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Suggested APA style reference: Hamlet, H. S., & Herrick, M. A. (2011). *Who's on first: Professional collaboration and children with chronic illness*. Retrieved from http://counselingoutfitters.com/vistas/vistas11/Article_82.pdf

Article 82

Who's on First?: Professional Collaboration and Children With Chronic Illness

Paper based on a presentation at the 2011 American Counseling Association Conference and Exposition, March 23-27, 2011, New Orleans, LA.

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The authors would like to thank Carol Anderson, MSN/Ed, RN, Program Coordinator, Oncology Services, The Reading Hospital Regional Cancer Center, Reading PA for her assistance regarding the Nurse Practitioner role.

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Consider the children you encounter on a daily basis – at school, in your neighborhood, at the shopping mall, in the park, at the grocery store. One in five of these children suffer from a chronic illness (Center for Disease Control and Prevention, 2008). But the term chronic illness alone does not describe the myriad of life-limiting health conditions suffered by approximately 20% of our nation's children. Consider the debilitating effects of a respiratory illness such as asthma, a condition that affects approximately 9% of children between the ages of 0 and 17 (Agency for Healthcare Research and Quality, 2010). Add to that the numbers of children with cerebral palsy, diabetes, cystic fibrosis, epilepsy, heart conditions, Addison's disease, cancer, kidney disease, and sickle cell anemia (Perrin, Bloom, & Gortmaker, 2007; Van Cleave, Gortmaker, & Perrin, 2010). Look again. How many of the children that you see are overweight? As childhood obesity rises to the level of a public health threat, the numbers of children dealing with chronic conditions can only increase (Agency for Healthcare Research and Quality, 2010).

When a child is diagnosed with a chronic illness, the familiar surroundings of family, school, and community are replaced by an unfamiliar environment, invasive

medical procedures, multiple care providers, and a complex schedule of medications and treatments (Rideout, 2007). From the initial referral to a specialist to the intermittent periods of inpatient and outpatient hospitalization, the child's medical condition requires first and foremost attention. However, as medical necessity governs the child's life, threats arise to healthy development in other life domains. According to Martinez and Erickson (2009), the educational and social/emotional problems faced by a child with a chronic illness are almost double in comparison to those faced by their healthy peers.

The Developmental Challenges of Chronic Illness

Educational

The first major challenge to healthy development lies in the educational domain. A child who is repeatedly unable to attend classes soon falls behind peers who are in school on a regular basis. The child living with a chronic illness is particularly vulnerable to this scenario because frequent absences from school are unavoidable. For this child, maintaining educational achievement becomes increasingly complicated when lessons in subjects, such as mathematics and reading, build upon prior knowledge. For example, a child whose 3rd-grade math achievement is compromised by repeated absences from classes lacks the full understanding of multiplication concepts critical to learning long division in the fourth grade. Similarly, spelling and vocabulary, commonly taught in the first through third grades, provide the basis for reading comprehension that is emphasized in the 4th-grade. A child who has not grasped key literacy skills struggles to comprehend fourth grade reading material. In addition, the child with a chronic illness does not have the consistent opportunities to practice the metacognitive skills of problem solving and critical thinking learned through daily interaction with teachers, peers, and class materials. Thus, frequent absences compromise the acquisition of skills that lead to advanced mastery of subject material and place the child at a distinct disadvantage when compared to healthy counterparts (Martinez & Erickson, 2009).

The gap between what peers are learning and the child's ability to keep up with academics widens with each hospitalization. Add to this the possible presence of a learning disability, cognitive limitation, or behavioral/emotional disorder and the gap expands. In the worst case scenario, the child becomes unable to effectively demonstrate true academic abilities and is subsequently placed in a classroom that operates at a level below his or her actual potential.

Social/Emotional

The second major challenge to a child with a chronic illness lies in the social/emotional domain. Long recognized as a mediator of stressful situations, social support has been linked to well being, self-esteem, and self efficacy (Chu, Saucier & Hafner 2010; Malecki & Demaray, 2006). For children and adolescents in particular, social support is a key factor in negotiating the developmental stages of childhood. Through interactions with peers, children develop a sense of self efficacy, learn skills in reciprocal social interaction, build problem solving skills, and experience a sense of community with others. When a child suffers from a chronic illness, however, the consistency and predictability of social support is compromised by lengthy and intermittent hospital stays. Removed from a significant social support network, the

hospitalized child misses the immediacy of social interactions that buffer stress and promote healthy coping skills.

