EDUCATIONAL NEEDS AND ACCOMMODATIONS FOR CHILDREN WITH BOWEL AND/OR BLADDER DYSFUNCTION

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ABSTRACT

The physiological and psychological effects of bowel and/or bladder dysfunction can negatively impact students, especially over time. Understanding the educational challenges and needs of these children is necessary to provide services and supports required by the Individuals with Disabilities Education Improvement Act and Section 504 of the Rehabilitation Act. A survey of 106 parents of children with bowel and/or bladder dysfunction and adults with such dysfunction revealed almost one-third (31.4%) never had any formal educational plan. Almost one-half (45%) missed more than a week of school in the previous year, and 7.9% did not attend school at all because of their condition. A list of potential accommodations needed by these children to be successful in school is provided and discussed.

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Dysfunction of the bowel and/or bladder can significantly impact not only a child's health status, as well as social-emotional and academic well-being. Because so little is written specifically about children with bowel and/or bladder dysfunction beyond medical settings, there is a need to learn more about the educational needs of these students. More specifically, the types of educational plans developed for children with bowel and bladder dysfunction, and what is or what should be included on those plans must be explored. As there is so little research specifically about students with bowel and/or bladder dysfunction, the broader category of special health care needs is presented in this introduction, with more specific information on bowel/bladder dysfunction included when available.

According to the 2005-2006 National Survey of Children with Special Health Care Needs, approximately 10.2 million (13.9%) children under the age of 18 in the U.S. have special healthcare needs (United States Department of Health and Human Services, 2008). Within this group are children with chronic health conditions affecting the bowel and bladder. Table 1 presents chronic health conditions typically impacting bowel and/or bladder function, including prevalence data. Another approach to estimating the number of children experiencing dysfunction of the bowel and bladder is to explore broader categories of pediatric enuresis (urinary incontinence) and encopresis (stool incontinence). Enuresis is reported in 23% of all 5-year-old children and declines to 10% of all 7-year-old children and 4% of all 10-year-old children (Robson, 2010). There are few studies reporting the prevalence of encopresis; however, estimates include from 1-2% of children younger than 10 years (Borowitz, 2010) to 4.4% of children aged 4-17 years (Loening-Baucke, 2006). While it cannot be inferred that the enuresis and/or encopresis of all these children can be attributed to chronic health conditions, the very nature of these forms of incontinence can have a significant impact on the child physically, educationally, and psychologically (Clay, 2004). Estimating how many children have chronic health conditions affecting bowel and bladder function is difficult as these conditions are often part of more extensive, rare diagnoses.

Further complicating identification of children is the fear of stigma attached to many chronic health conditions which may result in secrecy about them (Best, 2005). Because bowel and bladder function are viewed as private and personal matters, a tendency to not disclose the condition may be exaggerated because of the potential embarrassment of incontinence. Because of the tremendous amount of stigma attached to incontinence, families may not disclose the condition, including the severity of it, to school officials or others outside their family. If a student or family chooses not to disclose the impairment, service providers may not be aware of the effects of the condition, learning only of the condition when the student is in crisis and cannot conceal it (Best, 2005). Ludman, Spitz, and Kiely (1994) report parents of

Table 1.

Prevalence of Conditions with Concomitant Bowel and/or Bladder Dysfunction.

Diagnosis	Prevalence
Bladder Exstrophy	3.3 per 100,000 (Yerkes & Rink, 2009)
Caudal Regression	0.1-0.25 per 10,000 (Jaffe, Zeituni, & Fejgin, 1991 as cited in Singh, Singh & Sharma, 2005)
Crohn Disease	3.5 per 100,000 (Grossman & Mamula, 2009)
Cloaca	1 per 20,000 (Levitt & Pena, 2010a)
Cloacal Exstrophy	1 per 200,000-400,000 (Yerkes & Rink, 2009)
Down Syndrome	1 per 800 (Chen, 2010)
Hirschsprung's Disease	1 per 5000 (Neville, 2008)
Imperforate Anus	1 per 5000 (Levitt & Pena, 2010b)
Sacral Agenesis	1 per 25,000 (Letts & Jawadi, 2009)
Ulcerative Colitis	2 per 100,000 (Adkins & Azarow, 2008)

children with anorectal anomalies (which impact fecal continence) overcompensate for their child's condition, which results in later problems emotionally and behaviorally for the child across environments, which may further complicate things educationally. Because most health impairments are chronic in nature, the individual will go through periods where the condition is more managed and more exacerbated. The periods when there are few outward signs or pressing needs may give the appearance that the individual does not need supports, and the ongoing consequences of the illness are not planned for (Best, 2005). All of these factors are applicable to children with bowel and/or bladder dysfunction, and have an impact on the level of awareness and planning that occurs.

