she's having bowel accidents. I'm not gonna send her to school... I've told them when she's home sick, she's not coughing, throwing up, laying in the bed with a fever. She's able to do things. She's just not socially acceptable." When asked about the frequency of accidents leading to absences, both Emily and her mother indicated Emily often misses school when her bowel management routine does not work well and she "knows" she will have accidents that day. Both indicated she rarely had accidents at school now. When asked if she ever thought that Emily stayed home when she really could have gone to school, Emily's mother said, "I think she stays home sometimes erring on the side of caution...I can understand why... I mean, how embarrassing is that gonna be? Trust me, when she has an accident, you know it."

What was not altogether expected was the amount of decision-making power Emily had regarding whether or not to attend or remain at school on any given day. Emily not only stayed home from school when she was having frequent accidents, but also when she *anticipated* having accidents at school. When questioned as to how she knew she was going to have a "bad day," both Emily and her mother indicated that Emily "knew her body" and had come to be able to anticipate that she would have an accident later in the day. The interview with Emily, however, yielded a candid admission that she sometimes used her illness as an excuse to not attend school on certain days when she was in reality physically able to attend. Emily said, "Lordy, did I do it last year...I did not like my classes last year and I did not like getting up early last year, but now I'm used to it." When we followed up with Emily's mother regarding the times that Emily missed school unnecessarily, she said, "She took advantage of it a lot when I was sick last year...I have to wonder if she didn't stay home just because she felt like she needed to take care of everybody. I don't think she does it as much as she did."

In contrast to absences being ascribed to incontinence by both Emily and her mother, her teachers mainly believed her lack of attendance stemmed from her more visible conditions (primarily her amputation). The only teacher that spoke about Emily's incontinence attributed it to the stress of her amputation. "That was another period of a lot of absences where she was just so stressed out she just couldn't control her bladder or control any type of function with it." This misattribution or lack of understanding is evident throughout follow-up email and phone correspondences, and is consistent with literature that suggests the topic of incontinence is not discussed frequently among parents and school personnel (Best, 2005; Lundblad et al., 2010). While both Emily and her mother expressed they were open with school staff about her incontinence, the lack of awareness by teachers expressed in the interviews suggested otherwise.

These absences resulted in Emily missing large amounts of learning time. The impact of this missed time is further discussed in the following section.

We also found an incomplete and inconsistent support and communication system at school which contributed to academic underachievement. Emily was born with multiple, complex health conditions that required the attention and support of both her mother and professionals from birth. During initial interviews, Emily's mother described Emily's elementary school experiences as less than ideal, which contributed to her decision to homeschool Emily midway through fourth grade. According to Emily's mother, despite the elementary school's insistence on having the school nurse provide support to Emily relating to her catheterization and accidents, there was little follow-through. Her mother said, "At that time she was little enough that she needed help to clean up, and the nurses were not cleaning her up. They were letting her walk around school all day [after having an accident]. We were very unhappy with that. That was a big part of the homeschooling decision."

When Emily decided to return to public school as a freshman, her mother and the school once again developed a 504 Plan to outline Emily's support needs. When analyzing plans from Emily's freshman and sophomore years during our data collection process, the accommodations listed were very generic—extended time on assignments, waived physical education requirement, use of the school elevator, and exemption from the attendance policy. There was no mention of physical or mental health-related services or supports (including the services of a school nurse). When asked about this, Emily's mother indicated that Emily was fully self-sufficient in taking care of her needs at school and they did not need the nurse's assistance. Moreover, when asked about Emily's 504 Plan, only one of the three teachers interviewed was confident that she had seen it.

All adults interviewed indicated Emily was on "flexible" or "partial homebound" services. However, when reviewing her educational records, neither 504 Plan (current or previous year) indicated this support. While reportedly intended to support Emily through her frequent absences, the label of "flexible homebound" seemed to cause confusion, as it had never been applied in the past. When asked to define "flexible homebound," Emily's mother and teachers all said that there was a homebound teacher who could go to Emily's house as needed to work with her on assignments when she missed school. One teacher explained, "She had what we call a flexible homebound. It was like when she needed it, she would go on homebound. I think maybe that could have contributed to the confusion. Usually, when a child is given homebound, it's for six months to a year." No one interviewed could provide more specific operating parameters for this service, nor was it outlined in any school records.

Teachers were also unclear as to who was responsible for monitoring Emily's absences and missed assignments, or how to send/receive those missed assignments. These tasks were also not outlined in the 504 Plan, and teachers indicated keeping up with missed assignments was difficult on a day-to-day basis. As one teacher said, "I was so confused...I was told to make a list of—any day she wasn't there, just have a sheet of paper, write down whatever we did that day, that way when she did come I could give her the list. That's what I did. The problem we ran into with Emily was that when she did come to school, I would say, "Well, here's the list of stuff," and she would say, "Well, I'll get it from [the homebound teacher]." There was also a lack of

consistency in the length of time Emily was given to make up missed work. All teachers reported that three days was standard for all students at their school, but that Emily could take longer ranging from a week all the way to the end of the 9-week reporting period.

In addition to the logistical complexities of tracking missed assignments, teachers expressed uncertainty about how much work they should expect Emily to make up when she was absent. Emily did not make up all work in the same manner as the other students, with assignments often shortened or changed. Decisions to shorten, change, or waive the assignment were made on a day-to-day basis by the teacher, not in accordance with a pre-determined plan or schedule. Both teachers of Carnegie unit courses indicated significant concern for the content Emily missed while absent. One teacher said, "I mean there's going to be little things here and there that she's just not going to understand because she missed out on those—even if it's a small lesson, it's going to build on itself eventually."

Emily initially received a failing grade in one course, primarily because of incomplete work resulting from absences. While this teacher initially didn't believe Emily mastered the content needed to pass the course, Emily's passing score on the state-mandated End of Course Assessment helped persuade the teacher to allow Emily to make up work and receive a passing grade. Emily's overall educational progress as documented by her grades and is aligned with literature suggesting that gaps in knowledge can be attributed to absenteeism (Caldwell et al., 1997; Clay, 2004). While Emily passed all other courses, the teachers interviewed all agreed that she did not have the depth of understanding of the course content that other students had. They indicated that because she was absent so much, they changed and reduced the content significantly, perhaps altering the fundamental nature of the courses. This discrepancy in what the teachers felt Emily mastered as compared to what other students mastered was not clearly communicated to Emily or her mother, both of whom felt she had mastered the content based on her grades on her report cards. As there was no other way to convey progress or lack thereof, this is an understandable assumption on the part of Emily and her mother.

Emily's mother and teachers universally agreed that home-school communication was highly inconsistent, when present at all. Efforts to consistently provide needed accommodations and to hold Emily accountable for academic tasks were not sufficient. While there was a meeting at the beginning of each school year to develop a written 504 Plan, these plans did not outline communication strategies that would be used. In fact, Emily's mother only reported meeting with teachers during Open House other than during the 504 Plan meeting at the beginning of the year. While Emily's mother indicated she could call or email teachers when needed, this was only reported being done very late in the year after it was impossible to remediate problems. In hindsight, the teacher of the course Emily initially failed the previous year remarked on the lack of a systematic, clear approach for dealing with Emily's absences, and subsequently, her missed content. "I feel like we could've come up with a game plan because her mother is very nice and she's very dedicated to Emily's education...I really just feel like communication in the beginning would have solved all those problems." While teachers expressed great concern about missed content, Emily and her mother seemed less concerned. Both indicated that teachers let Emily know what was missed and she turned in most makeup work as assigned. Likewise, both Emily and her mother seemed to believe that Emily's absenteeism did not negatively impact her

educationally, as her grades were adequate for the most part. The only time in which they were dissatisfied with her grades was when her final report card indicated a course failed for the year. Finally, the outward persona presented by Emily often led to inaccurate assumptions by school personnel and sometimes her mother regarding her ability to cope with her condition.

Throughout the interviews, there were incongruent perceptions of Emily's ability to cope with her illness. On the one hand, all interviewed (including Emily) shared on more than one occasion that she appeared to handle her illness remarkably well. However, some stories shared seemed to suggest otherwise, such as instances where Emily cried about her condition or her peers' reactions to her. Her mother reported concern for Emily after she disclosed she had been cutting herself, which prompted her mother to secure psychological counseling for Emily. Both through the interviews themselves and the reports of all interviewed, Emily portrayed confidence and positive coping strategies outwardly. However, when probed, she admitted keeping much to herself or only sharing with her friends made through a summer program for children with incontinence. The idea of being "normal" was also reported by multiple participants.

While all teachers interviewed stressed how much Emily has had to endure regarding her illness, they did not seem to have a deep understanding of the academic and emotional implications of her illness, particularly her incontinence. Teachers suggested Emily's persona at school was one of outward confidence. One teacher said, "[Emily] doesn't have that self-consciousness that most teenagers have, which is kind of surprising. She really has exceeded what I probably would've expected from a kid with the extent of disability that she seems to have. She hides it and just doesn't seem bothered by it." When asked why she was surprised, her teacher responded, "I would think for most kids if you're out of school half the time, socially you would feel out of place... Those kinds of just self-conscious issues that most kids have, even without any kind of a disability. She just doesn't seem to have that." Later in an email, the same teacher said that Emily "seems to have pretty strong self-esteem. To me, she does not seem self-conscious about her physical disability, and she seems determined to do everything that everyone else can do."

Emily's mother reinforced a positive attitude and repeated what she told Emily in an interview, "You have nothing to be ashamed of. There is not a single thing wrong with you that you need to be ashamed of. You're different. So what? Everybody's different somehow." Emily's mother stated repeatedly that Emily handled her condition (including incontinence) and its ramifications just fine. When asked about her current feelings, Emily's mother spoke primarily about Emily's amputation, not her incontinence. She said, "This thing with her leg has been the most bizarre experience for me.... She's like, 'People stare at me.' I'm like, 'You don't think they stare at you? Well, you have no leg.' ... Of course, there are kids who stare at her. Well, what are you gonna do? I can't make everybody stop staring. I have to wonder, too, if it's more of a she perceives more stares than she actually gets. You know how it is."

Emily also spoke of calling attention to herself at school because of her time spent catheterizing herself via her Mitrofanoff for her urinary incontinence, "All the kids are like, 'Oh, why do you go to the office?' I did last year... I'm like, wait, wait, wait. Last year I drew attention to myself while walking to the office when I could've just gone to the bathroom like a normal person. 'Emily, you're an idiot.' This year I'm goin' to the bathroom like normal." This issue of normalcy was pervasive throughout the interview data, and marked in many ways an outward portrayal of resilience by Emily regarding her illness. Regarding a boyfriend, Emily shared, "We started

going out. Then one day he asked me out of the blue, ‘When will you be normal?’ That made me mad. That made Maria [her best friend] mad. She kind of cussed him out a little bit. It was all kinds of drama and I just said, ‘I’m done. Done. Done. Done.’ So I broke up with him and I’m actually really happy about that. When I say really happy about that, I mean—and he’ll still send me text messages saying, ‘You look so beautiful.’ I’m like, ‘Stop it.’”

Overall, remarks made by Emily, her mother and her teachers, along with our research interactions with Emily, she maintained an outward identity ostensibly different from the literature that linked anxiety, depression, and emotional distress with chronic illness and, particularly, incontinence (Baker-Towell & Towell, 2003; Funakosi et al., 2005; Luscombe, 2000; Mills, 2007; Mukherjee et al., 2007; Stjernqvist & Kockum, 1999; Yi et al., 2009). Emily even minimized statements of self-consciousness, downplaying that version of self after expressing “I can be myself at Rally [a camp for adolescents with bowel and/or bladder incontinence], like completely myself. I can do that at school, just not—it’s kind of the censored version of myself, if that makes any sense at all.” When asked, “What do you censor at school that you don’t censor at Rally?,” Emily replied, “That wasn’t the right word....I basically am myself at Rally and at school except they don’t have the medical problems. That’s about it.”