How the School Addresses These Challenges

In the educational domain, Federal laws insure that a child with a chronic illness is afforded the accommodations and modifications necessary to maximize the potential for academic success (Geist, Grdisa & Otley, 2003). A child with chronic illness is entitled to a Free and Appropriate Education (FAPE) under the rules and regulations of the Individuals with Disabilities Education Act (IDEA) of 1990 and may also be eligible for services under Section 504 of the Vocational Rehabilitation Act of 1973 (Office for Civil Rights, 2010). The accommodations and/or modifications implemented by the school are selected based upon the child's needs. An initial strategy used by schools to meet the needs of students with chronic illness is through teacher-student collaboration. For example, the child's teacher can develop packets of lessons and curricular materials for completion while the child is in the hospital. When the child returns to school, the teacher can alter the requirements of course material to accommodate the student's absence from the classroom. Teachers may reduce the number of math problems or spelling words per week. In some cases, a "study buddy" can help the child catch up with academic assignments and may also provide a social contact (Nabors, Little, Akin-Little, Iobst, 2008).

In the social/emotional domain, accommodations and modifications can be designed to support the development of social skills and peer relationships. For example, the school counselor provides individual counseling for the student with chronic illness. Educational programs can be presented to the child's peers to increase awareness and understanding of the illness. Small groups discussions can also be used to increase peer understanding of the effects of the child's illness (Peckham, 1993). The school counselor can also work with school, hospital, and community personnel to coordinate the child's re-entry to school (Kaffenberger, 2006; Prevatt, Heffer, & Lowe, 2000). The school nurse can collaborate with the school counselor on how the illness is impacting the child's social and emotional needs (Reel, Morgan-Judge, Peros, & Abraham, 2002).

How the Hospital Addresses These Challenges

When a chronically ill child is hospitalized, on-site education generally takes one of two forms. First, if the child is too ill to leave the hospital room, bedside schooling is an option. If the child is well enough to leave the hospital room, an on-site hospital classroom is used. Efforts are made to provide a curriculum consistent with the child's home school. If materials from the child's home school are not available, the hospital-based teacher provides grade-level work based on national standards. Physician consent is required for participation in hospital-based schooling and children are encouraged, but not required, to attend classes.

Hospital-based education programs generally include a social/emotional component in their curricula. Traditionally, it involves therapeutic and recreational play activities that help the child cope with the emotional aspects of the illness. To normalize a long-term stay in the hospital, education programs also include preparation for special

events such as holidays and birthdays (Arkansas Children's Hospital 2010; Children's Hospital of Philadelphia, 2010; KidsHealth 2010; MD Anderson Cancer Center 2010).

Innovations in technology are currently expanding the possibilities for both education and social/emotional development of the hospitalized child. Video conferencing, chat rooms, instant messaging, and social networking are increasingly becoming part of the hospital experience. Programs such as the STARBRIGHT World use Internet and e-mail to help seriously ill teenagers learn more about their illnesses as well as connect electronically with other hospitalized children (Hazzard, Celano, Collins, & Markov, 2002). The PEBBLES™ (Providing Education By Bringing Learning Environments to Students) uses two child-sized robots to transmit video, audio and documents between the child's home school classroom and the hospital room (Pebbles Project, 2010). The University of California, San Francisco Children's Hospital now partners with Skype to allow hospitalized children virtual visits with family, friends, and the home school classroom.

In essence, technology is now helping the child with a chronic illness maintain academic progress and interaction with peers by creating a virtual presence in the day-to-day interactions of school and home. Both scientific studies and analog reports suggest that these programs distract the child from physical pain and medical procedures as well as decrease social emotional variables such as loneliness and anxiety. In particular, these programs increase: a) personal mastery and self expression; b) coping skills and self esteem; c) health-related knowledge, d) participation with family and peers; and, e) connection between hospital and home-school academics (Hazzard et al., 2002; Holden, et al., 2002; Nicholas et al., 2007; Quinn, 2010; Vidinsky, 2010).

Collaboration: The Unifying Thread, or Not

As described above, the myriad of services available to the child with a chronic illness brings multiple providers into his or her life. Collaboration among these providers becomes the critical unifying thread for meeting the child's unique needs across life domains (Wheeler, Merkle, Garald, & Taggart, 2006).

