

Bridging the Gap: Education Services Within the Scope of a Child Life Program

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INTRODUCTION / HISTORY

Each year in this country, approximately six million children ranging from newborn to seventeen years old are hospitalized for a variety of conditions (www.ahrq.gov/data/hcup/factbk4/factbk4.htm). Many children who frequent our hospitals have chronic conditions. The estimated number of children in the US with a chronic illness ranges from 13.7% to 17% (Stein, R.E.K., Silver, E.J., 2002). This article will focus on the education of children with chronic conditions, also known as Children with Special Health Care Needs (CSHCN). While children with special health care needs comprised nearly 20 percent of all children in 2002, these children accounted for 45 percent of the total expenditures for all children's health care (Source: Agency for Healthcare Research and Quality, MEPS Statistical Brief #75: *Access to Needed Medical Care Among Children Under 18 Years of Age With Special Health Care Needs: 2002*).

In July, 1980, a major investigation was begun at Vanderbilt University to address the needs of chronically ill children and their families. The Vanderbilt study included children with 11 specific chronic diseases and disorders. This landmark study identified many gaps in service, some of which specifically related to the children's education: poor communication between healthcare providers and school staff, lack of information on specific illnesses for staff when children returned to school, frequent and/or intermittent absenteeism, inadequate home instruction, lack of educational support, poor identification of special learning needs, and a general lack of educational service coordination. (Hobbs, Nicholas, Ireys, Henry, Perrin, James, 1983). These gaps in educational services exist for children with many other chronic conditions (Kleinberg, 1982).

More recently, national attention has focused on the value of linking health and education services to improve the well-being of children and families. According to a study done by

the National Association of Children's Hospitals and Related Institutions (NACHRI), 70 of 74 of the hospitals that responded reported that they have partnerships with schools (2001). The American Academy of Pediatrics (AAP) has issued several policy statements on the education of Children with Special Health Care Needs, all of them calling for physician attention to the educational needs of their patients.

WHY SCHOOL SERVICES IN THE HOSPITAL?

The idea for hospital school programs is not new. As far back as 1959, Emma Plank stated, "Learning takes on a very different meaning when a child is hospitalized. Going to school in the hospital can be a link to the past and the future. It reassures a child that his parents, his home, school, and the hospital staff all work together and believe in getting well" (1959, p.47). Susan B. Kleinberg stressed the need for hospital school programming in her book, *Educating the Chronically Ill Child*, and recommended that educational strategies be implemented specifically for the child's medical condition (1982). School programming in the hospital keeps a child up with his/her studies, helps to maintain the educational process, and provides continuity in normal experiences.

In a 1979 article, Jerriann Wilson, Director of Child Life at Johns Hopkins Children's Center, cited the need for educational programming. Hospitalized children needed not only to continue the learning process, but also to remain connected to school as a familiar experience in the strangeness of a hospital setting. School programming in the hospital serves to emphasize the healthy part of a child during his/her confinement (Wilson, 1979).

Today it has become clear that school is an important and valued component of a child's stay in the hospital. Ninety-seven percent of hospitals surveyed report that they provide space and materials for hospital schools, with local educational systems providing the

teachers (NACHRI, 2001). Some hospitals hire and fund their own teachers. School in the hospital is also a standard of care of the Joint Commission on Accreditation of Healthcare Organizations. Academic instruction is provided to children and adolescents either directly through the hospital or through other arrangements, when appropriate (JCAHO, 2005).

Current education laws and state regulations address the educational needs of children wherever they currently reside, including a hospital or other healthcare facility. Every state in the US has regulations regarding hospital and/or home instruction, and almost every local school system has different policies regarding implementation of this important educational service. In New York, for example, the state regulations require home and/or hospital instruction to begin within a reasonable period of time. Local school district policies may define a "reasonable period of time" ranging from two to six weeks. Once initiated, students in grades K-6 must receive a minimum of 5 hours per week (preferably 1 hour per day) and students in grades 7-12 must receive a minimum of 10 hours per week (2 hours per day).