A chronic health condition has the potential to negatively impact a child's ability to participate in and benefit from schooling (Lowe, 2005). Legislation including Individuals with Disabilities Education Improvement Act of 2004 (IDEA) and Section 504 of the Rehabilitation Act, guarantee that such children are protected and supported through accommodations and/or services provided at school. Palfrey, Singer, Walker, and Butler (1986) report that 47.8% of students receiving special education services are affected by chronic health conditions and 17.8% have multiple health conditions; however, the converse is not necessarily true. That is, it cannot be inferred that the presence of a chronic health conditions necessitates special education services, or even educational accommodations. The physical and psychological effects of chronic health conditions (including those that impact bowel and/or bladder continence) can affect development, cognition, and learning, especially over time (Caldwell, Sirvis, et al. 1997). While specific educational outcomes for students with special healthcare needs in general are difficult to report, these students do repeat grades more frequently (Gortmaker, Walker, Weitzman, & Sobel, 1990) and have lower graduation rates (Data Accountability Center, n.d.). Brandstaetter, Leifgren and Silkworth (2005) cite frequent absenteeism, higher levels of distractibility, and limited endurance as detrimental effects of chronic health conditions that can result in decreased instructional opportunities and negatively impact the child's ability to learn critical content and thus necessitate academic accommodations.

In the *Irving Independent School District v. Tatro* (1984) decision, the Supreme Court upheld that schools must provide health-related services when necessary for the student to receive an appropriate education and when the service can be provided by someone with less training than a physician (Martin, Martin, & Terman, 1996). Despite the requirement to provide school health services, the 25th Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act (U.S. Department of Education, 2003) shows that only 52% of schools provide nursing/health services to children with disabilities as a support service. While this figure was obtained through reports dealing specifically for children receiving special education services, there is no evidence that a higher level of nursing/health services are provided to students not eligible for these services; rather they are in all likelihood offered less to students eligible under Section 504.

In order to appropriately document the child's needs and provide services, professional associations for school nurses including the National Association for School Nurses (NASN) and the American School Health Association (ASHA) recommend the development of an individualized healthcare plan (IHP) and an emergency care plan (ECP) (ASHA, 2002; NASN, 2008). These plans are developed by a school district nurse and outline school health services provided to the child, responsible personnel, and emergency procedures. IHPs are often very comprehensive and specific to the health needs of the child and the medical supports required during the school day. ECPs include basic information about the child's medical condition, medications (routine and emergency), and interventions to take in emergency situations (Herrman, 2005). Neither the IHP nor the ECP are designed to address the educational needs of children with special healthcare needs. Rather, these plans are specifically to attend only to the health-related care needed during school hours. When a student is impacted educationally and therefore eligible for services and supports under IDEA or Section 504, both the NASN and the ASHA recommend the IHP and ECP be included in individualized education programs or 504 accommodations plans (ASHA, 2002; NASN, 2008).

While maintaining good health status through appropriate medical services is the primary goal for any child with a chronic health condition, the educational impact of that condition must also be considered when planning for services and supports at school (Heller & Tumlin, 2004). The physiological effects of chronic illness can include a lack of concentration due to the effects of the illness, side effects of medication, pain, and fatigue (Caldwell, Sirvis, et al., 1997). Physical symptoms experienced more specifically by children with bowel and/or bladder dysfunction include stomach pain; fatigue; loss of appetite; tenderness in the abdomen; diarrhea; and bloating (Clay, 2004). Caldwell, Janz, et al. (1997) state that teachers want to interact with students in a safe manner, devote the time and attention necessary to all students in the classroom, and be supported and trained to meet the health care and special education needs of the student . Thus, as Cunningham and Wodrich (2006) suggest, it is necessary for teachers to receive disease-specific information about how to accommodate students in the classroom. This training should not only focus on the physical impact of the illness, but also the emotional impact. Students with chronic illness are also challenged psychologically by issues such as anxiety about their condition and/or treatments; acceptance and understanding of peers; poor self image; lack of experience (both personal and at school) because of their condition; and a lack of realistic expectations by service providers (Caldwell, Sirvis, et al., 1997). Nabors, Little, Akin-Little, and Iobst (2008) suggest that schools designate a school professional, such as the school psychologist or another member of the special education team, as a source for training teachers and staff which should include both the physiological and psychological ramifications of the illness.