When interviewing Emily’s mother as to if Emily ever mentioned anything about feeling different, Emily’s mother responded with a statement which began very positively, but then gave a disturbing description of behavior in conflict with previous statements. She said, “I think she’s well adjusted. I think she’s pretty happy. Obviously, there are some self-esteem issues. She’s just started on an antidepressant. We had some cutting going on. It’s hard enough to be a teenage girl; it’s super hard to be a teenage girl with medical issues.” When probed about the self-mutilation, Emily’s mother stated that a summer camp for teenagers with incontinence allowed Emily to explore those feelings with others who could empathize. Her mother recognized this was something for which they needed professional help and immediately began taking Emily to see a counselor. While the disclosure spoke to Emily’s bond with her mother, along with the supportive environments of Rally and summer camps in which Emily could be herself completely, the self-destructive behavior starkly contrasts the façade Emily, her mother, and her teachers portrayed. The somewhat dismissive way information regarding Emily’s need for professional counseling prompted a deeper examination into issues seemingly glossed in previous interviews.

Discussion

The three prominent themes presented are interwoven and raise questions about absenteeism as a potential indicator that speaks to the need for school support structures that address students with medical complexities through a more holistic lens. When the illness manifests in sensitive and potentially stigmatizing ways, finding the appropriate support is complicated, evidenced in Emily’s and her mother’s comments that school nurse care was unneeded. How to appropriately respond to Emily’s absenteeism seems to be a central issue, as meeting the needs of students with chronic illness at school is in and of itself a difficult task complicated by the incredible variation in the needs of students with complex medical challenges.

The fact that Emily missed school was not an unexpected finding, but the frequency of those absences as well as the amount of decision-making power Emily had regarding school attendance was somewhat unexpected. When probed as to the underlying rationale for erring on the side of caution when deciding whether or not to attend school, both Emily and her mother expressed fear of the social and emotional ramifications of having an accident at school. This aligns with data from previous studies suggesting parents tend to be overly cautious in cases where the potential for their child to experience embarrassment exists (Boyt, 2005; Gray et al., 2006; Lundblad et al., 2010; Weaver & Dobson, 2008; Williams et al., 1996). As adolescents mature, they become both more private about and more responsible for their physical health. During adolescence, it is often difficult for parents to ascertain if they should be pushed to attend school or if the adolescent's judgment regarding attendance should be honored. Emily's reported experiences further validate what has been reported about school attendance and incontinence—it is frequently difficult for parents and children to differentiate between physiological symptoms of incontinence and anxiety. As the physical symptoms are often similar (i.e., stomach discomfort), the process of discerning whether school attendance is a wise choice, or even a feasible one is made more challenging (Wheaton, Berman, Franklin, & Abramowitz, 2010). The admission that Emily sometimes was untruthful about her ability to attend school confounds the issue of school attendance. Parents must not only contend with the physical and social implications of accidents, and the fears relating to accidents, but also the real lure of skipping a day of school using incontinence as an excuse. These complicated, and often unobservable underlying factors made it difficult for Emily, her mother, and her teachers to determine how much Emily could realistically be expected to attend school. It also made attending to the barriers to attendance difficult, with potential causes being physical, emotional, or a combination of both.

Warranted or not, Emily's excessive absences from school had educational ramifications. The lack of a viable educational support plan and specific plans for frequent home-school communication resulted in what everyone agreed to be academic underachievement for Emily. There is much support in the literature (both professional guidelines and research) for formal supports at school (American School Health Association, 2002; Best, 2005; Clay, 2004; Filce & LaVergne, 2011; National Association of School Nurses, 2013; Shapiro et al., 1995) as these children are at risk for underachievement (Best, 2005; Clay, 2004; Wodrich & Cunningham, 2008). The lack of awareness of Emily's 504 Plan, the low level of individualization in this plan, the ambiguity of processes and responsibilities, and an overall absence of regular communication all contributed to Emily's lackluster performance at school. This manifested in mediocre and sometimes failing grades, drastically altered academic requirements which may or may not ensure adequate content preparation, and her teachers' professional judgment that overall her academic experiences are compromised by inevitable gaps in knowledge from absences.

When communication between school and home is inadequate, a similar question becomes apparent. How do schools address and adhere to written accommodation plans that are not specific enough for the unique needs of students with medical complexities? This question is further confounded when, as in Emily's case, teachers indicated lack of knowledge about her incontinence and its relationship to her absenteeism. While this was conveyed during the 504 planning meeting, a lack of working knowledge of this document by most teachers minimized the critical need for communication and support at school. The assumption that teachers were

aware of her conditions and needs on the part of Emily's mother, based on the 504 planning meeting, coupled with the need for privacy as to the day to day realities of incontinence, seemed to minimize the need for support. In Emily's case, a breakdown at all school levels seemed evident, noticeable both by the lack of an individualized, comprehensive 504 Plan document and further by the report that only one teacher had even viewed it.

The image presented to others as a strong, well-adjusted adolescent is problematic on several levels. Despite Emily's insistence that she did not need assistance at school from school health professionals, the probability that her condition and associated anxiety necessitated such frequent absences presented somewhat of a conundrum. It was surprising that there was no mention of collaborative working relationships with school health professionals, even if only in monitoring roles, in Emily's daily life. While this seemed to be Emily's preference, the self-reported evidence of her astute ability to maneuver around attendance policies coupled with her history of self-mutilation seemed to suggest otherwise.

Limitations

A single-case study is limited in its ability to produce generalizable findings. The exploratory and descriptive nature of this case study focused on generating detailed descriptions of one student's experiences, and to better understand complexities of chronic illness not easily measureable quantitatively. Likewise, the experiences of our research team, specifically a member whose experiences paralleled our case study, challenged the research team to systematically address potential subjectivity and scrutinize the relational intimacy formed between interviewer and interviewee.

Conclusions and Implications

A single-case study is primarily exploratory and descriptive in nature, and not intended to discover causal relationships among data generated. However, we believe our findings highlight provocative questions, often philosophical, but with potential to challenge beliefs and practice. When a student has complex medical needs, yet does not qualify for special education services, how is responsibility for deciding appropriate health care in school settings determined? How do schools ensure an adequate exploration of the individual needs is conducted, and an appropriate support plan is developed and monitored for effectiveness? How do schools, health care professionals, and families address communication challenges unique to medical conditions with potential stigma? In light of these uncertainties, we find the questions underlying policy and procedural decisions to be of critical importance for all stakeholders.

School counseling services should be actively involved on teams for all students with chronic illness, even when the students appear outwardly to be handling their condition well. Emily's case is illustrative, as literature shows increased anxiety and depression in children with chronic illness, including those with incontinence. Similar to school nurses, school counselors often have large caseloads. They also may not have extensive training in providing the type of emotional support needed by this population. However, with an awareness that many children with chronic illness have clinically significant anxiety, school mental health professionals can assist in daily

monitoring of the student's overall social/emotional wellbeing and make referrals for additional assistance when needed.

Educators must ensure that educational plans are *individualized*, as is required by federal mandates. Students with rare and stigmatizing conditions cannot be adequately served with cookie cutter support plans. They require more frequent monitoring of progress and communication among the student, family, and professionals. When a student misses school as frequently as Emily, more in depth measures should be taken including services such as more extensive homebound services, compensatory schooling in the summer, or the use of virtual schooling in tandem with the regular school year. The proliferation of online programs, particularly for high school, makes this a more accessible option than ever before.

All of these suggestions, however, require coordination. Many schools struggle to provide coordination for students with 504 Plans, as there are no additional funds to support case management for this population. Accommodations provided through Section 504 are the fiscal responsibility of local educational agencies, often causing a burden to rural and underfunded schools. Furthermore, even in states with funding for school nurses and other health professionals, those funds are often woefully inadequate to provide the level of individualized care for students with chronic illness at school.

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Article

THERE'S NO PLACE LIKE HOME: TRAINING, PRACTICES, AND PERCEPTIONS OF HOMEBOUND SERVICES

Constance C. Petit

California State University, Bakersfield

Philip P. Patterson

University of Alaska, Fairbanks

Abstract: Homebound services involve the delivery of special education in settings other than school sites. Such settings typically include students' homes or hospitals. Most often associated with early childhood special education and with students who are medically or physically fragile, homebound services can also be for those in need of interim alternative educational settings (IAES). Although homebound services have been available to some students with disabilities for more than 50 years, little research exists on that delivery model. This study investigated the training, practices and perceptions of service providers who work in homebound settings. Data from a self-administered survey of a national sample were analyzed. Key findings included: a widespread lack of training for professionals who delivered homebound services; an absence of school district or agency policies or procedure concerning the delivery of such services; and statistically significantly higher perceptions of self-efficacy by those who did receive training.

Keywords: *homebound instruction; home/hospital; home-based intervention; IAES*

Introduction

There are more than 6.5 million students in the United States who receive special education services. A small percentage of those students (2.2%) receive services in settings other than on public school campuses (Data Accountability Center [DAC], 2012). One optional delivery method to receive services is through homebound instruction. Not to be confused with homeschooling where parents assume the responsibility for the instruction of their children, homebound instruction can be described as publically supported special education services generally provided on a case-by-case basis, in a setting other than on a school site (Petit, 2013). While this service delivery model most often occurs in a student's home, it can additionally take place in a hospital setting or at a neutral location such as a public library (Patterson & Petit, 2008; Patterson & Tullis, 2007). Homebound services can also be referred to as *home/hospital services*, *home visits*, or *home-based intervention*.

Although homebound instruction has been a recognized alternative education approach since the 1950s (Florida State Department of Education, 1983), it has not been a frequent topic of K-12 special educational research (Petit, 2013). When mentioned in the literature, it often is on a peripheral rather than a primary basis (Searle, Askins, & Bleyer, 2003; Shaw, Glasner, Stern, Sferdensch, & McCabe, 2010; Shaw & McCabe, 2008). One exception to this phenomenon is in the field of Early Childhood Special Education, where homebound services are more readily addressed (Cook, Sparks, Rosetti, & Osselaer, 2008; Keilty, 2008; Prior & Gerard, 2007). Another exception includes the treatment of chronically ill children who are more commonly provided with homebound instruction (Clay, Cortina, Harper, Cocco, & Drotar, 2004; Hamlet, Gergar, & Schaefer, 2011; *Journal of School Health*, 2003; Shaw & McCabe, 2008). There are many unknown factors related to the provision of homebound services, especially on a national scale. Such factors include accurate data on the frequency of homebound services, populations receiving such services, the availability of training and direction for administering homebound services, and the perceptions of personal and pedagogical effectiveness experienced by the service providers. Furthermore, the absence or lack of research and literature in the field may well extend to other written documents. Hamlet et al. (2011) speculated that even guidelines and written policies governing homebound instruction are not always available to service providers and administrators.

One critical consideration of educating students with special needs should be identifying improvements in the delivery of instruction and related services. Homebound services are legally recognized placement alternatives; they are identified on the continuum of service options, which are addressed within the Individuals with Disabilities Education Improvement Act (IDEIA) of 2004 (U.S. Department of Education, 2013). An absence of research or guidelines addressing a service delivery approach does not excuse a lack of quality or effectiveness as a special education function. Neglecting the delivery approach or using a substandard service model not only jeopardizes students' learning, but could also result in litigation (Patterson & Petit, 2008).

The Context of Homebound Instruction

Homebound instruction can be a traditional alternative placement option to on-campus services (DAC, 2012; Special Education & Rehabilitative Services, 2007). It is often associated with early childhood special education and with students who are physically or medically fragile (Cook et al., 2008; *Journal of School Health*, 2003). It can also be an *interim alternative education setting* (IAES; Telzrow, 2001). IAESs are temporary placements (not exceeding 45 days), which allow students to receive educational services outside of their intended placements. Typically, such placements are for students in special education who are demonstrating major behavioral problems including drug or weapon possession, or for those exhibiting serious injurious behavior. Besides homebound settings, Bear, Quinn, and Burkholder (2001) list IAES as “schools within-a-school, intervention resource rooms, in-school suspension rooms, alternative classrooms, [and] mental health treatment facilities” (p. 7). These settings enable local education agencies (LEAs) to conduct further assessment, protecting the safety of all students, while still providing educational services (U.S. Department of Education, 2013).