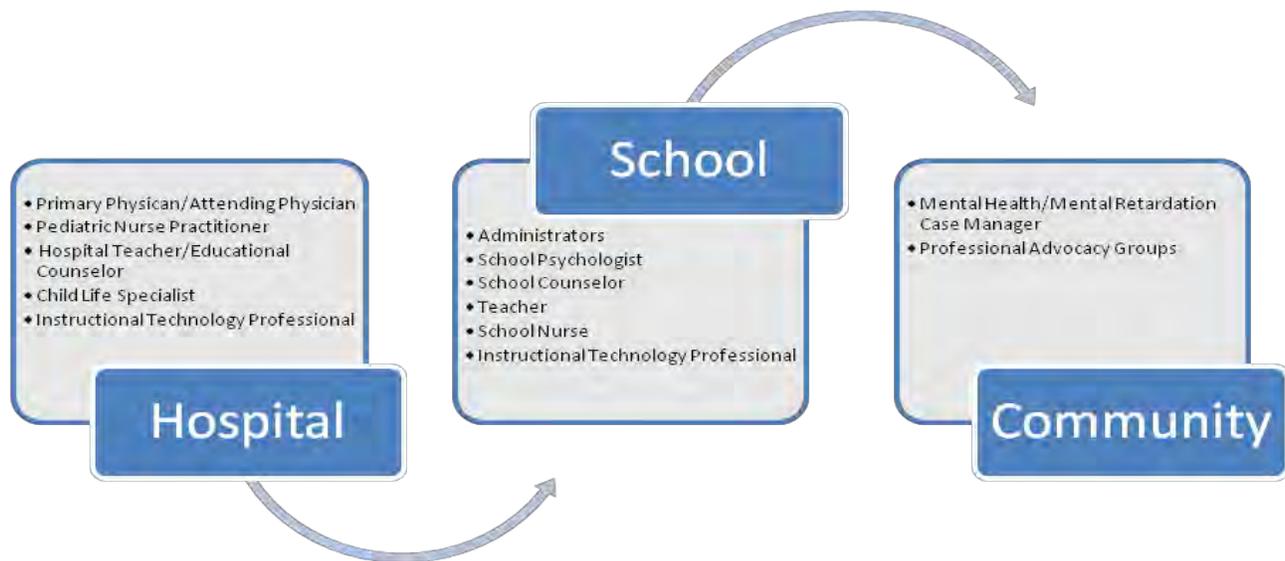
Collaboration among medical, school, and community professionals follows *best practice* recommendations for enhancing academic performance and the overall school experience of children with chronic illness (McCabe & Shaw, 2010; Shaw, Clayton, Dodd, & Rigby, 2004). For example, Segool, Mathiason, Majewicz-Hefley, and Carlson (2009) found that collaboration among school professionals, medical professionals, and parents leads to comprehensive and holistic treatment for children. Some specific benefits of collaboration include: a) improved psychosocial adjustment (Engelke, Guttu, Warren, & Swanson, 2008), b) increased communication with the family (Thies, 1999), and c) improved health care at school. However, despite the positive findings and general agreement regarding the benefits of interdisciplinary collaboration, Gardner (2005) holds that interdisciplinary collaboration as a practice norm is quite rare.

According to Gardner (2005), collaboration involves key stakeholders working together to provide an interdisciplinary coordination of care and services. For a child with a chronic illness, collaboration, ideally, provides a synthesis of different care perspectives and, as a result, a better understanding of the complexity of meeting the child's needs. However, the presence of multiple perspectives and varying responsibilities often

impedes the practical implementation of interdisciplinary collaboration. In many cases, professionals do not know or understand the roles of their fellow service providers. That said, the question becomes: “Who’s on First?” The answer: a clear identification of the roles and responsibilities of service providers.

Roles and Responsibilities

The chart below lists the multiple service providers involved with a child with a chronic illness. This is followed by a definition of each professional’s roles and responsibilities.