In order to best plan for and meet the needs of students with chronic illness, there must be open, frequent communication between home and school. This level of communication may be difficult for some parents who struggle with the need to fully disclose their child's condition (Best, 2005). Caldwell, Sirvis, et al. (1997) provide several suggestions for home-school communication including sharing information about the learning and healthcare needs of the student, critical components of educational programs that are uniquely designed for the student, and resources available to the school, family, and student. Further, an understanding of the emotional impact of the condition on the family (not just the child) is important and should be considered (Ludman, Spitz, & Kiely, 1994).

Students with chronic illness miss school more frequently than their peers (Caldwell, Sirvis, et al., 1997). High levels of absenteeism have been linked to poorer academic progress (Carroll, 2010; Peterson & Colangelo, 1996). Some students with chronic illness miss a portion of each day when they leave the classroom for routine procedures (such as changing, catheterization, etc.). They may also be absent frequently for routine doctor and therapy appointments, as well as required surgeries and procedures (Caldwell, Sirvis, et al., 1997). When frequent school absences are due to a health condition, the student has less time in which instruction and learning can occur. This can lead to inadequate levels of knowledge and a decreased understanding of critical course content (Needham, Crosnoe, & Muller, 2004). The effects of missing part of a school day—especially frequently—can also be detrimental to the student's progress. Similarly, if a student has attention or stamina issues relating to a health condition, the sequence of subjects throughout the day can also be an important consideration. Sufficient school attendance is an issue that presents challenges, as some students will require shortened class periods or school days due to fatigue and discomfort associated with chronic illness (Clay, 2004). This can further exacerbate the gaps in learning found in this population.

When a child has bowel and/or bladder dysfunction, personal assistance may be needed When a child's health condition has a significant impact on bowel and/or bladder continence, the need for personal care accommodations such as scheduled and frequent restroom breaks, availability of an extra set of clothes, and access to a private restroom away from peers may be necessary (Clay, 2004). In more complex cases, this assistance may include conducting clean intermittent catheterization, changing ostomy appliances, or tube feedings (Caldwell, Janz, et al., 1997).

Children with special health care needs may also require dietary accommodations such as making diet modifications through school nutrition services, eliminating specific foods, monitoring fluid requirements, assisting with required feeding procedures, and adjusting the schedule for eating around administration of medication (Caldwell, Janz, et al., 1997). While the National Food Service Management Institute (2006) requires fluid and fiber content in school meals reflect minimum requirements, children with special health care needs often have difficulties with regulating fluid and/or fiber consumption. Fiber draws water from the body to aid in digestion which requires a higher intake of fluids to prevent constipation (American Dietetic Association, n.d.), especially in children with disorders impacting the gasterointestinal system.

PURPOSE OF THE STUDY

There is very little reported in the professional literature on the educational impact of bowel and/or bladder dysfunction. This exploratory study was designed to learn what types of plans are being developed for students with bowel and/or bladder dysfunction, how such conditions impact school attendance, and if certain accommodations were thought to be needed by these children in the educational setting, thus providing further validity for these accommodations and a point of reference for parents and professionals. This information was gathered to inform both current practice and future research on the educational experiences of children with bowel and bladder dysfunction.

METHODS

PARTICIPANTS

Two national non-profit support organizations assisted in participant recruitment via their organizations' electronic mailing lists, list-servs, and websites. Participants recruited for the survey were not representative of the general population, rather they are parents of children with bowel and/or bladder dysfunction or they have that type of dysfunction themselves. Because participants are all members of support organizations through which they were recruited for participation in the study, it can be assumed that they all have some level of need relating to this dysfunction. An appeal to participate was sent to approximately 1000 potential participants. These distribution lists were not edited by the researcher or the organizations and therefore also included at least some ineligible to participate such as professional members. The introductory message stated the survey was intended to be completed only by parents/guardians of children with bowel and/or bladder dysfunction or adults with such dysfunction. There were 120 total responses; however 14 surveys were excluded because they were completed by affected individuals younger than 18 years of age who were not included in the Institutional Review Board Approval for the study. Thus, 106 surveys were analyzed in the study.