The provision of homebound services to students with disabilities is determined by multidisciplinary teams and documented in Individual Education Programs (IEP) or Individual Family Service Plans (IFSP). The LEA is then responsible for providing appropriate instruction and related services that meet the legal requirements for the use of educational settings (Etscheidt, 2006). In selecting homebound services as a delivery method, IEP and IFSP team members should consider the restrictive nature of homebound services. Because of the potential for limited interaction with peers, homebound instruction is often seen as one of the most restrictive educational settings (Patterson & Tullis, 2007). Another consideration is the assurance that students receiving homebound services have access to the general education curriculum (Bradley, 2007).

The designation of homebound services is a decision of IEP or IFSP teams. The nature and impact of the student’s disability may affect the amount of time for which homebound instruction is provided. The extent of homebound instruction appears to fall in one of three categories: short-term (American Academy of Pediatrics, 2000; Bradley, 2007; Macciomei & Ruben, 1989), transition or interim (Etscheidt, 2006; Searle et al., 2003; Shaw & McCabe, 2008; Telzrow, 2001) and long-term (American Academy of Pediatrics, 2000; Boreson, 1994; Scarborough et al., 2004; Shaw & McCabe, 2008). Depending upon the needs of individual students, services could include academic instruction, speech and language therapy, physical therapy, and occupational therapy. Homebound services are not limited to those provided by special education teachers but could also include related services (Patterson & Petit, 2006).

Determining actual services related to homebound instruction can be difficult to interpret when examining data. According to the *Digest of Educational Statistics* (National Center for Educational Statistics, 2012) approximately ½ of 1% of students, ages 6 to 21, with categorical disabilities received homebound instruction from 1989 through 2010. If accurate, this statistic indicates that homebound services are relatively uncommon. Data on specific student disability populations who received homebound services is available for years 2008 to 2010. Those disability groups receiving homebound instruction at rates equal to or greater than 1% of the total special education student population included students with emotional disturbances, orthopedic

impairments, other health impairments, deaf-blindness, multiple disabilities, and traumatic brain injury (National Center for Educational Statistics, 2012).

While the general policies and procedures of special education are determined by legislation, Lustig (2009) reported that there is a lack of “explicit federal statutory or regulatory guidelines on the appropriate use of homebound placements” (p. 5). Therefore states follow available federal regulations when establishing special education practices but also utilize a degree of autonomy for program development centered on their specific populations and needs. When not implicitly decreed by a state, districts may rely on their own interpretations for delivery, while in some instances, the courts interpret the guidelines. This individuality in developing specific policies and practices (or not) may be a factor in procedural variations and conflicts between different states and school districts (Lustig, 2009). The lack of explicit guidelines creates the potential for a wide range of conflicting placement and delivery practices. This is especially problematic in the field of special education where legal challenges abound. Katsiyannis, Yell, and Bradley (2001) indicated that, “perhaps no other area of educational law...has been more highly litigated than the education of students with disabilities” (p. 326).

One potential area of variation is within the rate, frequency, and duration of homebound services, however, this has not been nationally studied. The North Carolina Association for the Education of Chronically Ill Children (NCAECIC; 2009) polled southern states and determined that weekly instruction was frequently the requirement, but there was a wide range in the number of weekly instructional hours provided. Responses from Florida, Louisiana, South Carolina and Virginia suggested that four to ten instructional hours per week were determined by the grade level of the student.

Individual state’s guidelines should indicate the appropriate type of certification required to provide homebound instruction (Lustig, 2009). The majority of service providers are teachers but speech and language pathologists, paraprofessionals, and physical or occupational therapists can provide services (Patterson & Petit, 2006). However, service providers may inadvertently be underprepared to deliver homebound instruction. LEAs, who generally determine how educators are chosen to provide homebound instruction, may base their decisions on seniority, economy, or other factors rather than levels of preparation or competence (Patterson & Petit, 2008). “Once selected, service providers may have little direction with regards to delivering or documenting instruction, collecting appropriate data and collaborating with the classroom teacher or parents” (Petit, 2013, p.4).

There is a potential that the use of homebound instruction could increase as a result of provisions within the reauthorization of IDEIA in 2004. In the latest version of this federal law, criteria for placing students in IAESs were expanded. Even before this reauthorization, Katsiyannis and Smith (2003) noted an apparent increase in the use of IAES. With the expanded criteria of IDEIA 2004 comes the potential increase in use, however, the practices concerning homebound instruction may not have experienced a change or improvement in the way they are delivered. One example includes site or program administrators who may be unfamiliar with the practices associated with IAES (Telzrow, 2001) and may therefore be ill prepared to supervise or evaluate the delivery of homebound services.

Purpose of the Study

The purpose of this study was to examine several aspects of homebound instruction with specific regard to those who provide such instruction and their perceptions of this service model. The frequency, rate, and format of services along with an examination into the levels of preparation and training service providers possessed when delivering homebound instruction was conducted. The perceptions service providers held regarding the delivery model of homebound instruction for students with disabilities were investigated, and finally, the perceived effectiveness of this model by service providers who deliver homebound instruction was gauged.

Methods

The design of this research study was quantitative using a self-administered survey dispensed to a national sample of potential homebound service providers. The survey was created as a one-time data collection instrument. It was distributed in two formats: hard-copy and electronic.

Participants

The survey was constructed to collect data from educators and/or specialists who had provided or were currently providing educational support to students with disabilities in a homebound instructional setting. Members from two national professional organizations were selected as potential participants based on their probability of providing homebound instruction. The Division of Physical, Health and Multiple Disabilities, a subset of the Council for Exceptional Children (CEC), was the largest group with 400 members at the time of this research. The mailing list was procured following the guidelines from CEC. These members and potential respondents received the research survey in the mail. At the time of this study, CEC's protocol did not allow for the use of email addresses of its members.

The second professional organization used for this study was the Association for the Education of Children with Medical Needs (AECMN). This group of 84 members strives to support service providers of homebound instruction to students who have medical needs. These members received the survey electronically via email using the organization's protocol for the use of member contact.

Instrumentation

Data collection was accomplished using a survey constructed to examine the common practices associated with homebound instruction sessions such as frequency and duration, along with the attitudes and perceptions of service providers. The survey investigated the training or preparation service providers received and asked participants to indicate the types of degrees, certifications, or licenses as well as the number of years of experience they possessed. Categorical scales were used to evaluate these types of responses while summated rating scales were used for the examination of perceptions and attitudes (Johnson & Christensen, 2008).

The printed version of the survey followed a booklet format using both sides of legal-sized paper which reduced the appearance of size with the intent of producing higher response rates

(Krathwohl, 2009). Related topics were grouped (Dillman, Smyth, & Christian, 2009) using headings in both the printed and electronic versions (Krathwohl, 2009). The rating scale sections included five possible participant responses ranging from Strongly Disagree to Strongly Agree. The electronic version was constructed using SurveyMonkey; participants received an email with weblink access to the survey.

Validity and reliability of the survey was established using a combination of safeguards. The survey in draft form was reviewed by university colleagues familiar with homebound instruction and survey design. Revisions were made based on feedback and suggestions. Next, an expert panel of special educators with a combination of 30 years of experience was interviewed after completing the survey. Additional revisions were incorporated based on their recommendations. Finally, individual prompts in the survey were tested for reliability or consistency using Chronbach's alpha.

Data Collection

The approach for data collection followed the suggested practices standard to the use of a survey as a research instrument. Participants initially received a pre-notice postcard or email message (Dillman et al., 2009). A cover letter detailing the research purpose accompanied the self-administered questionnaires (Krathwohl, 2009) which were delivered one week after the pre-notice and included a stamped, self-addressed return envelope. Two weeks later, a reminder notice was sent to the participant pool. Those who received the mailed version of the survey also received a small monetary incentive (\$1.00).

The overall returned response rate for the 400 mailed surveys was 45% while the overall returned response rate for the 84 electronic versions was 46.4%. The sum of useable surveys collected by both methods was 192. These 192 respondents provided information on several key components of the research such as preparation to deliver homebound services and the availability of guidelines for delivering homebound instruction but not all of the 192 respondents were homebound service providers. Of that sum, 92 indicated that they were service providers for homebound instruction. There were 22 surveys returned as undeliverable which accounted for an additional 5.5% of the 400 mailed surveys.

Results

Data analysis was accomplished using descriptive and inferential statistics. Frequency tables represented the descriptive portion. An independent *t*-test was conducted to test the hypothesis regarding a statistically significant difference of the perceptions associated with model and personal effectiveness while multivariate analysis of variance (MANOVA) was used to analyze the inferential statistics examining the extent, if any, of differences of the individual constructs of model effectiveness and personal effectiveness.

Demographic Information of Sample

The majority of the respondents were female ($n = 173$) between the ages of 50 and 59 ($n = 46$) who resided in the South ($n = 58$) and had between 6 and 15 years of teaching experience ($n =$

51). Most were special educators ($n = 88$) but a significant group indicated they possessed both general and special education certification ($n = 59$). A smaller group of specialists and related service providers ($n = 12$) participated as well. Large school districts were the most represented by the respondents ($n = 56$). Refer to Table 1 for complete demographic characteristics of participants.

Table 1

Demographic Characteristics of Participants

Characteristic	All Respondents ($n = 192$)		Service Providers ($n = 92$)	
	<i>n</i>	%	<i>n</i>	%
Gender				
Male	18	9.4	7	7.6
Female	173	90.1	85	92.4
Age (years)				
25-29	17	8.8	6	6.5
30-39	32	16.7	18	19.6
40-49	42	21.9	23	25.0
50-59	46	24.0	21	22.8
60+	36	18.7	14	15.2
Geographic location of residence				
Northeast	43	22.4	27	29.3
South	58	30.2	30	32.6
Midwest	47	24.5	16	17.4
West	41	21.4	18	19.6
Credential, certification, degree, or licensure				
RN/LVN	1	0.5	1	1.1
Early childhood (special ed)	14	7.3	4	4.3
Special education	88	45.8	45	48.9
General education	12	6.3	8	8.7
Both special & general education	59	30.7	29	31.5
Administrative	6	3.1	2	2.2
Specialist	12	6.3	3	3.3
Teaching experience (years)				
0-5	37	19.3	15	16.3
6-15	51	26.6	25	27.2
16-25	44	22.9	24	26.1
26-35	42	21.9	21	22.8
36+	11	5.7	5	5.4
School district or service area student enrollment				
1-1,500	36	21.3	21	26.6
1,501-3,000	17	10.1	9	11.4
3,001-5,000	22	13.0	8	10.1
5,001-10,000	14	8.3	9	11.4
10,001-15,000	10	5.9	4	5.1
15,001-20,000	14	8.3	5	6.3
20,001+	56	33.1	23	29.1

Note. Specialist refers to those who may be psychologists, speech and language pathologists, etc.

The Status of Training to Provide Homebound Instruction

Survey respondents were asked to specify whether they had received training, and if so, where the training occurred. The possible responses were: (a) a teacher preparation or certification program, (b) a school district or agency, or (c) a conference or workshop. Of the service provider responses, 19.8% ($n = 18$) indicated they received training in a preparation or certification program; 25% ($n = 23$) reported receiving training from a school district or agency; and 18.5% ($n = 17$) received training at a conference or workshop. The majority of service providers (75% - 80%) had not received training for delivering homebound instruction. Table 2 demonstrates the compilation of data. Six service providers indicated they received training from two sources.

Table 2

Homebound Instruction Service Provider Training

Training opportunity type	All Participants ($n = 189$)			Service Providers ($n = 91$)		
	No	Yes	% Yes	No	Yes	% Yes
Preparation/certification program	156	33	17.2	73	18	19.8
School district/agency	155	33	17.2	68	23	25.0
Conference/workshop	157	32	16.7	74	17	18.5

The survey also asked participants to report whether their agency or school district possessed resource materials such as guidelines, manuals, or handbooks pertaining to the delivery of homebound instruction. The majority of service providers (66.7%) indicated their agencies or districts did not have these resources.

