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ABSTRACT

These guidelines are intended to help educators and other school personnel in Kentucky better manage the inclusion of students who require health services in either special or regular educational settings. The brief manual has sections which address: definitions; related Kentucky regulations; results of a statewide survey on personnel, qualifications, and policies regarding delivery of health services in classrooms; belief statements; placement and Individualized Education Program development; provision of related services; training of unlicensed school personnel to perform special health care procedures; emergency procedures; and transportation issues. Much of the document is comprised of 12 appendices which include: recommendations for dealing with specific health care procedures; guidelines for developing appropriate individual education programs for students with special health care needs; sample letters and forms; information on preventing transmission of communicable diseases; and listings of local health departments and home health coordinators, national resources and information centers, and related statewide training projects and materials. There are 14 references and an annotated bibliography of 88 related documents and readings. (DB)







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Kentucky Systems Change Project

Services for Students with Special Health Care Needs

Guidelines for Local School Districts

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Jennifer L. Leatherby, M.S.

A project conducted by the Interdisciplinary Human Development Institute—University Affiliated Program, University of Kentucky for the Kentucky Department of Education, Office of Education for Exceptional Children. Funded by the U.S. Department of Education, Office of Special Education Programs, grant number G0087C3061-90 and 91.

SERVICES FOR STUDENTS WITH SPECIAL HEALTH CARE NEEDS

Guidelines for Local School Districts

September. 1992

prepared for the

Division of Special Learning Needs and the Division of Exceptional Children Services

Kentucky Department of Education

by

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FOREWORD

There was a time when the ability to care for one's self was a prerequisite to admission into many public schools. No child who was not toilet trained would be permitted to attend! With changes in attitudes and laws have come changes in student populations. Consequently, now we are fairly accustomed to teaching students who have not yet learned to toilet themselves and those students who have not yet learned to feed themselves.

The newest change in today's school is the inclusion of students whose care needs extend beyond those that might be considered basic, such as feeding and toileting or changing. Many of these students require the provision of health care services that extend way beyond that which has been traditionally identified as school health services. In today's public schools we are educating students who require specialized health care services such as gastrointestinal tube feeding or catheterization for elimination of urine or continuous oxygen through a ventilator to assist their breathing. These student who previously attended school in either hospitals or at home, are now being educated in school based classrooms. Consequently, numerous questions and issues arise regarding their education and their needs for related or medical services. Students with special health care needs have proved to be a challenge to personnel in every level of education systems.

Administrators, transportation providers, teachers, nurses, therapists and other personnel in the schools have come together in planning to meet the needs of these students. These personnel have often felt like pioneers, newly meeting the challenge of the students without the benefit of prior experience or resources to assist them in their efforts.

While the entry of each new student with special health care need will continue to present individual challenges, a body of both published and unpublished literature has emerged that can serve to guide administrators and program planners in providing for safe educational environments for these students, their peers and school personnel. This literature is based on case law, research and practical experience with educational and health care service delivery to children with special health care needs who have become students in special and regular educational settings. While no one document could possibly provide all the information needed, the authors of "Services for Children with Special Health Care



Needs: Guidelines for Local School Districts" have drawn from the extant literature and have very effectively synthesized, complied, referenced and/or augmented it. Its content should enable the authors to meet their goal of providing "...districts and parents with a basic understanding of what needs to occur to appropriately service children with special health care needs" (p.5).

Donna H. Lehr, Ph.D Associate Professor Boston University Chair, TASH Critical Issues Subcommittee on Individuals with Special Health Needs



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STUDENTS WITH SPECIAL HEALTH CARE NEEDS

Historically, many children with special health care needs did not survive to school age or were served at home or in hospital settings. With advances in health care and medical technology, more of these children are surviving, living at home, and being served by local school districts in Kentucky. These school districts are faced with financial, educational, legal, and health related issues that they have never faced before.

In the summer of 1990, the Kentucky Systems Change Project for Students with Severe Handicaps organized a subcommittee of its Advisory Board to develop state guidelines for providing health related services to children with special health care needs. This endeavor was requested by the Kentucky Department of Education, Office of Education for Exceptional Children to provide needed direction for local school districts. This document includes information that addresses definitions related to students with special health care needs, related Kentucky regulations, the results of a statewide survey of teachers regarding service provision, belief statements regarding quality service provision, placement and development of individualized program plans, provision of related services, training of unlicensed personnel to provide health care services, emergency procedures. and transportation issues. Many of these issues will require further exploration and development. However, we believe that the information in this document will provide local school districts and parents a basic understanding of what needs to occur in order to appropriately serve children with special health care needs. The appendices include additional information about specific health care procedures. other health concerns, developing IEPs, sample forms for training and accumentation, related readings, and other recommended resources.