The estimated response rate calculated using eligible surveys was approximately 10.6%, much lower than the 39.6% response rate reported by Cook, Heath and Thompson (2000) in their meta-analysis of electronic surveys. However, Cook, Heath and Thompson contend response representativeness is more important than response rate, with results being more accurate when the sample is known to be representative of the target population. Because respondents in this study were exclusively parents of children with bowel and/or bladder dysfunction or adults with such dysfunction themselves, and because a relatively large sample size was attained (N=106), results may be viewed with some level of confidence.

Medical diagnoses represented in the sample and descriptive statistics are provided in Table 2. While over half of respondents reported only a single diagnosis from among this list, a significant portion reported they or their children had multiple diagnoses. Of the eligible surveys, 6 were completed by parents of children aged birth-two; 12 by parents of children aged 3-5; 37 by parents of children 6-11; 7 by parents of children 12-14; 21 by parents of children 15-18; and 23 by parents of those over age 18 or affected adults responding on their own behalf.

Table 2.

Medical Diagnoses Represented in the Sample.

Medical Diagnosis	% (N)
Anal Stenosis	0.9% (1)
Bladder Exstrophy	13.2% (14)
Caudal Regression	8.5% (9)
Cloaca	9.4% (10)
Cloacal Exstrophy	6.6% (7)
Currarino Triad	0.9% (1)
Down Syndrome	1.9% (2)
Hirschsprung's Disease	10.4% (11)
Imperforate Anus	43.4% (46)
Neurogenic Bladder	20.8% (22)
Renal Defects	12.3% (13)
Sacral Agenesis	12.3% (13)
Tethered Spinal Cord	23.6% (25)
Tracheo-Esophageal Fistula/Esophageal Atresia	2.8% (3)
Ulcerative Colitis/Crohn Disease	12.3% (13)
VATER or VACTERL Association	14.2% (15)
Other	30.2% (32)

Note. Diagnoses reported are not mutually exclusive and do not add up to 100 percent.

PROCEDURE

In order to help maintain confidentiality of respondents and to facilitate efficient dissemination of the survey, an online survey was developed using an online survey hosting site. Directors of two national non-profit parent and youth support organizations for families of children with bowel and bladder disorders disseminated the link to the survey via their electronic mailing lists and list-servs. The request to participate in the survey included a brief description of the survey, a description of how the resulting data would be used, and a statement acknowledging that participation was confidential and voluntary. Data were collected over a period of approximately 8 weeks. Prior to analysis, submissions were examined to ensure respondents met the criteria of being 18 or older.

MEASURES

An online survey was developed for this study based on a review of the literature on both the needs of children with special health care needs in general, and children with bowel and/or bladder dysfunction in particular. The resulting survey included questions relating to the characteristics of the affected individual upon whom the responses were based: age, diagnoses, types of current and past educational plans, and potential accommodations needed by the affected individual. A list of 39 potential accommodations was developed through a review of the literature. The accommodations were then compared to seven individualized education programs and/or 504 plans provided by parents of children with bowel and/or bladder dysfunction. Solicitation of these plans was accomplished through the list-serve of the Pull-through Network, a non-profit parent support organization for children with such conditions. The master list of accommodations was updated and then organized into seven sections:

- Attendance and Scheduling Accommodations (4 items);
- Health and Personal Care Accommodations (10 items);
- Academic and Non-Academic Program Accommodations (8 items);
- Collaboration and Communication Accommodations (4 items);
- Dietary Accommodations (2 items); Logistical Accommodations (6 items); and
- Awareness and Training Accommodations (5 items).

While some of the 39 accommodations are similar, they were left as reported or provided for the purposes of this study. When presented with the list of accommodations on the survey, respondents were asked to indicate which they felt were needed in order for the affected individual to fully participate in daycare or school. Further, they were told that it did not matter if they actually get these accommodations as a part of a formal plan at this time, just if they felt they were needed to be successful.

Finally, respondents were asked to indicate how many absences the affected individual had in the last year due to his/her bowel or bladder condition. Options given were: none, 1-3 days, 3-5 days, 1-2 weeks, more than 2 weeks, does not attend school but does receive regular homebound services, and parents chose to home school because of the condition.