Reported Services of Homebound Instruction

Using survey responses, data were collected on the standard services and practices associated with homebound instruction. The most frequently reported settings for instruction outside of a K-12 classroom were in the home (54.3%) or a hospital (22.8%). Reported caseloads ranged from one student per week (52.6%) to five or more per week (26.3%). Instructional sessions occurred most frequently twice per week (33.3%) for a period of 60 to 89 minutes each (43%). Survey participants reported the most frequent duration of service periods exceeded 16 weeks (32.1%). Responses pertaining to the instructional setting, frequency, rate, and duration are represented in Table 3.

Table 3

Setting, Frequency, Rate, and Duration of Typical Services

Instructional variables	<i>n</i>	%
Location of instruction (<i>n</i> = 92)		
Student home	50	54.3
Hospital	21	22.8
Both student home and hospital	13	14.1
Community facility	4	4.3
Public facility	2	2.2
Other	2	2.2
Number of students instructed per week (<i>n</i> = 76)		
1	40	52.6
2	9	11.8
3	4	5.3
4	3	3.9
5+	20	26.3
Number of visits per student per week (<i>n</i> = 75)		
1	5	6.7
2	25	33.3
3	23	30.7
4	7	9.3
5	15	20.0
Instructional minutes per student per week (<i>n</i> = 79)		
<30	1	1.3
30-59	26	32.9
60-89	34	43.0
90-119	7	8.9
120-179	6	7.6
>180	5	6.3
Duration of services in weeks (<i>n</i> = 78)		
1-3	12	15.4
4-6	14	17.9
7-10	18	23.1
11-15	9	11.5
16+	25	32.1

Determinants for Homebound Instruction

Determining the reasons students receive homebound instruction was another focus of this study. Surveys included possible reasons for homebound services and respondents were asked to designate the three most frequent reasons. Possible choices were: (a) serious or chronic illness; (b) short-term medical conditions such as illness or injury; (c) suspension; (d) expulsion; (e) waiting for alternative placements; (f) discipline for such violations as violence, bringing

weapons to school, or drug possession; (g) behavior/mental health attributed to such conditions as a phobia or depression; and (h) being a pregnant minor. Respondents were also able to write in reasons not listed. In summary, medically-related causes were clearly the most frequent reasons accounting for the top two responses: serious or chronic illness (44.6%); short-term medical condition (31.5%); and discipline violation (7.6%).

Service Providers Perceptions of Effectiveness

Statements in the survey measured service providers' perceptions of the effectiveness of homebound instruction as a service model and their perceptions of their personal effectiveness when delivering homebound instruction. Seven prompts measured service model effectiveness and six prompts measured personal effectiveness. Chronbach's alpha was used to measure internal consistency indicating satisfactory results for model effectiveness ($\alpha = .74$) and good results for personal effectiveness ($\alpha = .85$).

To establish whether there were significant differences in these variables between those who were trained and those who were not trained, an independent *t*-test was conducted. For *model effectiveness*, Levene's test for equality of variance showed no significant difference between the two groups ($F = .51, p = .48$). Assuming equal variances, this independent test did not reach statistical significance, $t(86) = -1.98, p > .05$, however there was a medium effect size ($d = .43$) with a marginally significant difference between those trained ($M = 22.93, SD = 4.82$) and those not trained ($M = 20.72, SD = 5.58$). For *personal effectiveness*, Levene's test showed no significant difference between the two groups ($F = .76, p = .39$). Assuming equal variances, this independent test reached statistical significance, $t(86) = -2.73, p < .01$, and a medium effect size ($d = .59$). The results of the *t*-test indicated there was a significant difference on perceptions of personal effectiveness between those trained ($M = 26.02, SD = 3.55$) and those not trained ($M = 23.52, SD = 4.88$) but there were no significant statistical differences in the perceptions of model effectiveness (Table 4).

Multivariate analysis of variance (MANOVA) was used to examine the differences in the individual prompts for model effectiveness and personal effectiveness. For model effectiveness,

Table 4

Difference of Perceived Effectiveness between Not Trained and Trained Service Providers

Variables	<i>M</i>	<i>SD</i>	<i>t</i>	<i>p</i>
Service model effectiveness				
Not trained ($n = 46$)	20.72	5.58	-1.98	0.05
Trained ($n = 42$)	22.93	4.82		
Personal effectiveness				
Not trained ($n = 46$)	23.52	4.88	-2.73	0.01
Trained ($n = 42$)	26.02	3.55		

there were no significant group differences amongst the prompts based on training or no training (Wilks' $\lambda = .92$, $F(7, 77) = .91$, $p > .05$, multivariate $\eta^2 = .08$), however for personal effectiveness, two of the prompts resulted in significant differences between trained and not trained service providers (Pillai's $T = .20$, $F(6, 79) = 3.32$, $p < .01$, multivariate $\eta^2 = .20$). Pillai's Trace was used because the assumption for equal variances was violated for homogeneity of variance using Box's Test when evaluating *personal effectiveness* (Box's $M = 62.38$, $F(21, 25468) = 2.74$, $p < .001$). A medium effect size (partial $\eta^2 = .07$) for the statement "I believe that I am effective when instructing homebound students" for those trained to provide homebound ($M = 4.54$, $SD = .55$) and for those not trained ($M = 4.16$, $SD = .85$) was indicated, while a large effect size (partial $\eta^2 = .18$) for the statement "I believe I have been adequately trained to provide quality instruction," for those trained ($M = 4.15$, $SD = .94$) and not trained ($M = 3.09$, $SD = 1.31$) resulted. In other words, those who had received training reported higher perceptions of personal effectiveness (Tables 5 and 6).

Table 5

Mean Scores and Standard Deviations for Measures of Perceptions of Personal Effectiveness based on Not Trained and Trained

Group	I believe I am qualified		I believe I am effective		I believe I have adequate training		I provide a positive experience for students		I feel personal satisfaction		My efforts to provide quality are successful	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Not trained	4.00	1.09	4.16	0.85	3.09	1.31	4.40	0.69	4.11	1.03	4.09	0.95
Trained	4.39	0.74	4.54	0.55	4.15	0.94	4.49	0.67	4.32	0.76	4.24	0.83

Table 6

Post-hoc Univariate Analyses of Trained Service Providers Personal Effectiveness Perceptions

Source	<i>F</i>	<i>p</i>	η^2
I believe I am qualified	3.72	.057	.042
I believe I am effective	5.93	.017	.066
I believe I have adequate training	18.19	.000	.178
I provide a positive experience for students	0.36	.552	.004
I feel personal satisfaction	1.10	.297	.013
My efforts to provide quality are successful	0.64	.424	.008

Discussion and Recommendations

The provision of homebound services to students with disabilities is not a new practice; it dates back at least 50 years (Florida State Department of Education, 1983). Surprisingly, there is a paucity of information regarding the incidence of homebound services, trends in populations receiving such services, the training for its implementation, documented policies and procedures pertinent to homebound services, and the satisfaction related to such services. This study explored these variables.

Several implications and concerns became apparent during the review of available literature and the analysis of data from this study. One major concern was the availability of accurate incidence statistics concerning the placement of students with disabilities in homebound settings. Although the National Center for Educational Statistics (NCES; 2012) maintains an annual database of student placements, their statistics represent a snapshot during a finite period of time and as such do not reflect the potential for multiple placements throughout a given school year. This practice is particularly troubling since homebound instruction, as indicated in this study is typically short-term rather than for an entire school year. Hence, the data from the NCES may not accurately represent the number of students who were serviced in homebound settings at some time during an annual report period. The practice of only identifying single placements at the time of data collection would be akin to measuring the rainfall for one week out of the year and using that information to represent the rainfall for the entire year. Not having accurate statistical data impacts perceptions of practitioners and policymakers concerning the prevalence of homebound services, populations receiving such services, as well as possible use and misuse of this placement option. The likely perception of homebound services being seldom utilized may marginalize their important functions.

Due to the expanded definition of *interim alternative educational settings*, there has been some concern regarding the inappropriate use of homebound services (Etscheidt, 2006; Lustig, 2009). The respondents to this study indicated that the primary reason their students received homebound instruction was because of medical issues such as serious, chronic, or short-term illness. These medically related reasons were indicated by almost 70% of the respondents. This is in keeping with estimations by the *Journal of School Health* (2003), which speculated that 10-15% of all school age children experience chronic illness and that a portion of these students with chronic illness would require homebound instruction. In addition to medically related reasons, respondents were able to specify whether homebound instruction was used as a consequence of suspension, expulsion, or for other behaviorally related issues (e.g., school phobia, violence, drugs). The data collected from this study demonstrated a relatively low use of homebound instruction for behavior or disciplinary related reasons. This is in contrast to concerns expressed by Etscheidt (2006) and Lustig (2009) who speculated about the potential for an increased use of homebound instruction as a disciplinary recourse. Based upon the results of this study, there is no evidence to suggest that homebound services have become dumping grounds for students with behavior problems, which have resulted from triggered automatic reactions rather than thoughtful placements.

Methods of delivering homebound instruction covered a wide range of options including the number, length and frequency of visits. Even though a wide range of options is available, the

majority of the respondents expressed similar experiences. Most respondents indicated they commonly instructed one student at a time. Additionally, the instructional visits occurred two to three times weekly with each visit lasting between one and one-half hours. The duration of services most frequently covered an interval of 16 or more weeks. These findings are similar to those described in studies by Soles (1975) and Telzrow (2001).

The findings of this study confirmed the assertion by Patterson and Petit (2008) that there is a lack of training designed to prepare service providers in the delivery of homebound instruction. Approximately one-fourth of the respondents indicated that districts provided them with training, while less than 20% indicated that they received training from teacher preparation programs, or from professional development opportunities such as conferences or workshops. The results indicated that the majority of these service providers delivered services without benefit of having received any form of direct training concerning homebound services.

Another important finding from this study was that a majority of school districts do not appear to have written protocols available in the form of documented procedures, guidelines, handbooks, or manuals. Conversely, a majority of service providers reported that they were required to document their instructional sessions, take data on student progress, and report such information to administrators. The information gathered on these two seemingly opposing findings infers that there may be district or agency expectations regarding the delivery of homebound services, however, such expectations may be conveyed either verbally or in informal written fashion such as through emails or memorandums.

While few service providers reported that they had received direct training, the analysis of data from this study established that for those who did, the training positively impacted their perceptions on how effective they were when delivering homebound services. This statistically significant finding has bearing on the overall experience of homebound instruction. Those who were trained perceived themselves to be more effective.

The concept of teacher self-efficacy has been well researched since first introduced by Bandura in 1977 (de la Torre Cruz & Casanova Arias, 2007). Teacher self-efficacy espouses the notion that teachers, who believe their instruction to be effective, do in fact, see growth in student learning. Correspondingly, teachers who doubt the efficacy of their instruction, see minimal student growth. Self-efficacy is developed through a variety of experiences including mastery experiences, physiological and emotional states, vicarious experiences, and social persuasion (Bandura, 1997). Direct training is an important factor in the development of self-efficacy. The results from this study parallel these assertions; survey respondents who received training in homebound delivery expressed higher degrees of personal effectiveness.

There are several important recommendations to be made as a consequence to the findings from this study. The first recommendation understandably concerns the training of homebound instructors. Because homebound instruction is administered through school districts or agencies, these entities are an appropriate starting point. Professional development offered at the agency, school district, or school site level could pinpoint the needs of students in homebound placements as well as echo district or agency policies concerning homebound services. Remembering that special education is a highly litigious field (Katsiyannis et al., 2001), districts

and agencies do well to ensure that personnel are not only qualified but are also appropriately trained.

Teacher preparation programs at universities and colleges also have an obligation to equip special education teachers with the skills they will need to provide a continuum of services. Early childhood special education teacher preparation programs are more likely to provide training in conducting homebound instruction because of the emphasis on providing services in the natural environment (Klass, 2003). However, K-12 teachers may at some time in their careers be asked to provide homebound instruction even on a part-time or temporary basis. As such, teacher preparation programs must recognize the potential need for ensuring that candidates have, at the very least, an awareness level knowledge of the practices and approaches used for homebound instruction.