Public Law (PL): 101-478: The Individuals with Disabilities Act (IDEA) is federal legislation that mandates a child's right to a "free and appropriate public education (FAPE) ... in the least restrictive environment (LRE)." Students currently classified under special education law (IDEA) may have home and hospital instruction specifically included in their Individualized Education Plan (IEP). Other students with chronic medical conditions may have a 504 Accommodation Plan on file with their school to address their needs as a "person with a disability" under Section 504 of the Rehabilitation Act of 1973.

HOSPITAL SCHOOL MODELS

Traditionally, there have been three models for hospital-based school services. Most school districts require a letter from a physician stating there is a medical need for instruction to begin. There are different requirements for additional documentation, depending on the school district or the individual Board of Education.

Often, the hospital and local school districts (including large city Boards of Education) work collaboratively to provide instruction to

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children in the hospital. The hospital staff may initiate the referral for instruction. Each school district or city Board of Education is then responsible for the provision of direct teaching services and additional services, depending on the child's individual needs. However, children have a right under law to receive hospital or home instruction without IEP's or 504 Accommodation Plans. The hospital teacher may be on-site full-time while actually a school district employee. This model does not necessarily provide opportunities for collaboration between the hospital and the child's home school.

Another model for hospital instruction occurs when the hospital works with one or more educational/tutoring agencies on a contractual basis. Each educational/tutoring agency works independently and provides different services. School districts are billed directly for the services by these agencies. In this model, hospital staff would initiate a referral to the agency, and could stay involved in the educational process depending on the relationship with the tutorial agency.

A model that is less common, but very effective, occurs when hospitals fund their own school programs. In this model, the teachers are a part of the child life program and the healthcare team. Teachers offer valuable information at team meetings and psychosocial rounds. They often act as the liaison to the schools for the children who are hospitalized, gathering important information such as the child's IEP or 504 Accommodation Plan, if the child has special needs. Sometimes the teacher is also in charge of the school reentry program, which may include other disciplines from the hospital, depending on the way the hospital is structured, and the design of the child life program. Other times, staff from another discipline, such as child life or social work, is the coordinator of the school reentry program. It is often possible to seek reimbursement from the child's school district but this depends on local policies and procedures. This type of program was implemented at North Shore University Hospital in Manhasset, New York in the late 1980's. It is a model that works extremely well but it isn't always possible, due to funding, staffing constraints, and agreements with local school

districts or Boards of Education. To implement the type of program such as the one described may take a great deal of advocacy on the part of child life staff and other disciplines in the hospital.

COMMUNICATION WITH THE CHILD'S SCHOOL

When a child's day is interrupted by a chronic illness or hospitalization, his/her daily routine is changed, and contact with friends, family and school is interrupted. It is also important for the child who is in the hospital or at home for long periods of time to maintain contact with his/her school. Emotional support from teachers or classmates can help a child adjust to health issues more easily.

With parental consent, initiating contact with the child's teacher can be an important step for the child's well-being. It is important to make sure the child has textbooks, school assignments, and other materials so the child can keep up with his/her studies while in the hospital. Child life specialists can find out if any special accommodations are needed. Many hospital school programs request the IEP or the 504 Accommodation Plan if the child has one, so activities and space can be modified to meet the child's needs.

Following are some suggestions to help make the child continue to feel a part of the class:

- Cards, letters or pictures from classmates
- Photos of the class and of staff in the school
- Tape recorded messages that the child can play
- A video tape of the class
- Phone calls to the child (with parental permission)
- Visits from classmates and staff (with parental permission)

Before the child is discharged from the hospital, check with the parents and the school district to make sure the child has the necessary medical documentation for home instruction or to return to school.