RESULTS

TYPES OF PLANS

Respondents were asked to indicate if the affected child had an individualized family service plan (IFSP), individualized education program (IEP), individualized accommodations plan (504 plan) and/or an individualized healthcare plan (IHP) either currently or in the past. These data are presented in Table 3. Of the 102 responding to this item, 31.4% (n=32) reported never having any sort of plan developed for the affected child in the school setting. Despite the conditions of the target group for the study being health related, only 9 respondents indicated having an IHP either currently or in the past. Of those responses, IHPs only were reported in 4 cases (4%) and in conjunction with other plans (IEPs or 504 plans) in 5 cases (5%). The most frequently developed plan reported was an individualized accommodations plan, with 34.3% (n=35) reporting having this type of plan now and/or in the past, followed closely by individualized education programs reported by 33% (n=34). When data were filtered to only include affected school-aged children (kindergarten—high school graduation) with current plans in place, there were 65 responses showing 23 (35.4%) with 504 plans, 19 (29.2%) with IEPs, and 5 (7.7%) with IHPs. Initial review of the data on individualized family service plans (IFSPs) showed 10 respondents indicating they have or have had an IFSP. However, closer investigation of these data revealed 1 survey reported data for an individual aged 6-11, and two reported data for individuals over age 18. Because IFSPs are primarily developed for individuals aged birth—2, these three responses were excluded from analysis. Only one respondent (<1%) indicated the child was age birth—2 and did currently have an IFSP. The remaining 6 were those who had had an IFSP in the past.

ABSENTEEISM

Of those responding to the survey, 89 provided data on number of days missed due to the bowel and/or bladder condition. According to National KIDS

COUNT data (Annie E. Casey Foundation, 2009), 5.8% of students aged 6-17 missed eleven days of school or more because of illness or injury. Respondents in this study reported a higher absentee rate, with 22.5% (N=20) reporting missing more than two weeks because of their bowel/bladder condition and an eAccording to National KIDS COUNT data (2007), 5.8% of all students in the United States miss 11 days of school or more per year due to illness or injury. The results of this study showed a higher absentee rate for children with bowel and/or bladder dysfunction , with 22.5% of the sample reporting missing more than two weeks because of their condition. An equal number reported missing 1-2 weeks. Twelve additional respondents (13.5%) reported missing 3-5 days; 15 (16.9%) reported missing 1-3 days; and 15 (16.9%) reported missing no days. There were 7 respondents that did not regularly attend school; 4 (4.5%) received homebound educational services because of their condition and 3 (3.4%) chose to home school because of the condition.

ACCOMMODATIONS

Table 3 provides details about accommodations that respondents felt were necessary in order for the affected child to benefit from their school experience. Of the 39 accommodations listed, 12 were identified as necessary by over half of the respondents. The accommodation identified as needed most often by respondents (87.7%) was "provide unrestricted access to the restroom". Related to restroom access is "provide assistance in the bathroom, including changing and cleaning when necessary" which was identified as needed by 58.5% of respondents. In associated areas, 66% felt that a private restroom with storage for supplies should be provided; 51.9% said

Table 3.

Plans Developed for Children with Bowel and/or Bladder Dysfunction.

	IFSP		IHP		504 Plan		IEP		No Plan
	Total		Total		Total		Total		
	Past	Now	Past	Now	Past	Now	Past	Now	
All (N=102)	8 (7.8%)		9 (8.8%)		38 (37.3%)		36 (35.3%)		32 (31.4%)
	5	3	2	7	13	25	13	23	
School-aged only (N=65)	n/a		5 (7.7%)		23 (35.4%)		19 (29.2%)		17 (26.2%)

Table 3. *(Continued)*

Accommodations Needed by Individuals with Bowel and/or Bladder Dysfunction.

Category Accommodation	% (n)
Academic and Non-Academic Program Accommodations	
Allow for extended time, alternate testing days, and/or additional breaks during testing	50.0% (53)
Establish a plan to be followed when schoolwork is missed	49.1% (52)
Adapt or waive the physical education curriculum	44.3% (47)
Furnish prompt homebound services for extended periods of illness and/or hospitalization	36.8% (39)
Provide duplicate copies of textbooks for home	32.1% (34)
Accommodate involvement in extracurricular activities	31.1% (33)
Arrange for adult tutor at school and/or home	25.5% (27)
Provide appropriate technology (including assistive technology)	18.9% (20)
Other	1.9% (2)
Collaboration and Communication	
Provide parents/students the teacher's phone number and/or email for more frequent communication	69.8% (74)
Establish communication with health professionals, school nurse and home	60.4% (64)
Schedule periodic home-school meetings	24.5% (26)
Maintain daily journals/logs documenting health and/or academic issues	20.8% (22)
Other	4.7% (5)
Dietary Accommodations	
Provide unrestricted access to fluids	58.5% (62)
Provide dietary accommodations through school nutrition services	26.4% (28)
Other	9.4% (10)

Table 3. *(Continued)*

Accommodations Needed by Individuals with Bowel and/or Bladder Dysfunction.