Furthermore, it is recommended that districts and agencies, minimally, develop and/or adopt written guidelines, manuals or handbooks. While not a substitute for training, written procedures and guidelines would establish a framework for the provision of homebound instruction. The written materials could address issues such as safety, documentation, lesson content, instructional strategies, and basic dos and don'ts. The wide use of technology affords districts and agencies a readily available medium to allow convenient online access to electronic documents, manuals, handbooks or guidelines.

The scarcity of empirical research in the area of homebound services remains a concern. Homebound services have been addressed peripherally in studies, but have rarely been the primary topic, particularly for students in grades K-12. Since homebound services appear to occur on a relatively infrequent basis, finding respondents who have instructed in a homebound setting can be problematic. This study relied on two professional organizations for respondents, however, there is a strong possibility that the majority of special education teachers and related service providers do not belong to professional organizations and were therefore not within the study respondent pool. Future research would benefit from a larger respondent pool, especially one that includes better representation from related service providers. Moreover, the researchers of this study recognize the value that qualitative research could contribute greatly to the understanding and improvement of homebound services. The investigation through qualitative approaches of the rich, personal experiences of service providers who may detail unanticipated practices, factors, and variables stands to benefit students who receive instruction in a homebound setting by informing the community that provides these services.

Conclusion

IDEIA (2004) provides for a continuum of placements as well as the use of interim alternative educational settings. Homebound instruction can be a primary as well as interim placement. In either instance, school districts are obligated to provide appropriate educational services for students. Appropriate instruction is not limited to the use of the least restrictive environment but also encompasses suitable instruction by a qualified and trained service provider. Results from this study may be cause for speculation that due to the low-incidence nature of this service model, the provision of homebound instruction is often administered in a less than formal manner. Although homebound instruction is often provided as an interim placement, students receiving these services are nonetheless entitled to a well-structured, instructionally sound, and accountable program.

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Article

EDUCATIONAL IMPLICATIONS OF COSTELLO SYNDROME: THE TEAM APPROACH

Nikki L. Murdick

Saint Louis University

Barbara C. Gartin

University of Arkansas

Abstract: Since the 1990s the number of children with disabilities placed within the general education classroom has steadily increased. Many of these children are provided special education services under the generic disability title “intellectual disability.” Over the past decade, there has been a significant amount of research concerning rare genetic syndromes that result in separating developmental disabilities into categories using similar origins and characteristics. Costello syndrome is one of these rare syndromes. Although information is available to medical practitioners, it has seldom been communicated to educators. The authors have taken the available data and, using a team approach, made recommendations for involving medical and health professionals in educating students with Costello syndrome.

Keywords: *Costello syndrome; rare syndrome; multiple disabilities; educational implications*

Introduction

Over the past 30 years there has been a surge in research that resulted in the identification of rare syndromes within the category of intellectual disability (e.g., Williams, Angelman, Costello). With the identification of individuals with common characteristics and issues comes the possibility of developing a greater understanding of their shared needs and the involvement of professionals providing services that could improve their quality of life. Costello syndrome (CS) is one of the rare syndromes where there appears to be a lack of transfer of medically-focused information into the educational arena. The lack of current medical information becomes a significant issue as children with complicated disabilities enter inclusive general education classrooms. With the passing of the legislation and regulations such as Individuals with Disabilities Education Improvement Act (IDEA) of 2004 (P.L. 108-446) and No Child Left Behind Act (NCLB) of 2001 (P.L. 107-110), the general education environment has been identified as the primary placement for students with disabilities. This paper will introduce educators to the needs of children with CS and the team approach used to enhance their quality of life.

History of Costello Syndrome

In 1971, Dr. Jack Costello, a pediatrician in New Zealand, identified two non-related individuals as having a cluster of characteristics that might be a new syndrome. After publishing his findings in 1977, no further research was published on this possible syndrome until Der Kaloustian, Moroz, McIntosh, Watters, and Blainchan (1991) reported another individual with similar characteristics. This new syndrome was named Costello syndrome and was defined as “a distinct multiple congenital malformation syndrome characterized by postnatal growth retardation, distinctive face, lax skin, and developmental delay” (International Costello Syndrome Support Group, 2004). Not all children with CS evidence all the aforementioned characteristics, but all who receive this diagnosis typically have a constellation of these characteristics present for that identification to be made. For example, characteristics that may be most recognizable are deeply creased palms and feet, curly hair, loose skin known as cutis laxa, and facial characteristics of a wide mouth, thick lips, high forehead, and large earlobes (Macnair, 2004; Nasca, Strano, Musumeci & Micali, 2003; National Organization of Rare Disorders [NORD], 2002).

The decade of the 1990s was a time when cases of children with what is now considered CS were reported internationally and information on the syndrome expanded rapidly (Borochowitz, Pavone, Mazor, Rizzo, & Dar, 1992; Davies & Hughes, 1994; Der Kaloustian, 1993; Di Rocco et al., 1993; Fryns, Vogels, Haegeman, Eggermont, & Van Den Berghe, 1994; Izumikawa, Naritomi, Tohma, Shiroma, & Hirayama, 1993; Kondo, Tamanaha, & Ashimine, 1993; Philip & Mancini, 1993; Say, Gucsavas, Morgan, & York, 1993; Siwik, Zahka, Wiesner, & Limwongse, 1998; Teebi & Shaabani, 1993; Umans, Decock, & Fryns, 1995; van Eeghen, van Gelderen, & Hennekam, 1999). During the 1990s, the name Costello syndrome became the accepted nomenclature for the disorder (Costello, 1996; Johnson et al., 1998; Martin & Jones, 1991; Zampino et al., 1993).

The number of identified cases of individuals with CS throughout the world is 200-300 with a reported prevalence ranging from 1 in 300,000 to 1 in 1.25 million (U.S. National Library of Medicine, 2014). The search for the cause of CS has continued over the intervening decades with the primary focus being genetic factors (Delrue, Chateil, Arveiler, & Lancombe, 2003; Estep, Tidyman, Teitell, Cotter, & Rauen, 2006; Johnson et al., 1998; Kim et al., 2007; Kutsche, 2003; Macnair, 2004; Madhukara & Kumaran, 2007; Maroti et al., 2002; Tartaglia, Cottare, Zampino, Geld, & Rauen, 2003). Presently the causation is seen as mutations in the HRAS gene. The HRAS gene provides instructions related to cell growth. In this case, “the overactive protein directs cells to grow and divide constantly” (U.S. National Library of Medicine, 2014) often resulting in cancerous tumors (Gripp, Hopkins, Doyle, & Dobyns, 2010; Gripp & Lin, 2012). According to McCormick et al. (2013), p.G12A or p.G12C HRAS genes have more severe characteristics than those with other HRAS mutations. Unfortunately, the dissemination of this expanding research base to the educational community has not occurred. For educators to plan appropriate programs for children with CS, medically related information and its implications for appropriate educational programming is needed.

Characteristics and Their Impact

For the individual with CS, it is necessary to recognize the diversity of his/her needs resulting from this syndrome. Because a person with CS may exhibit variations in type and severity of characteristics, each individual must be viewed as unique. Following is a discussion of frequently occurring characteristics and their implications for family members and school personnel who are involved in educational planning. It should be noted that there exists a continuum of severity within the syndrome and that not all characteristics are present in every person with CS. Thus, these variations can be addressed in the individualized educational plan (IEP) so as to specifically meet the needs of the *individual* with CS.

Physical, Medical, and Health Characteristics

The unique physical characteristics associated with CS may be the first indication that the infant has this rare syndrome. A number of external physical characteristics are frequently noted in children with CS and are present at birth, such as macrocephaly, prominent forehead and wide mouth, ulnar deviation, cutis laxa (loose skin) or redundant skin folds on the neck, arms, and legs. Many children with CS have vision issues identifiable at birth or later including strabismus (crossed eyes), nystagmus (moving eyes), or acute nearsightedness (Johnson et al., 1998; Proud, 2003). Joint laxity may be noted early in life and can, along with the child’s ulnar deviation, cause or result in significant gross and fine motor concerns (Kawame et al., 2003; Lin, Harding, & Silberbach, 2004; Philip, 2002). This joint laxity may result in delays in walking with significant limitations in ambulation (King, 2003; Yassir, Grottkau, & Goldberg, 2003). In addition, some children with CS have hypotonia, or muscle laxness, (Umans, Decock, & Fryns, 1995) and may need splints to support joints and musculature. Shortness of stature is a common characteristic as well as the development of scoliosis or kyphosis as the child matures (Lin, 2003; Yassir, Grottkau, & Goldberg, 2003). Among other possible physical markers are Chiari malformation and the presence of rare tumors and/or cancers such as Rhabdomyosarcoma or bladder cancer (Delrue Chateil, Arveiler, & Lacombe, 2003; Gripp et al., 2002). Chiari malformations are structural defects in the bony structure that holds the cerebellum and part of

the brain stem. As a result, these parts of the brain are pushed downward into the funnel-like opening of the spinal cord (known as the foramen magnum) resulting in possible issues with the functions controlled by these areas of the brain and a blockage of cerebrospinal fluid (National Institute of Neurological Disorders [NINDS], 2014). Depending on the severity of the malformation, surgery to correct the spinal issue or insertion of a shunt system may be required.

The medical characteristics alone are not specific to a diagnosis of CS and, thus, cannot be used as the sole criteria for identification. For example, one of the earliest medical characteristics often is the presence of congenital heart defects including mitral valve prolapse, atrial or ventricular septal defects, and pulmonary stenosis (Hou, 2000; Lin et al., 2002; Waldburg, Buehling, Evert, Burkhardt, & Welte, 2004; Williams, 2014). Children with CS have normal birth weight that declines rapidly after birth for no apparent reason (Kawame et al., 2003; NORD, 2002). According to Kawame et al. (2003), this physical decline, known as failure to thrive, is seen as a result of sucking and swallowing concerns that frequently occur. Another health concern is the presence of gastro-esophageal reflux (Macnair, 2004). In cases of severe feeding difficulties, a naso-gastric tube, or G-tube, may be necessary and, in some cases, tube feeding may continue until the age of two (Philip, 2002).

The occurrence of seizure activity is often present in persons with CS (Kawame et al., 2003) and may occur at different times in the individual's life. For example, it may be present at birth, may originate later in life, may continue throughout life, may stop and never return or sometimes may return later in life (Delrue et al., 2003; Kawame et al., 2003). Regardless of the time of onset, it is a significant medical concern and should be treated by medical specialists.

As a result of the complex and varied nature of the characteristics of individuals with CS, educators and other professionals should be aware of how medical issues and health concerns change throughout the lifespan of the individual. As the physical, medical, and health issues differ according to the age of the child, the following discussion is organized by age rather than by characteristic.

Birth to 5-years-old. During infancy and early childhood (birth to age 5 years), parents and professionals will work as a team and must focus on the development, implementation, and ongoing revision of an Individualized Family Service Plan (IFSP) as required by IDEA. The child's complicated medical and health needs may require a diverse team of professionals including cardiologists, neurologists, orthopedists, and ophthalmologists who may provide the requisite medical care for the child. At this age, medical specialists have an important role that includes the provision of medical and health information to the family and other professionals who are working with the family. Occupational therapists (OT), physical therapists (PT), nutritionists, and speech-language pathologists (SLP) are important partners in the development of appropriate programs for infants and young children with CS. The nutritionist will determine methods for meeting the nutritional needs of those children who have the characteristics of failure to thrive or inability to eat. In conjunction with the nutritionist, the SLP has a critical role working with the child and his/her family to address issues of sucking, chewing, and swallowing. When muscle laxity is present and impacts the health and development of the child, the family might need the expertise of a PT to assess and determine the proper physical supports necessary for feeding. The OT may be needed to address issues with the family related to the selection and



Figure 1. Helaina at 16 months



Figure 2. Helaina age 2-years

use of specialized equipment. In addition, OTs can assist the parents in identifying developmentally appropriate puzzles, blocks, peg boards, and wind-up toys for developing, strengthening, and refining the child's fine motor skills. The PT will also address any issues related to increasing the child's range of motion, balance, coordination, and locomotor skills including walking which is often delayed. If the child requires orthotics, splints, braces, or mobility aids, the OT and the PT can work with the orthopedist and the family in the appropriate selection and use of such items.