The Hospital

Primary Physician/Attending Physician. The Primary Care Physician provides the child’s health care before and after hospitalization. When the child is hospitalized, the Primary Care Physician generally plays a coordination and oversight role as multiple physicians, surgeons, and specialists become involved in the child’s care. The Attending Physician determines the type and level of care needed and provides hospital-based treatment. If the child’s health care needs are not specified on the insurance company’s approved providers/procedures list, the Attending Physician negotiates with the child’s care manager to secure approval for the recommended treatment. The Attending Physician also writes the child’s discharge summary and makes recommendations for outpatient care and school re-entry. Both the Attending Physician and Personal Care Physician provide consultation regarding the accommodations and modifications (e.g., meeting academic deadlines, concentrating on academic tasks, doing homework, etc.) necessary for successful adjustment to the home school. (Mayer et al., 2005; Percelay, 2003).

Pediatric Nurse Practitioner. The Nurse Practitioner plays a prominent role in the provision and coordination of hospital-based care for all patients. In conjunction with the Attending Physician, the Nurse Practitioner: a) performs assessments and makes diagnoses, b) develops and manages the treatment plan, c) oversees the work of other health-care providers (e.g., nursing assistants), d) provides patient education and counseling, e) suggests preventive health interventions, and f) makes referrals to providers within the healthcare system (Allen, Fennie, & Jalkut, 2008). When the chronically ill child enters the hospital, the Pediatric Nurse Practitioner performs these traditional roles as well as consults with hospital-based teachers, child-life specialists, community caseworkers and mental health professionals, and the child's school personnel (Rideout, 2007). The Pediatric Nurse Practitioner is also a key person in communicating with the child's family, listening to their concerns, and supporting them through the complexities of the child's illness (Wilson, 2005). In addition, the Pediatric Nurse Practitioner can identify psychosocial or behavioral issues (e.g., Attention Deficit Hyperactivity Disorder, Depression, Anxiety, etc.) and make referrals for mental health treatment (Allen et al., 2008). As cure rates and life expectancies for children with chronic illnesses increase, Pediatric Nurse Practitioners are being called upon to monitor the long term physical and psychological effects of treatment and help the child maintain a healthy lifestyle while negotiating developmental transitions (Bradwell, 2009; Rideout, 2007).

Teacher/Educational Counselor. The hospital-based teacher is generally certified to teach a variety of subjects and special education classes from kindergarten to grade twelve (KidsHealth, 2010). The teacher works in conjunction with the child's Home School Teacher, Pediatric Nurse Practitioner, and Attending Physician to develop an academic plan based on the child's academic level and medical condition. The teacher then provides either bedside or classroom-based instruction that includes both academic lessons and activities to promote social/emotional development. When the child is ready for discharge from the hospital, the teacher assists in planning for the child's re-entry to the home school and forwards attendance records to home school personnel. If the child is not able to attend school upon discharge, the teacher assists in developing a plan for home-bound instruction (Arkansas Children's Hospital, 2010; Children's Hospital of Philadelphia, 2010; MD Anderson Cancer Center, 2010).

Child-Life Specialist. The Child-Life Specialist is trained in child development and family systems with a particular emphasis on the challenges inherent in health care and hospitalization. In practice, the Child-Life Specialist attends to the developmental needs of the chronically ill child when faced with experiences such as separation from school, family, and friends, invasive medical procedures, and intermittent hospitalizations. The Child-Life Specialist identifies potential stressors, designs activities to facilitate self-expression, and helps the child build coping skills. The Child-Life Specialist also provides therapeutic play activities and arranges activities that normalize the hospital stay (e.g., birthdays, holiday celebrations). In conjunction with the hospital teacher, the Child-Life Specialist assists with the coordination of school schedules and education time (Child Life Council, 2010; Rabetoy, 2008).

Instructional Design and Technology Professional. The hospital-based Instructional Design and Technology Professional works in collaboration with teachers and software companies to provide the child with access to the latest in computer

technology. The Instructional Design and Technology Professional also evaluates the availability of computers, identifies and resolves software and hardware problems, and assures that the child has safe and appropriate access to network participation (Nicholas et al., 2007).

The School

Administrators. School Administrators advocate for the health and well-being of all children in their school system by fostering respect for diversity and an understanding of individual differences (American Association of School Administrators, 2010). School Administrators write, implement, and oversee protocols directed toward helping the child remain successful in school while dealing with a chronic illness. School Administrators also collaborate with multiple health care providers and school personnel to implement district-wide changes as various needs arise (Shaw et al., 2004).