Category Accommodation	% (n)
Logistical Accommodations	
Allow unrestricted access to restrooms	87.7% (93)
Provide private restrooms with storage for supplies	66.0% (70)
Provide accessible restrooms	57.5% (61)
Provide lockers/storage for materials and supplies	51.9% (55)
Provide preferential seating	30.2% (32)
Arrange for trained personnel on field trips	28.3% (30)
Other	4.7% (5)
Awareness and Training Accommodations	
Provide training to staff on confidentiality and privacy issues	55.7% (59)
Provide education to peers, teachers, and other school staff as requested, particularly on the educational impact of health care issues	50% (53)
Identify and train back-up personnel if primary staff are unavailable	35.8% (38)
Provide in-depth training to staff with primary responsibility for implementing or assisting with health/personal care procedures	34.9% (37)
Provide counseling services at school	30.2% (32)
Other	3.8% (4)

lockers/storage for materials and supplies were needed; and 57.5% felt it was necessary to have accessible restrooms.

Communication was the focus of two other highly identified accommodations, with “provide parents/students the teacher’s phone number and/or email for more frequent communication” identified by 69.8% and “establish routine communication with health professionals, school nurse, and home” identified by 60.4%. Given the frequent number of absences reported by this population, it is not surprising that a majority of respondents felt it was

Table 4.

Accommodations Needed by Individuals with Bowel and/or Bladder Dysfunction.

Category Accommodation	% (n)
Attendance and Scheduling Accommodations	
Adjust attendance policies	61.3% (65)
Adjust schedule of staff assisting child with personal/health care	34.9% (37)
Adjust schedule or shorten day	25.5% (27)
Provide rest periods	17.0% (18)
Other	17.0% (18)
Health and Personal Care Accommodations	
Provide assistance in the bathroom, including changing and cleaning when necessary	58.5% (62)
Use universal precautions	45.3% (48)
Develop an individualized healthcare plan	40.6% (43)
Develop an emergency plan	39.6% (42)
Provide latex-free materials	35.8% (38)
Provide trained personnel to perform health care procedures	27.4% (29)
Administer medications	25.5% (27)
Establish health alert systems for staff	23.6% (25)
Evaluate school environment for latex and eliminate	14.2% (15)
Provide beepers/pagers/cell phones to alert trained personnel	9.4% (10)
Other	8.5% (9)

necessary to adjust attendance policies (61.3%), and allow for extended time, alternate testing days, and/or additional breaks during testing (50%,). Allowing unrestricted access to fluids was also highly rated by respondents (58.5%). Finally, a need for awareness of the condition and its impact was reflected by 55.7% of respondents; and 50% indicating that education to peers, teachers, and other school staff as requested, particularly on the educational impact of health care issues.

DISCUSSION

The purpose of this study was to explore the educational needs of students with bowel and/or bladder dysfunction as well as the level of planning done for them. More specifically, respondents indicated what types of plans are developed for students with bowel and/or bladder dysfunction, how school attendance has been impacted by these conditions, and if certain accommodations were thought to be needed by these children in the educational setting. The results provide insight into current planning practices as well as a starting point for determining the support needs of this group of children and are discussed in the following sections.