The early interventionist is an essential member of the team to work with family members to develop and/or increase the child's activities of daily living skills such as self-feeding and self-dressing and also assisting with the development of fine and gross motor skills, if they are delayed. To encourage fine and gross motor development the early interventionist, and possibly OTs or PTs, will work together to prepare a sequential motor development plan that can provide guidance for the family and others in identifying appropriate play activities for encouraging growth in motor skills and in developing a safe, but challenging environment for the child. If vision concerns are present and these concerns impact the child's ability to process sensory information visually, then the early interventionist may work with the family to create activities to assist in developing visual perceptual skills such as eye gaze, visual tracking, pattern perception, and depth perception.



Figure 3. Helaina at age 3-years

Age 6 to 12-years-old. Around the age of 6 and continuing until age 12, the child is considered an elementary-school aged child. As the child transitions into the inclusive classroom, orthopedic and vision issues may continue. As a result, orthopedists, neurologists, and ophthalmologists may continue their involvement with the transdisciplinary team. OTs and PTs will continue their involvement as needed, focusing on mobility within and around the school, appropriate playground access and activities, adaptation of physical education, and activities of daily living (ADL) when appropriate.

The SLP may continue providing services as needed in the areas of receptive and expressive language development and speech development. These services may include pull-out services for individual work on the formation of speech as well as language development. In addition the SLP may provide consultative services to the classroom teacher and to the parents in the form of information concerning therapeutic activities for implementation at home and within the classroom setting.

Medical issues continue for these children. Although neither general nor special education teachers act as providers of medical services, both have an essential role as monitors of the child's health. They also serve as reporters to the family and other medical professionals concerning health concerns that they may note in the classroom setting. Often classroom teachers are not experienced in recognizing the complex medical issues presented by children with CS but will need to become aware that some children will have possible physical activity restrictions per medical direction. Medical and health issues will vary significantly in children with CS, although common responses to these issues include physical restrictions.

As children with CS are often delayed in physical development, general and special education teachers need to address issues related to the child's visual perceptual skills, visual-motor skills, and fine and gross motor skills. Although there are many methods for meeting the needs of the individual child, adaptive physical education is one possible strategy. Children may also need modifications or adaptations in learning to print, to use scissors, to color, to run, and to climb steps. Minimizing the number or amount of copying and writing activities may be essential. For many children the use of circling or underlining answers in lieu of written answers may be advantageous. The use of computers with large font is helpful for those students who have developed the fine motor skills essential for using the keyboard.

If vision issues are present in conjunction with motor issues, the child's ability in the area of academics may be impacted; therefore, teachers will need to address these issues when planning school activities. When planning educational activities, the teacher should ensure that information is presented both orally and visually. Any directions or instructions that are written will need to also be presented with auditory input to reinforce the child's responses. When presenting written assignments such as worksheets, children with visual issues may need to have material that is not visually "crowded" with additional space between items.



Figure 4. Helaina 16th birthday

Age 13 to 21-years-old. As the child transitions into middle school then secondary school, medical and health issues continue. Teachers should be aware of the continuing complicated medical and health needs of adolescents with CS. Information needs to be shared concerning possible vision problems that may impact the student's ability to function in a classroom, possible orthopedic and medical issues that might result in his/her continued need for modifications in the physical environment, and potential curricular and instructional adaptations. Adaptations described for children ages 6 to 12 years can be useful for this age student as well. In addition, if there are physical or orthopedic concerns, then adaptive physical education might



Figure 5. Helaina as an adult

be an appropriate recommendation. Additionally, where mobility is an issue, a wheelchair may be needed if the student will need to travel any distance or need to move quickly.

Since the student is rapidly approaching the time of transition to adult services, both general and special education teachers will be involved in developing educational plans that address (a) the use of assistive technology, (b) the acquisition of appropriate leisure and recreational skills, (c) the development of ADL skills, and (d) pre-vocational skills. In selecting the skills to be taught, teachers should be sensitive to the adolescent's unique characteristics as well as future plans and community resources. To support the family members during this time of transition to postsecondary/adult services, teachers should provide information on community and state resources and the eligibility criteria for resources of specialized care.

Teachers should begin to talk with the parents and the student about individual medical and nutritional needs so that transition planning can occur. Particularly important is the need for the person with CS to become involved in his or her medical program to the greatest extent possible. The level of participation of the adolescent in his/her personal program is dependent on the ability of the adolescent. However, efforts toward self-regulation, self-care, and self-advocacy should be supported.

Cognitive Characteristics

Some of the cognitive characteristics of children with CS include developmental delay, intellectual disability, and memory deficits (Axelrad et al., 2004; Hennekam, 2003; Hou, 2000; Phillip, 2002; Proud, 2003). Receptive and expressive language differences related to cognitive abilities continue throughout the child's life (Johnson et al., 1998; King, 2003). In addition, the development of adaptive behavior and emotional and behavioral skills seem to be delayed (Axelrad, Glidden, Nicholson, & Gripp, 2004). However, a strength often noted in children with CS is their expansive, friendly personality (Hou, 2000), although it has been noted that irritability, hypersensitivity, and shyness might be present during the early years (Kawame et al., 2003).

As a result of the varied cognitive issues of individuals with CS, educators and other professionals must recognize these issues and how they may change throughout the lifespan of the individual. A discussion of cognitive issues and how educators may respond to them at different ages is discussed below.

Birth to 5-years-old. When addressing the cognitive characteristics of infants and young children with CS, important members of the transdisciplinary team, aside from the parents, are the SLPs and the early interventionists. As a result of tracheotomy tubes and naso-gastric tubes that are required by many infants, vocalizations and language development may be delayed. Both the SLP and the early interventionist will work with the family and the child to encourage the emergence of speech and language. As many children with CS appear to favor visual input, the use of sign language or other forms of communication such as the Picture Exchange Communication System or communication boards can assist in the development of the child's language (Harding, Lindsay, O'Brien, Dipper, & Wright, 2011).

Additionally, the early interventionist will work with the family to identify developmental landmarks and associated behaviors such as basic motor and perceptual skills and to provide activities to support and refine their development. As a result of the variability of developmental skills, intervention and support from other professionals (e.g., OT, PT, nutritionist) may be needed.

Age 6 to 12-years-old. At the beginning of elementary school, the child may still be functioning at the pre-academic level. SLPs will need to continue assisting with the child's speech development as well as with receptive and expressive language development. Teachers should remember that auditory and visual perceptual issues when paired with potential memory issues may impact early learning ability so classroom support is important.

Teachers and family members often state that the child with CS has an expansive personality or has "people pleasing behaviors." This expansiveness means that children often see everyone as a friend and may have difficulty controlling verbal outbursts such as calling out to friends during class. In addition, this may result in inappropriate physical behaviors such as hugging and kissing friends and teachers. These behaviors can become a safety concern as children may walk up to strangers or leave a safe environment without an understanding of the potential consequences of such behavior. All persons involved with the student should understand that these behaviors are

not necessarily under the child's control so he/she should not be punished, but encouraged to substitute more socially appropriate behaviors.

General and special education teachers will focus on educational planning that considers the child's cognitive level and its impact on academics as well as the child's language skills, memory skills, and motor skills. Learning to read has been identified as an area of significant difficulty for many children with intellectual disability, including those with CS (Allor, Champlin, Gifford, & Mathes, 2010; Allor, Mathes, Roberts, Cheatham, & Al Otaiba, 2014; Connor, Alberto, Compton, & O'Connor, 2014). A delay in the development of auditory perceptual skills may impact on the child's ability to learn to read through the phonics method. Alternative reading instruction such as a Rebus approach (Gately, 2006; Rani, 2012), a linguistic approach (Weaver, 2002), or a sight word approach (Browder, Wakeman, Spooner, Ahlgrim-Dezell, & Algozzine, 2006; Emenova & Behrmann, 2011) should be considered.

As a result of fine motor issues and possible vision issues, handwriting can become a major difficulty for children with CS. Handwriting instruction may need to be modified. Additionally, because of the child's difficulty with fine motor tasks, tasks requiring the use of scissors, pencils, instructional manipulatives, and art supplies may need to be modified or taught using adapted tools and materials. As children with CS have significant issues that impact their educational progress in school, the issue of system-wide alternative assessment must be addressed from the very beginning of their school program. For many of these children, portfolio assessment or other alternative forms of assessment should be considered in lieu of traditional forms.

Age 13 to 21-years-old. Beginning at age 13, plans focusing on transitioning students into secondary school and the community should be added to the educational program of adolescents and young adults with CS. Therefore, vocational rehabilitation counselors, transition specialists and other related service personnel may become a part of the transdisciplinary team. Families and schools might collaborate to assist the student in developing ADL skills for use at school and at home. Additionally, recreation and leisure activities might be taught at school and practiced during family time. When planning for the student's future as an adult, the issue of independent living and self-advocacy should be addressed with the parents and the person with CS. Training in self-advocacy and independent living skills will vary according to the abilities of the student. Teachers should target functional academics using appropriate academic modifications and compensatory equipment when needed. Pre-vocational and vocational skills become more important as the student nears graduation. All these areas must be addressed if the student with CS is to be prepared to function optimally in today's society.

Family Issues

For the family of a child with CS, every day brings a challenge. Without family support, a child with CS will not be able to function optimally in the home, school or community. However, the family also needs support. It is essential that families have information readily available when challenges occur. One potential source of support is the internet which can be used to connect families to current information through the government sites on Rare Syndromes (i.e., NORD or Orphanet). It can also provide a way for families to look at future potential challenges that their child with CS may encounter. In addition, the internet can be used to connect families of children

with CS through websites as well (e.g., International Costello Syndrome Support Group-UK and Costello Syndrome Family Network-United States). See Table 1 for a list of CS internet resources that are useful in locating information and connecting with families of individuals with CS. While this article is addressing only the needs of a child birth through 21 years, the individual with CS will continue to need support throughout the lifespan. When families come together, they can provide support to each other that can last a lifetime. Developing supports is a critical task for families and teachers and other professionals on the team should provide information, support, and assistance as needed.



Figure 6. Helaina with friends and family

Summary

Children and youth with Costello syndrome (CS) present a complex multi-systemic set of issues that must be addressed as the child moves through the educational system. Beginning at birth the child with CS and his/her parents will need support from a variety of individuals including medical professionals, early interventionists, occupational and physical therapists, and speech-language pathologists. As the child with CS moves through the educational system, the team members may vary but the complex systemic nature of this syndrome requires that support be provided for medical and educational issues throughout life. However, through this continuing team involvement, the individual with CS should have a greater opportunity to benefit from his/her school experience and successfully transition into the community. Likewise, families

benefit from developing supportive relationships with other families of individuals with CS which can last a lifetime.



Figure 7. Helaina age 20

Table 1

Websites Related to Costello Syndrome

Title of Site	Website Address
Archives of Pediatrics and Adolescent Medicine	http://archpedi.ama-assn.org/issues/v154n6/
Atlas of Genetics and Cytogenetics in Oncology and Haematology	http://atlasgeneticsoncology.org/Kprones/CostelloID10075.html
Costello Syndrome Family Network-United States	http://www.costellosyndromeusa.org
Genetics Education Center	http://www.kumc.edu/gec/support/costello.html
Genetics Home Reference	http://ghr.nlm.nih.gov/condition/costello-syndrome
International Costello Syndrome Support Group	http://www.costellokids.org.uk/welcome.htm
Medical News Today	http://www.medicalnewstoday.com/articles/221715.php

National Library of Medicine	http://www.ncbi.nlm.nih.gov/entrez/query
National Organization of Rare Disorders (NORD)	http://www.rarediseases.org/
Online Mendelian Inheritance in Man (OMIM)	http://www.omim.org/entry/218040
Orphanet	http://www.orpha.net/consor/cgi-bin/OC_Exp.php?Expert=3071
Right Diagnosis	http://www.rightdiagnosis.com/c/costello_syndrome/intro.htm

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Article

OBSESSIVE COMPULSIVE DISORDER: WHAT AN EDUCATOR NEEDS TO KNOW

Amrita Chaturvedi

Saint Louis University

Nikki L. Murdick

Saint Louis University

Barbara C. Gartin

University of Arkansas

Abstract: The presence of obsessive compulsive disorder (OCD) impairs social, emotional and academic functioning. Individuals with OCD may have co-morbid disorders including attention deficit hyperactivity disorder, depression, oppositional defiant disorder, or Tourette syndrome. Challenges occur when students with OCD become a part of the general education classroom. This article provides an overview of OCD and presents information to assist teachers and school staff to successfully meet the needs of students with OCD.