School Psychologist. The school psychologist facilitates the student's academic achievement and social-emotional development (National Association of School Psychologists, 2009). In practice, the School Psychologist uses a comprehensive battery of tests and assessment instruments to determine the child's learning needs, identify behavioral issues, and make recommendations for suitable academic placements. In doing so, the School Psychologist also reviews the child's attendance records and academic performance. Should academic performance appear compromised by repeated absences, the School Psychologist refers the child for Other Health Impairments (OHI) Services (Wodrich & Spencer, 2008). This process identifies a child with a chronic illness. The School Psychologist then follows Federal guidelines (i.e., IDEA of 1990 and Section 504 of the Vocational Rehabilitation Act of 1973) in writing an Individualized Educational Plan and a 504 Plan that specifies the child's needs, goals, and necessary accommodations and modification for success in school.

School Counselor. The School Counselor provides educational, personal/developmental, group, and career counseling services to all children. When working with a child who is chronically ill, the School Counselor collaborates with community, hospital, and school-based providers to assure that the special needs of the child are addressed. The School Counselor is also a key contact person between the school and the child's family. In addition, the School Counselor assists with the child's re-entry by assuring that the necessary accommodations and modifications are in place and networking with health care and mental health specialists in the community (American School Counselor Association, 2004).

School Nurse. The School Nurse plays a medical case manager role in the school life of the child with a chronic illness. The School Nurse provides direct health care, crisis intervention, medication management, and prevention education. The School Nurse also advises the child, family, and school personnel on methods to improve the child's quality of life and quality of care (Engelke et al., 2008; National Association of School Nurses, 2006).

Teacher. The Teacher provides the tools and opportunities for the child with a chronic illness to succeed academically both in the classroom and during periods of hospitalization. This includes developing and implementing classroom accommodations and modifications, collaborating with the hospital-based teacher, and working with the child's classmates to understand the child's illness. The teacher also sets the behavioral

and social expectations of respect and tolerance in the classroom. By doing so, the child with a chronic illness has an equal opportunity to be regarded positively among peers (Shiu, 2001).

School-Based Instructional Design and Technology (IT) Professional. The Instructional Design and Technology Professional in the school plays a role similar to that of the hospital-based Professional. The Instructional Design and Technology Professional insures that the child with a chronic illness has access to computer technology to facilitate academic achievement and social/emotional development (Seels & Richey, 1994).

The Community

Mental Health/Mental Retardation Case Manager. In the event that a child with a chronic illness appears to be also suffering from a mental health or mental retardation issue, a community-based case manager becomes involved in the child's overall treatment. First, the Case Manager will help secure the assessment and consultation services necessary to further explore the problem. If the child is determined to have a mental health or mental retardation diagnosis, the Case Manager helps the family explore treatment options and makes referrals to various human service agencies. The Case Manager then coordinates and monitors the variety of services applicable to the individual child and family. For example, if a child with a chronic illness is unable to attend school, the Case Manager may assist the family in networking with the school district and making arrangements for homebound instruction. The Case Manager may also work with school personnel to assure that the child receives the accommodations and modifications stipulated in the Individual Education Plan. Across settings and services, the case manager acts as an advocate on behalf of the child and family (J. Reichart, personal communication, October 18, 2010; Service, Access and Management, 2010)

Professional Advocacy Groups. Professional Advocacy Groups dedicated to specific childhood illnesses offer family-school-community partnerships on behalf of the child with a chronic illness. Professional Advocacy Groups provide information, consultation regarding assistive devices, and legislative advocacy to address the needs of the child, family, and school. For example, the American Diabetes Association conducts the *Safe at School Campaign*. This initiative is "dedicated to making sure all children with diabetes are medically safe at school and have the same educational opportunities as their classmates" (American Diabetes Association, 2010, p. 2).

Conclusion

As the number of children living with chronic illnesses grows, so does their presence in the school community. The result is a heightened awareness of the medical, educational, and social/emotional challenges that these children encounter on a daily basis. Critical to addressing these challenges is a spirit of collaboration among the multiple professionals involved in the child's care. However, good collaboration models break down in actual practice. This article posits that a clear understanding of the roles and responsibilities of each provider holds the key to effective interdisciplinary collaboration. Empowered with information that answers the question "Who's on first?",

professionals involved in the care and well being of the child with a chronic illness can work together to effectively address challenges across life domains.

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