SCHOOL REENTRY PROGRAM – HELPING THE CHILD ADJUST TO RETURNING TO SCHOOL

Children with chronic illnesses often have accompanying learning difficulties. Some are associated with the illness directly, others are

the results of treatment, impairments due to head trauma, or they may be unrelated problems. These children must be evaluated for special education services (Kleinberg, 1982). For this reason, children with chronic illnesses who are discharged from the hospital are in need of a school reentry program, to support them with their continued educational needs. Following are key components of a comprehensive school reentry program:

- **Parent Education:** A child life staff member can be designated to serve as the contact person for the healthcare team, and this can be communicated to the parent upon the child's discharge, in case the parent has questions or additional need for support. Before the child is discharged, develop a parent information packet. Include a parent consent form and any pertinent medical documentation that is necessary for their child to return to school. Explain to the family what a school reentry program is and how it can be tailored to meet the needs of their child. Let parents know that reentry services are optional. They can make a decision now or at a later date. Often, school reentry is needed at different critical points in the child's education. Discuss with parents the federal laws (see below) as they relate to education and the rights of Children with Special Health Care Needs. Refer families to local support groups and other agencies for advocacy and information, such as advocacy groups, parent support, sibling programs, school referrals, respite care, socialization groups or summer camps.
- **School Reentry Team:** Some hospitals have multidisciplinary school reentry outreach teams already in place, including education, medical and psychosocial staff within the hospital. If such a program does not exist already, contact the school and establish a collaborative relationship by identifying the education, medical and psychosocial staff who will continue to care for the child within the school and hospital. Parents should be included on the team to support family-centered care.
- **School Reentry Plan:** Facilitate discussions between the family and the healthcare team regarding the child's needs during the school day, and help to develop a plan. Discuss this plan with the school team. Parents are a critical part of the

healthcare team and must be involved in the development of their child's school reentry plan, because they are the experts in knowing what their child needs. Work with the family to design a school reentry visit. This visit could be for the child's class or an in-service for the faculty, and may even include parents of classmates.

- **Required Health Documentation:** Check again before the child is discharged to see if the school requires any medical documentation to facilitate the return to school.
- **Siblings:** Recognize and acknowledge sibling issues and the need for support. Let the parents know that a child life specialist is available to provide sibling support.
- **Ongoing Care:** Staff members might serve as liaisons to families. It is helpful to call parents to see how their child is managing the return home and back to school; continue to offer support to the child and the family, and ask if they have any questions. Reaching out to the child's family might be helpful. Also, a note to a child can brighten his/her day. This way of systematically reaching out to families may send a positive, caring message and may help support them during the school reentry process.

SUMMARY OF LEGISLATION

In order to help children maintain their educational process and ensure a successful school reentry, it is necessary to become familiar with the laws affecting children with special needs in school.

Until 1969, most children and individuals in need of specialized services were unable to attend school. There were few options and most children were served in state facilities. Finally, parents in Pennsylvania brought a class action lawsuit against the schools, claiming that civil rights were being ignored. Twenty-seven court cases later, the Education of All Handicapped Children's Act of 1975 (EHA) was signed into law. Children with disabilities in the US became entitled to a free, appropriate, public education (FAPE) in the least restrictive environment (LRE). Public Law 101-478: The Individuals with Disabilities Act essentially replaced the landmark EHA. IDEA was most recently revised in December, 2004.

IDEA requires public schools to locate and identify children with disabilities who may be in need of specialized education. These children will "have available to them a free, appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment and independent living." [20 U.S.C. {1400(d)}. The statute includes specific requirements about eligibility for services, the components of the IEP, designates the IEP team members, and outlines the comprehensive procedural requirements related to disputes and complaints. However, the law is always changing and evolving. To understand IDEA you need to read the statute, the regulations, and cases that have interpreted the statute (Peter and Pamela Wright, 2004).

Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA) are both civil rights provisions barring discrimination against persons with disabilities, and are very helpful in the education of children who may have special needs but don't require specialized education. Under these laws, individuals must have an impairment that substantially limits one or more major life activities to be designated a "person with a disability." Under Section 504, an Accommodation Plan is developed that outlines reasonable accommodations and services that children need to fully participate in all activities of school. The plan may include such accommodations as preferential seating, a second set of textbooks to keep at home, or intermittent home instruction. School district teams, with parents and sometimes other professionals, develop IEP's and Accommodation Plans.