Keywords: *obsessive-compulsive disorder; social-emotional functioning; instructional accommodations; collaboration*

Introduction

It is estimated that obsessive compulsive disorder (OCD) affects approximately 1 – 4% of children and adolescents (Adams, Smith, Bolt & Nolt, 2007; Dyches, Leininger, Heath & Prater, 2010). *The Diagnostic and Statistical Manual of Mental Disorders* (DSM) lists the requisite characteristics of OCD as involuntary, recurring, and unwanted obsessions and/or compulsions (American Psychological Association [APA], 2013). In the *DSM*, obsessions are defined as thoughts, ideations, impulses, urges, or images that cause fear, worry and/or anxiety and compulsions are defined as stereotypical and repetitive behaviors or mental acts performed to alleviate fear, worry, and anxiety caused by obsessions (APA, 2013). Although the exact cause of OCD is still unknown, chemical imbalance in the brain is widely implicated as a possible causation for the disorder (Helbing & Ficca, 2009). In some cases, environmental factors such as death, divorce and/or other traumatic experience can manifest or trigger latent OCD symptoms. Studies show that 40 – 80% of OCD cases have a childhood onset (Helbing & Ficca, 2009; Nakatani et al., 2011) and onset can occur in children as young as 2 – 3 years old (Paige, 2007). OCD often co-exists with other disorders such as attention deficit hyperactivity disorder (ADHD), oppositional defiant disorder (ODD), Tourette syndrome (TS), and depression. These co-morbid conditions often complicate the diagnosis of OCD and present additional challenges and difficulties in areas of the social, emotional, behavioral and academic life of the impacted individuals.

Classroom Implications of OCD

Students with OCD may experience significant impairment in the areas of social, emotional and/or academic functioning. However, early identification and intervention increases the likelihood of positive social, emotional and academic outcomes for children and adolescents with OCD (Cameron & Region, 2007). Teachers play an important role in the success of students with OCD. According to Leininger, Dyches, Prater, and Health (2010), “teacher attitudes are critical to the success of students with OCD” (p. 234). In order for teachers and school personnel to adequately meet the needs of students with OCD, first and foremost they have to become familiar with, and educate themselves about, OCD. Teachers must be cognizant of the fact that, although there are certain common symptoms/behaviors present in individuals with OCD, the impact of these symptoms on individuals may differ greatly. Thus, the next step will be for teachers to understand the nature and severity of the individual student’s condition and its implications for the student’s social, emotional and academic functioning. Understanding that obsessions and compulsions tend to wax and wane with time and are often exacerbated by stressful situations will better equip teachers to meet the needs of students with OCD. Also, it is important to know the type and nature of obsessions and compulsions can change with time. Some individuals can manifest mild and moderate symptoms; whereas, others can have severe symptoms that may prove to be incapacitating (APA, 2013).

Even though the type and severity of obsessions and compulsions may vary from individual to individual, certain symptoms/behaviors are common among individuals diagnosed with OCD. Some common obsessions include: germs and contamination; cleanliness; need for symmetry; rearranging, repeating, counting and ordering items; and forbidden or taboo thoughts, especially thoughts that are sexual, religious or aggressive in nature. Obsessions and compulsions are time-

consuming and often disrupt the day to day lives of affected individuals. It is vital for teachers to remember that obsessive and compulsive behaviors cannot be controlled. When individuals are prevented from performing or carrying out these behaviors, extreme anxiety or panic attacks can be triggered (Merlo & Storch, 2006). However, some individuals can learn to delay these behaviors and then perform them later (Adams, 2004).

Furthermore, it is imperative for teachers to take into consideration that OCD often co-exists with other disorders such as ADHD, Tourette syndrome and depression. Fifty-one percent of children identified as having OCD also have ADHD (Helbing & Ficca, 2009). OCD may go undiagnosed in the presence of ADHD because OCD and ADHD have common “deficits in the adaptation of behavior (i.e., initiation, execution, or withholding) to environmental situations” (Vloet et al., 2010, p. 961) and obsessive thoughts and compulsive behaviors may lead to distractibility and off-task behaviors. Students with OCD and co-morbid Tourette syndrome have even more challenges controlling inappropriate thoughts and behaviors than if they had only one of the two conditions (Hansen, 1992). The impact of OCD with Tourette syndrome results in further complications in day to day functioning and can lead to further difficulties in the areas of motor skills, intellectual and executive functioning, focusing, problem solving and decision making (Chaturvedi, Gartin, & Murdick, 2010; 2011).

Despite the fact that most children and adolescents with OCD have an overall IQ in the average range (Keller, 1989), completing a school day can prove to be mentally and emotionally stressful and physically exhausting. Significant challenges may exist in day to day school life. This may be attributable to the fact that the IQ scores of children with OCD are lower on performance tasks as opposed to verbal tasks. The following sections highlight challenges faced by students with OCD and suggest ways teachers can help students overcome those challenges.

Social Issues

Social issues are a significant concern as students with OCD are more likely to be bullied, victimized, mistreated and socially excluded by their peers (Helbing & Ficca, 2009). They have fewer friends because of the negative perceptions held by others and as a result of not participating in social activities with their peers. Children with OCD report having difficulty making friends, keeping friends, and participating in age-appropriate activities (Langley, Bergman, McCracken, & Piacentini, 2004; Piacentini, Bergman, Keller, & McCracken, 2003).

Bullying. One major issue for children with OCD is bullying and peer victimization. Students with OCD are more likely to be bullied and excluded as a result of being misunderstood or because of their peers’ negative attitudes toward their disabilities. Storch et al. (2006) found more than 25% of participants with OCD were victimized by their peers on a regular basis. Peer victimization can manifest in the form of name calling, spreading of rumors, kicking, hitting and social ostracization. Storch et al. also found a positive correlation between symptom severity and peer victimization. The more severe the obsessions and compulsions, the more victimized the participants were, which in turn, increased their symptoms of depression and loneliness.

Teachers can address the problem of bullying by focusing on the similarities that exist among students and the differences that make each student unique. By modeling respectful, positive

interactions with students with OCD, teachers can set an example for other students to follow. By spreading awareness and sharing information about OCD with other students, teachers can create space and opportunities for positive and constructive discussions and dialogue about the condition. Students with OCD and/or parents or other individuals who have OCD can be invited to share their experiences as part of classroom activities. Teachers can use books and movies on disabilities in general and OCD in particular that portray individuals with the condition in a positive light. The Appendix contains a list of educational resources on OCD available for teacher use. Furthermore, teachers can facilitate and encourage communication between students by providing a supportive and structured classroom environment. Teachers can pair students with OCD with other students to work on assignments and projects or to participate in social activities. Such group work should be closely monitored by teachers to ensure groups are goal-directed, exhibit positive and respectful interactions, and meet the intended objective(s) of the assignment.

Isolation, depression, and low self-esteem. Due to the involuntary and uncertain nature of the condition, students with OCD tend to be socially withdrawn, depressed, and have low self-esteem and confidence. Depression is the most common co-occurring condition with OCD (Canavera, Ollendick, May, & Pincus, 2010). Approximately 60 – 80% of adults with OCD report having depression (Besiroglu, Uguz, Saglam, Argargun, & Cilli, 2007) and 20 – 62% of children have co-morbid OCD and depression (Bolhuis et al., 2013). Individuals with OCD and co-morbid depression have obsessions and compulsions that are more severe in intensity and more frequent in nature compared to individuals who only have OCD. They are also found to have a lower level of perceived control as a result of their co-morbid depression (Peris et al., 2010). Additionally, the co-occurrence of OCD and depression can increase the likelihood of individuals having self-doubt and lower levels of self-esteem and can lead to negative peer relations and social isolation (Canavera, Ollendick, May, & Pincus, 2010). Individuals with OCD often try to hide their condition out of shame, embarrassment, and fear of being ridiculed and victimized by others (Helbing & Ficca, 2009; Leininger et al., 2010; Paige, 2007). They may also go to great lengths to hide their obsessions and compulsions out of fear of being ostracized by their peers. They may avoid certain places, things and people that trigger anxiety and stress. The presence of OCD increases the risk of substance abuse and suicidal thoughts (Sloman, Gallant & Storch, 2007). Often misunderstood and viewed as “abnormal” and “crazy” when their obsessive and compulsive behaviors are visible to others, individuals with OCD tend to have lower self-esteem and are often socially withdrawn. Individuals with OCD tend to be perfectionistic (Ye, Rice, & Storch, 2008). The need to be “perfect” has negative repercussion on social and emotional functioning. It can lead to constant self-criticism, low self-esteem, depression and negative peer interactions and relations.

In order to help students with OCD succeed, teachers must create a classroom environment where students feel welcomed, safe, accepted, and understood. However, classroom acceptance does not always occur. Rejection of the student may be the result of a lack of awareness and understanding on the part of his/her peers about the nature of OCD and how it affects individuals. According to Holtz and Tessman (2007), “children’s misinformation, fear, and feelings of dissimilarity towards individuals with disabilities may create negative attitudes” (p. 533). Hence, teachers should encourage acceptance and understanding of students with OCD.

Teachers can focus on students' areas of strength and interest to help boost their self-esteem and confidence.

Academic Issues

Even though most students with OCD have average intelligence they will require appropriate support and accommodations to be academically successful (Keller, 1989). The accommodations and support system provided to students must be individually tailored to meet their needs. Teachers should first collect data on the nature, severity and duration of the obsessions and compulsions and identify if a pattern to these behaviors exists. Teachers should ask questions like: When and where do these behaviors take place? Are there any triggers or stressors present when these behaviors take place? Is the student spending an inordinate amount of time and energy in trying to control these behaviors? How does the student cope with these behaviors, if at all? Are there co-morbid conditions present? What are the effects of these disabilities on the student's academic performance?

Once data answering these questions are collected teachers can devise a plan that addresses these behaviors. Most students with OCD have certain common underlying challenges and behaviors that impede their success in the classroom. When they receive services under IDEA, they are classified under the disability category of either Emotional/Behavioral Disorder (EBD) or Other Health Impairment (OHI). Also, students with OCD may qualify for services under Section 504 of the Rehabilitation Act of 1973 (Adams, Smith, Bolt & Nolten, 2007). The following sections address how teachers can meet the needs of students with OCD by appropriately structuring and accommodating the classroom environment, curriculum and instruction, and assessment. Collaboration with parents and appropriate school personnel is essential if students with OCD are to succeed. Also, alternative and innovative strategies should be considered when traditional strategies are unsuccessful.