DEVELOPMENT OF FORMAL PLANS

Despite the evidence showing the negative impact of special healthcare needs on children physically, psychologically, and educationally, the results of this study suggests that plans for these students are not consistently developed. When analyzing the data on plans developed, perhaps the most surprising finding was the extremely low number of children for whom IHPs had been developed (only 9 of 102). Based on the strong advocacy for IHP development by the two main professional associations for school nurses, it was expected that this number would be much higher. The low number of IHPs reported suggests that further study on access to school health services and/or school nursing services may be warranted. The low numbers may be reflective of the scarcity of school nurses on site at schools that are available to assist in the planning for children with special healthcare needs. Further, unless a child receives special education services, funding for school health services often comes from local, not federal funds. Because of the private nature of these conditions, the stigma often associated with incontinence, and the variability in needs of children with these conditions over time, the need for these services may not appear critical enough to school officials to warrant IHP development. On the other hand, however, IEPs or 504 plans were reported much more frequently than IHPs, with approximately two-thirds of respondents reporting having IEPs or 504 plans at some point in time (33% and 34.3% respectively), almost one-third of respondents (31.4%) said no educational plan had ever been developed. This suggests that, at least for some students, school officials do concur that the chronic health conditions have had an educational impact, and accommodations and/or services are warranted. It may also suggest that plans that are required by law (such as 504 plans and IEPs) are more likely to be developed and implemented than those suggested by professional organizations (such as IHPs).

ABSENTEEISM

Another notable finding was the absenteeism levels reported by respondents, with almost half (45 percent) missing more than a week of school and an additional eight percent not attending school at all because of their condition. This finding has implications not only for potential accommodations (such as adjusting attendance policies, planning for missed schoolwork, etc.), but also could impact the child's academic progress over time. When paired with the relatively low percentages of students with bowel/bladder dysfunction who have educational plans in place, this finding gives beginning evidence of the need for early intervening for these students; and not waiting until they are experiencing high levels of school failure before providing accommodations.

ACCOMMODATIONS NEEDED

Students with the same or similar medical diagnoses can have very different needs in the educational setting (DePaepe, Garrison-Kane, & Doelling, 2002). Educators, medical professionals, families, and students must work together to consider the unique needs of the individual child in order to develop a plan that is most likely to support him/her in the school setting. Because many educators are not aware of the educational impact of special healthcare needs, and many parents are not aware of the availability of accommodations specifically identified to meet their child's needs, it is necessary to provide a beginning point for discussion, collaboration, and plan development. The accommodations needed by students with bowel and/or bladder dysfunction have not been specifically reported in the literature.

Accommodations classified as logistical accommodations received the highest number of responses. It is not surprising that the most frequently identified accommodation for children with bowel and/or bladder dysfunction is unrestricted access to the restroom. These children struggle to maintain continence, which can have significant social ramifications. Participants in the research were impacted by these conditions to such an extent that they've joined support organizations, which suggests they (affected adults) or their children continue to experience challenges as a result of their condition. Given this, it was expected that this accommodation would have been identified for an even higher number of respondents. It was also not unexpected that access to private and accessible restrooms was identified by a significant number of respondents. In most school settings, the student restrooms are not very private and if a student has an accident or needs to spend extended periods of time in the restroom, a less conspicuous setting may be preferred. This would extend Best's (2005) theory that parents are very concerned about stigma of the condition, and therefore would want to arrange a setting for their child where privacy may be maintained. Similarly, providing discrete storage for things like extra clothes, cleaning supplies, etc. would be needed.

Despite the literature that suggests parents may be unwilling to disclose their child's condition to others, the results of this survey indicated they wanted more communication, at least with the teacher. This accommodation received the second highest response rate overall (second only to unlimited access to the restroom), indicating a need for frequent, convenient communication between home and school. The high response level could also indicate that parents want more awareness and true understanding of the impact of the condition on the child at school, which is supported by the responses indicating a need for education to peers, teachers, and other school staff on the impact of health care issues. However, this must be balanced with respect for the child's privacy as indicated by slightly higher numbers identifying a need for staff training on confidentiality and privacy. This suggests a delicate balance among sharing enough information with the appropriate people, while respecting the privacy of the child and family for this very personal area. Concerns about stigma and the child's psychological well-being that have been reported in the literature complicate the provision of these types of accommodations.

Many respondents also indicated they wanted communication among health professionals, the school nurse, and home. This, too, is not surprising given the medical nature of the conditions. However, accomplishing this may prove to be problematic, as many medical professionals do not interact with school personnel at all; and many schools do not have an on-site school nurse. This level of communication is important for other types of accommodations including dietary accommodations which often require a physician's order.

A category with somewhat lower ratings was Academic and Non-Academic Program Accommodations. In this category, the most frequently identified accommodations were non-academic in nature, focusing on more procedural adaptations for the student rather than those more commonly used for students with learning difficulties. The accommodation with the highest percentage of responses was *allow for extended time, alternate testing days, and/or additional breaks during testing* with half indicating this accommodation is needed. The increased focus on standardized testing, and thus the greater amount of attention given to all testing may explain the number of respondents indicating their child may need this accommodation. This may be particularly needed if a child makes frequent, unexpected trips to the restroom, or frequently arrives at school late due to problems with bowel or bladder management procedures that must be done in the morning before school.