Definitions

All children have health care needs related to school attendance. These needs may include something as simple as having a temperature taken or applying a bandage to a skinned knee. Other students may have conditions and/or illnesses that require special health care considerations such as the student who must have daily insulin shots due to diabetes. Additionally, some students may have special health care needs that require more intensive health care services or a broader range of services.

Under certain circumstances, students with specific health impairments may be eligible for special education services based on their health care needs. P.L. 94-142 specifies that a student is eligible for special education and related services or support services due to a health impairment if the following conditions exist:



- 1. The child has limited strength, vitality or alertness, due to chronic or acute health problems such as a heart condition, tuberculosis, sickle cell anemia, hemophilia, epilepsy, rheumatic fever, nephritis, asthma, lead poisoning, leukemia, or diabetes; and
- The condition(s) of the child adversely affects the child's educational performance.

The key to eligibility for children with health impairments is the extent to which the health impairment impacts the child's ability to perform in school. For example, many students with diabetes do not receive special education services due to the fact that the condition does not adversely affect their educational performance. Likewise, students with epilepsy do not automatically qualify for special education because of this condition. While the student with epilepsy may require health services in the form of seizure monitoring, special education is not required unless epilepsy negatively effects the student's educational performance.

There is yet another category of students who do not fit under the categorical label of "Other Health Impaired". These students require intensive health care services and are generally placed in special education based on their primary handicapping condition: multiple handicaps, severe handicaps, or deaf-blindness.

For the purposes of this document, children with special health care needs are described as those children who require individualized health related interventions to enable participation in the educational process. Included within this population are children who:

- 1. have unstable medical conditions or who may require emergency medical procedures,
- 2. require special health care procedures during the school day, or
- use a particular medical device that compensates for the loss of a body function and who require substantial, and complex or frequent health care to avert death or further disability (adapted from Iowa Department of Education, 1988).

This document will primarily focus on the provision of services for students whose primary handicapping condition is a physical disability, multiple disabilities, or severe and profound disabilities including deaf-blindness, and require the special health care interventions or procedures that are described in Appendix A. These procedures include administering medications, catheterization, gastrostomy tube feeding, glucose monitoring, ileostomy and colostomy care, nasogastric tube feeding, respirator dependent, seizure monitoring, and tracheostomy care and suctioning. In addition, many students who require these procedures may have additional health related concerns such as prevention of bone and joint deformities, bowel care, cast care, congenital heart disease, feeding/eating



disorders, nutritional concerns, othotics care (braces and splints), prosthetics care, shunt monitoring, and skin care (see Appendix B for descriptions and related information).

Related Kentucky Regulations

Currently, there are no Kentucky regulations for provision of educational services for students with special health care needs. However, there is a wealth of general health related information in the *School Health Services Manual* (Department of Education, 1990) and all teachers in Kentucky need to have access to this document and training related to its content.

When determining if unlicensed school staff can administer health care procedures, two questions must be answered: a) Does the procedure have to be administered by a physician?, and b) Do the current state nursing laws state that the procedure(s) can only be administered by a registered or practical licensed nurse? If the procedure can only be administered by a physician, then it is a medical service (not a related service and the school system is not obligated to provide it) and unlicensed school personnel cannot perform the service. If the procedure can be administered by a registered or licensed practical nurse, it is a health related service; and thus, a review of a state's current "Nurse Practice Act" provides us information on whether or not the procedure can only be administered by a nurse or whether a nurse may teach, supervise and delegate the performance of the procedure to others. A review of Kentucky Revised Statute Chapter 314 (Kentucky Nursing Laws, 1992) defines nursing practice, in summary, as the performance of acts requiring specialized knowledge, judgement, and skill; and permits nurses to teach, supervise and delegate the performance of selected acts to unlicensed personnel who possess adequate training and skill to perform the act in a safe, effective manner. KRS 314.011 (2) states: "Delegation means directing a competent person to perform a selected nursing activity or task in a selected situation under the nurse's supervision and pursuant to administrative regulations promulgated by the Board of Nursing". The term "supervision" is defined by the Kentucky Board of Nursing to mean the provision of guidance by a qualified nurse for the accomplishment of a task with periodic observation and evaluation of the performance of the task including validation that the task has been performed in a safe, effective manner. Thus, unlicensed school personnel may perform selected nursing acts under the delegation and supervision of a nurse and/or physician. The nurse or physician is not required to be on site to provide direct supervision when unlicensed personnel have been trained by a nurse and/or physician to perform the act. The only health care procedures discussed in Appendix A that cannot be performed by a teacher (even with training) include administering injections, nasogastric tube feedings and medications via this route, and sterile urinary catheterization. In addition, a student who is respirator/ventilator dependent requires complex, specialized health care support performed by a licensed health care provider.