There are many resources included on the CLC Web site at the link below, to help child life professionals stay up-to-date with the most recent revisions and information.

http://www.childlife.org/Information_Central/resource_pages/daily_clinical.htm#school

In addition, some hospitals have Family Resource Centers, where staff and parents can go to access the most recent information available on laws that affect the education of children with special healthcare needs. A child life specialist or librarian in the Family Resource Center can help parents navigate the complex educational system.

THE LAW AND CANADA

In Canada, the education laws are referred to as 'human rights.' "Canada has always been active in its involvement with the exceptional child. From the policies makers at the federal and provincial levels through the teachers in training at the university and colleges" (www.ccc.sped.org). Accommodations for children and adults are very important in Canada. Provincial and territorial governments provide the legal basis for operating the educational systems and provide the framework for which educational services must be provided. These services vary from province to province and territory to territory. Many Canadian child life programs have been leaders in school reentry programs for children who have been hospitalized. (www.ccc.sped.org/ab/canadian.html.)

THE CHILD LIFE SPECIALIST AS EDUCATION ADVOCATE

Education advocacy often seems to fall outside of the realm of child life services. In actuality, child life specialists are uniquely qualified to advocate for children in schools. They have advocated on behalf of children in the hospital setting for decades. Child life specialists are aware of the needs of children and understand the importance that school plays in their lives.

To begin, staff will need to familiarize themselves with the federal and state regulations, and local education policies, and be able to provide parents with this information. Child life specialists can initiate referrals for services while children are hospitalized and follow up to ensure they are received. Child life specialists can collaborate with school districts and often need to familiarize school personnel with state regulations regarding hospital school services. It is also helpful to explain what other school districts in the surrounding areas are doing for children in the hospital.

Because child life specialists have developed relationships with a family during hospitalization, they are able to support them through the difficult process of accessing services for their special needs child. Because child life specialists practice family-centered care, they are also able to encourage this focus in the development of plans for children's educational needs due to illness. They can be an invaluable source of information and ideas for the Special Education Team

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(with parental consent, of course). Additionally, a child life specialist, via conference call or in person, can make valuable contributions to an educational plan discussion with the school. It may also be very helpful to the following groups of providers for the child:

- **Early Intervention Team (EI):** for infants, birth through two years, eleven months
- **Committee on Preschool Special Education (CPSE):** for children three to five years of age
- **Committee on Special Education (CSE):** for children five years and up
- **Section 504 Committee:** protects all children with disabilities from discrimination who do not qualify for IDEA. "Section

504 protects children whose disabilities directly interfere with their ability to learn or whose disability substantially limits one or more 'major life activities,' such as seeing, walking, breathing or learning." (www.insideschools.org/st/ST_504.php)

A child life program can initiate a School-Health-Parent Task Force and include several staff members from various disciplines, staff from local school districts, and parents from various districts, whose children are either frequently hospitalized or have a chronic medical condition. It is always helpful to have a physician and local state representative on your task force. Once school district personnel understand the challenges that chronically ill children and their families face on a daily basis, they often listen and respond appropriately.

The Child Life and Education staff at North Shore University Hospital in New York initiated a School-Health-Parent Task Force on Long Island in 1990. Due to the efforts of many parents, hospital staff and school district personnel, intermittent home instruction was something that was possible to implement on Long Island. This service addresses the needs of children who miss one or two days of school each week because of a chronic condition, but usually don't miss enough consecutive days to receive services under the standard policy. With this service they can receive some home instruction and still attend school when they are well enough. This term and service, 'intermittent home instruction' remains intact today across Long Island.

CONCLUSION

Child life specialists play an important role in the well-being of children in hospitals, at home, in the community, and in the schools. Their work is important in helping children with special health care needs and their families negotiate the complex educational system.

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