Interdisciplinary collaboration. To ensure that students with OCD succeed, it is imperative that teachers engage in continuous, constructive and positive collaborative processes with the multidisciplinary team involved in the education of these students. The multidisciplinary team includes the parent, the child's teacher(s), and other school employees such as the school psychologist or examiner, nurse, counselor, social worker, occupational therapist, and school administrator. Parents are an important part of the team. Without their input and help, teachers will find it difficult to meet the needs of students with OCD. Parents are a valuable and crucial resource for teachers as parents understand their children and know things no one else knows about their child. Parents can provide information about the student's at-home behaviors and stressors that trigger symptoms/behaviors outside the school setting. Sometimes, students with OCD suppress their obsessive and compulsive behaviors at school only to have them manifest with more severity once they arrive home. With collaboration and communication, teachers and parents can implement methods to support students with OCD both in school and at home. Some questions for both teachers and parents to consider are: How are obsessive and compulsive behaviors affecting the student in school and at home? What support and help can be provided when these obsessions and compulsions occur? Are there any stressors or triggers leading to such behaviors? Once the answers to these questions are shared, appropriate coping skills can be developed for students with OCD. Also, it is important for parents to know if the student with

OCD had a good or bad day at school. Likewise, teachers should know if students with OCD had a negative episode or experience before they got to school. Such information can be shared and exchanged by means of notes sent with the student, emails or phone calls. Having access to such information can enable both teachers and parents to better support students with OCD.

The school psychologist, counselor, occupational therapist, nurse and social worker are other individuals with whom teachers should collaborate. These individuals have specialized knowledge about psychiatric conditions, which include OCD. By consulting with and sharing information about students with OCD with these school personnel, teachers will be better equipped to address the needs of these students. Teachers can also collaborate with these individuals to educate others and reduce stigma associated with OCD. Since many students with OCD take medication, teachers may be required to monitor and report the effects of these medications on the performance of students in their classrooms. Most medications for OCD have side effects. Teachers can learn about these potential side effects by talking to the school nurse who will be in charge of administering medications to students in school. A commonly used treatment for individuals with OCD includes cognitive behavioral therapy (CBT). Teachers can consult with school psychologists and counselors and gain access to knowledge relevant to CBT and how it affects individuals with OCD. Such understanding can enable teachers to provide well-rounded support to students with OCD. Another important member of the multidisciplinary team is the school social worker. Social workers act as a liaison between parents/family and the school. Issues concerning student's family, social and community life that affect the student's education are usually referred to the social worker. Hence, it is important that teachers work collaboratively with social workers.

Task initiation and completion. Students with OCD often have problems initiating and completing assigned tasks, paying attention in class, and focusing on classroom activities. These problems arise as a result of being distracted and overtaken by obsessive thoughts and compulsive mental and/or physical acts. Teachers can address these problems by providing pre-determined cues to enable the student to get “unstuck” and to start or continue the work (Leininger et al., 2010). Teachers can use proximity to check with the student at frequent intervals and encourage him/her to stay focused and on task. Teachers can divide assignments, tasks, and activities into smaller sections so that it is easier for the student to successfully complete the task. To allow the student to release stress during class, teachers can allow frequent breaks to release both mental and physical tension. It is crucial that teachers never ask the student with OCD to “control or stop” his/her obsessive and compulsive behaviors and/or to “not worry” about them (Paige, 2007). As it is, the student with OCD is already distressed and embarrassed by his/her behaviors and has no control over them. By making such requests and/or demands, teachers will only exacerbate the student's behavior which in turn will cause him/her to be further alienated and depressed.

Tardiness and attendance. Another common issue that students with OCD face is being tardy and/or absent from school or classes. Many students may struggle with their obsessive and compulsive rituals in the morning which may cause them to be late to school. Getting from one class to another can also be a challenge. Students with OCD may try to avoid places, individuals, activities, or objects that trigger their ritualistic behaviors or put undue stress on them (Helbing & Ficca, 2009). Teachers should not penalize the student for tardiness, but should have a pre-

determined plan of action for what will occur when the student arrives late or returns after an absence (Black, 1999). When coming to class tardy, teachers can leave handouts with all the instructions and directions for the entire class period on the student's desk. Thus, when the student gets to class late, he/she can just look at the handout and quickly join the rest of the class. If the student is absent, these papers can be saved and given to the student upon her/his return. Similarly, teachers can provide handouts of the class lectures and notes to all students and not just the student with OCD. This action reduces any perception of favoritism or special treatment of the student with OCD.

Note taking and written assignments. Another area of concern for teachers of students with OCD includes the completion of in-class worksheets and other written assignments. As a result of perfectionist behaviors, these students may need to write, erase, and rewrite answers several times. Hence, students with OCD may be unable to submit their work on time. Teachers can address this particular challenge by allowing students to record/tape their answers, to use the computer, or to be allowed extra time to complete the work. For example, writing by hand and staying on task may be a challenge for students with Tourette syndrome because of their tics; for students with ADHD because of inability to pay attention and focus; and for students with depression because of the lack of motivation and emotional inability to move forward. See Figure 1 for overlap of characteristics between OCD and co-morbid ADHD, Tourette syndrome and depression. Irrespective of the nature and intensity of OCD symptoms/behaviors and/or the existence of co-morbid conditions, students with OCD will require appropriate social, emotional and academic supports to succeed in classrooms.

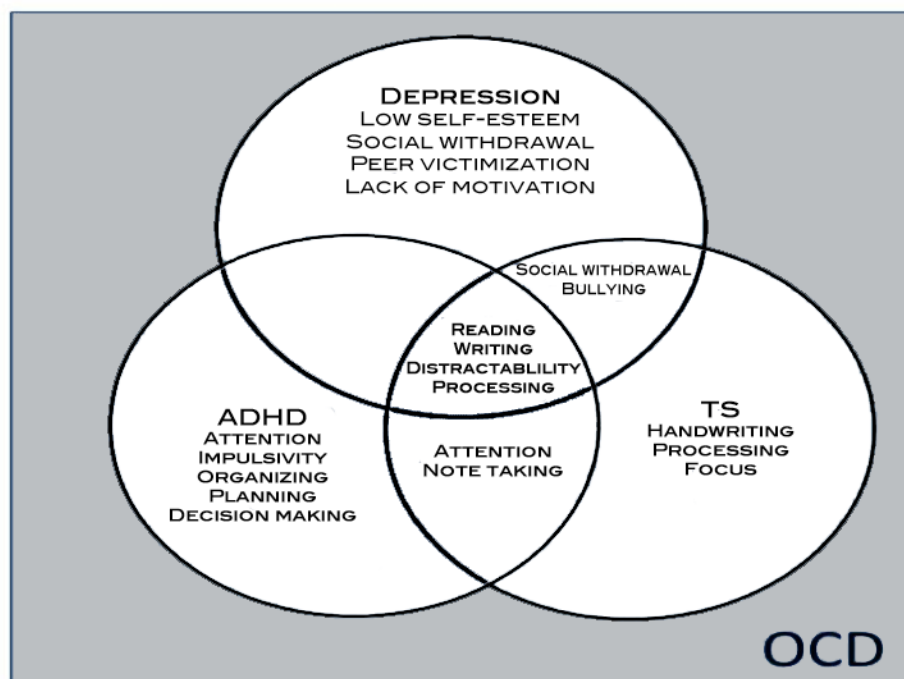


Figure 1. Overlap of characteristics of OCD and co-morbid disorders.

Timed tests and assignments. Because of the inherent stress related to content evaluation, students with OCD also struggle with tests and exams. Additionally, students with OCD often perform poorly when placed under additional stressful situations such as timed tests. Hence, teachers should not use rigid time constraints with students with OCD. This does not mean that students with OCD be given less work to do, but it does mean they may be given additional time to finish assignments when necessary. Teachers can allow the student to work in a place where he/she feels comfortable and allow the student to incorporate breaks as needed (Leininger et al., 2010). Creating a safe and comfortable space in the classroom that is separated from other students can become a refuge for the student and provide him/her a quiet place to de-stress, calm down and regain focus. Providing un-timed tests and exams in a quiet and comfortable environment can help alleviate some of the stress and struggles for these students.

Class transitions. Transitions are another area of difficulty for students with OCD (Leininger et al., 2010). They have difficulty transitioning from one activity, topic and environment to another. Since students with OCD function better in a structured and predictable environment (Paige, 2007), teachers should communicate clearly to students what is expected of them and provide adequate support to meet those expectations. Teachers can help students prepare for transitions by providing advance notice and standing near the student when changes occur. Teachers should train all students in classroom routines, provide a handout of scheduled activities to the students, and post class schedules in the classroom so they are visible at all times.

Mindfulness Based Intervention (MBI). MBI as a form of intervention for individuals with disabilities was first introduced by Kabat-Zinn (1982). He defined mindfulness as, “the awareness that emerges through paying attention on purpose, in the present moment, and non-judgmentally to the unfolding of experience” (Kabat-Zinn, 2003, p. 145). Bishop et al. (2004) operationally defined mindfulness as consisting of two components: (1) self-regulation of attention, and (2) an attitude characterized by curiosity, openness, and acceptance of one’s experience. The core of MBI includes awareness of breathing, awareness of bodily sensation, awareness of actions, awareness of mental states, and shifting attention from past and future to the present moment (Hwang & Kearney, 2013). Even though research on the efficacy of MBI is still in nascent stages, an existing body of research does show that MBI has a positive effect on the emotional, social, and mental health of individuals with disabilities. Studies have found a decrease in parent-rated occurrences of inattention, hyperactivity, and impulsivity in children with ADHD after receiving MBI training (Van der Oord, Bogels, & Peijnenburg, 2011); improved attentional readiness in individuals with bipolar disorder (Howells, Ives-Deliperi, Horn, & Stein, 2012); reduction in anxiety, social problems, oppositional defiant behavior, and conduct problems in adolescents with learning disabilities and ADHD (Haydicky, Wiener, Ducharme, Badali & Milligan, 2012); a decrease in externalizing and internalizing behaviors in adolescents with ADHD, oppositional and conduct disorders, and autism (Bogels, Hoogstad, van Dun, de Schutter & Restifo, 2008); and a reduction in symptoms of depression and anxiety in adults with intellectual disabilities (Idusohan-Moizer, Sawicka & Albany, 2013).

Students with OCD often exhibit co-morbid symptomatology (i.e., anxiety, depression, inattention, and social problems); thus, they may also benefit from MBI. By practicing mindfulness students can learn to accept their obsessions and compulsions as experiences that are fleeting in nature. Such acceptance can reduce the anxiety and worry associated with the

occurrence of obsessions and compulsions. Teachers can incorporate a few minutes of mindfulness breathing in their schedule at the beginning of class every day in which the whole class can participate. Such practice can provide all students, and especially students with OCD, an opportunity to become centered, calmed and focused.

Conclusion

Teachers of students with OCD face unique challenges as a result of the student's obsessive and compulsive behaviors. However, early identification and intervention can enable these students to learn appropriate coping skills and reduce the negative implication of OCD. Teachers should understand the nature and implications of having OCD on an individual's life. To help these students succeed teachers should collaborate with other school personnel and parents and tailor their instruction to meet the individual needs of students with OCD. Since one of the most debilitating effects of OCD is on the student's emotional and social life, teachers should take appropriate steps to promote a climate of acceptance and help the student foster positive relationships with peers.

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Author Note: Correspondence should be addressed to: Amrita Chaturvedi, College of Education and Public Service, 3500 Lindell Blvd, Fitz 203, Saint Louis University, St. Louis, Missouri 63103. Email: achaturv@slu.edu

Appendix

Additional Resources for Educators and Parents

Videos

- *OCD in the Classroom: A Multi-Media Program for Parents, Teachers, and School Personnel*
- *The Touching Tree: A Story about a Boy with OCD*
- (Additional videos available at <http://www.ocfoundation.org/>)

Books

- Cooley, M. L. (2007). *Teaching kids with mental health & learning disorders in the regular classroom: How to recognize, understand, and help challenged (and challenging) students succeed*. Minneapolis, MN: Free Spirit.
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Information on Mindfulness Based Intervention (MBI)

For persons seeking additional information concerning mindfulness based intervention in the classroom, resources and information can be found online through organizations like Mindfulness in Education Network (MiEN), Omega NYC and the Garrison Institute Initiative on Contemplative Teaching and Learning. Some mindfulness based programs in the field of education that have been developed recently include CARE for Teachers, offered by Garrison Institute Initiative on Contemplative Teaching and Learning; MindUp, a curriculum for students in grades P-8 developed by Horne Foundation; and Learning to BREATHE, a curriculum for adolescents to regulate emotions, attention, and stress (Rocco, 2012).