The next highest rated item was *establish a plan to be followed when schoolwork is missed.* Just under half of all respondents indicated this is a needed accommodation, which was slightly higher than the percentage reporting missing more than a week of school. As stated earlier, there is great variety in the presenting needs of this population—and therefore some more affected children may experience higher levels of absenteeism. However, the results do suggest that, while a small percentage are unable to regularly attend school despite their illness, most are able to attend school—although with absenteeism levels slightly higher than the typical population. The results of this study seem to suggest that the majority of these students miss enough school to need diligence to ensure they maintain progress, but not enough to warrant more intensive planning and supports, such as homebound services. These students are not likely to be covered in policies to provide remedial educational services to children missing school through homebound educational services, which are designed for students unable to attend school for extended periods of time. This makes it even more critical that schools and parents proactively plan for likely absences from school.

When presented items relating to accommodations more directly relating to teaching and learning, fewer numbers of respondents identified these as needed. Because health impairments do not necessarily have concomitant learning problems, affected individuals, parents and teachers may not understand the educational impact of chronic health conditions and be unaware of the needs of the child academically. Also, because most children with chronic illnesses do not have cognitive impairments, they may be able to master academic content well enough so that they are not failing in their courses. However, if that child misses content over time, the cumulative effect of seemingly minor academic issues will add up and there may be potential for gaps in learning to begin surfacing in adolescence. Considering the higher than typical level of absenteeism reported by respondents in this study, attention to the academic progress of students with special healthcare needs is warranted, with further study of the academic impact over time needed.

A particular accommodation that could help remediate some of the potential academic problems is the use of technology, including assistive technology (Merbler, Hadadian, & Ulman, 1999). While receiving relatively low numbers of responses, using technology could help with gaps in knowledge that may be caused by frequent absenteeism or lower levels of stamina. However, schools and families may have varying experience with technology and may not have not considered how commonly available tools as well as emerging educational technology (i.e., Skype, online learning tools, virtual schools/classes, etc.) could benefit these students.

LIMITATIONS

While this study provides a better foundation for better development of educational plans and provision of educational services to students with bowel and/or bladder dysfunction, much more needs to be done. Because of the tremendous variability in this population, it is tremendously difficult to gather data from a large enough sample. The data gathered here was taken primarily from the responses of families of children with bowel and/or bladder dysfunction as well as adults with these conditions themselves. Further, because this is such a diverse and geographically spread group, the sample was drawn from family support organizations. It is possible that there are other children out there with more or fewer educational need. Next, this population has limited formal educational training and therefore primarily made their determinations based on their individual experiences. The data reported here are purely the opinions of the respondents, and there are no data that suggest that the provision of these accommodations will result in better educational outcomes.

IMPLICATIONS FOR FUTURE RESEARCH AND PRACTICE

An understanding not only of the physical needs, but also the psychological effects is critical to ensuring that children with continence issues are well supported during the school day. Educators must assist families in understanding the various options for support available to these children and ensure that appropriate plans are developed. There is a tremendous need for more extensive research with this population of students. Children who were born with or who developed conditions that significantly impact their bowel and/or bladder continence begin life with the full continuum of cognitive abilities and disabilities as the general population. Because high levels of absenteeism have been correlated with decreased academic achievement in students with chronic health conditions, further study is needed to fully understand the scope of the problem as well as the educational impact. While this study provides preliminary data on absenteeism for this population, it does not provide further information about partial day absences or tardiness to school, also shown to be detrimental to student achievement. Further study of missing learning time for children with bowel and/or bladder dysfunction should be conducted in order to better understand the issue of absenteeism and any potential educational impact on this population. Future research must be conducted to analyze policies that are barriers to fully supporting these children in educational settings, including requirements for educational plans as well as when and how homebound educational services are provided. The impact of high quality plans and supports on educational outcomes for this population must also be studied. Specific strategies for not only educators, but for families as well must be developed, tested, and disseminated so that critical learning can occur and positive outcomes are seen.

Finally, educators must proactively seek innovative instructional solutions so that students with any chronic healthcare need have consistent, comprehensive, and high-quality educational experiences both during periods of health and illness.

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