Results of Statewide Survey

Given the above information, a statewide survey of teachers in SPH, TMH, MH, and OHI units (classrooms) was conducted to determine the current trends in the delivery of health related services for students with special health care needs in Kentucky (Smith, Leatherby, & Wasson, 1991). The survey was designed to answer four main questions: 1) Who is performing health care procedures in the classroom?, 2) What type of training did this individual receive?, 3) Who provided the training?, and 4) What district policies or guidelines determined the process of the delivery of these procedures? This survey was an adaptation of a similar one conducted in Kansas (Mulligan-Ault, Guess, Struth, & Thompson, 1988).

Of the 503 surveys mailed to all teachers in SPH, TMH, MH, and OHI classrooms in Kentucky, 272 were returned for a return rate of 54%. Of the 272 that were returned, sixty-five (23.9%) were not applicable because health care procedures were not required for any of the students in the classroom. Nineteen (6.9%) of the surveys contained omissions regarding their training in performing special health care procedures. Follow-up phone calls were conducted in September, 1991 to obtain the missing information and those 19 surveys were added to the sample. Thus, a total of 207 surveys were the sample for the study.

The results of the survey indicated that:

- 1. Over half (53.6%) of the teachers reported that no nurse was available to assist them, while 45.8% indicated that a nurse was available.
- 2. When nurses were available, 23.1% of the teachers reported that a nurse only came upon a specific request, 31.5% reported that a nurse was in their classroom only two to four times a year, and just 17.8% reported that a nurse was in their classroom at least once a day.
- 3. When teachers who have a school or itinerate nurse available where asked about the role of the nurse, they indicated that the two primary roles of the nurses were most frequently consultant (32.8%) and less frequently the direct service provider (12%).
- 4. Of the teachers responding, 63.2% reported no correspondence with their students' family physicians, while 31.8% indicated they did correspond with their students' physicians.
- 5. When teachers were asked if they had **written instructions** for the procedures they performed, 82 or 39.6% of the teachers reported "NO", 57 or 27.5% reported "YES", and 58 or 28% provided no response. One teacher commented that the instructions were received "over the phone".
- 6. Numerous answers were provided to the question of who determines who should perform the procedure. These included ARC determines



- (34.7%), parent recommends/determines (31.4%), teacher decides (20.7%), and nurse recommends (10.6%).
- 7. The 27 health care procedures that were listed in the survey and performed in the classrooms of the teachers surveyed ranked in the following order of frequency: 1) handling and positioning, and medication administration (both performed in 96.6% of the classrooms): 2) wheelchair care and monitoring (performed in 61.8% of the classrooms); 3) bowel care (performed in 55% of the classrooms); 4) braces care/monitoring fit (performed in 48.3% of the classrooms); 5) cardiopulmonary resucitation (CPR) (trained to perform in 47.3% of the classrooms); 6) skin care and monitoring (performed in 41.5% of the classrooms); 7) teeth and gum care (performed in 40.5% of the classrooms); 8) diet monitoring (performed in 33.3% of the classrooms); 9) gastrostomy tube feeding (performed in 28.9% of the classrooms); 10) splint care/monitoring (performed in 20.7% of the classrooms); 11) cast care (performed in 16.9% of the classrooms); 12) shunt monitoring (performed in 14.9% of the classrooms; 13) catheterization and postural drainage (both performed in 14% of the classrooms); 14) percussion (performed in 9.6% of the classrooms); 15) monitoring blood/urine glucose levels, bulb syringe suctioning of tracheostomy, machine suctioning of tracheostomy, and changing trach tubes (all four procedures performed in 6.2% of the classrooms); 16) changing trach ties (performed in 5.7% of the classrooms); 17) colostomy or ileostomy care (performed in 3.8% of the classrooms); 18) nasogastric tube feeding (performed in 2.8% of the classrooms); 19) administering enemas (performed in 2.4% of the classrooms); 20) oxygen supplement (performed in 1.4% of the classrooms); 21) delee suctioning (performed in 0.96% of the classrooms); and 22) prosthesis care (performed in 0.4% of the classrooms).
- 8. Of the 27 health related procedures or concerns listed on the survey (see #7 above), 92.5% or 26 of the procedures were performed most often by teachers. Only two procedures were performed more often by other persons: Catheterization performed most often by the teacher assistant (41.3%) and delee suctioning was performed most frequently by a nurse (100%). In addition, paraprofessionals or teacher assistants were performing 22 of the 27 procedures (81.4%) and nurses were performing 21 of the 27 (77.7%).
- 9. When teachers were asked to indicate how they were trained to perform the procedure, direct training via consultation by a nurse or other licensed health care provider was most often used as a means of training (55.5%) when training braces care, cast care, catheterization (informal training provided by family members with equal frequency, see below), colostomy and ileostomy care (informal training provided by family members was indicated with equal frequency, see below), handling and positioning, oxygen supplementation, percussion, postural drainage, prosthesis care, skin care, splint care, teeth and gum

care, machine suctioning, changing trach tubes, and wheelchair care. Informal training by family members was the most common training method used (44.4%) when teachers received training in catheterization (training provided via consultation from a nurse or other licensed health care provider was indicated with equal frequency, see above), colostomy and ileostomy care (training provided via consultation from a nurse or other licensed health care provider was indicated with equal frequency, see above), diet monitoring, administering medications, monitoring blood/urine glucose levels, skin care, bulb syringe suctioning, changing trach ties, gastrostomy tube feeding, and nasogastrostomy tube feeding (training being provided via formal inservice training was indicated with equal frequency, see next statement). Formal inservice training was utilized most often (7.4%) with the two procedures of CPR and nasogastric tube feeding (informal training provided by family members was indicated with equal frequency, see above). Preservice training (college or university) was listed most often (3.7%) only for bowel care.

10. When the teachers were asked who conducted the training, family members were the most frequent providers of training. Family members provided training most often in 14 of the 27 procedures listed on the survey (51.8%) including braces care, catheterization. colostomy/ileostomy care, diet monitoring, enema administering, administering medications, monitoring blood/urine glucose levels (training provided by nurse and physician with equal frequency, see below), shunt care, skin care, teeth and gum care, bulb syringe suctioning, changing trach ties, gastrostomy tube feeding, and nasogastric tube feeding. Nurses provided training second most often (22.2%) primarily in procedures of CPR, monitoring blood/urine glucose levels (training provided by family members with equal frequency, see above), oxygen supplementation, postural drainage. machine suctioning, and changing trach tubes. Physical therapists also provided training in 10 of the 27 procedures listed. They provided training most often in the procedures of cast care (40%), percussion (45.4%), prosthesis care (100%), splint care (60%), and wheelchair care (47.3%). Occupational therapists provided training in 7 of the 27 procedures including braces care, cast care, handling and positioning, percussion, skin care, splint care, and wheelchair care. University professors and instructors provided training in 5 of the 27 procedures. and provided training most often in bowel care and establishing bowel habits. Doctors provided training to some teachers related to 14 of the 27 procedures, but did not provide training most frequently in any of the 27 procedures included in the survey.

The results of the statewide survey indicated that teachers are providing the majority of the health related services for students who require them during the school day. When teachers or other unlicensed school staff are the designated health care service provider/implementer, they have not been trained by a nurse, physician, or other licensed health care provider. In most cases, unlicensed school



personnel who are performing the procedure or providing the service on a regular basis do not even have written instructions to follow. In addition, few districts have written policies or procedures for the delivery of special health care services and related training specifications. It is recommended that school districts follow the training model described in the following section to ensure that unlicensed school personnel are adequately trained to reduce the risk of liability and provide a safe and healthy learning environment for students.

Belief Statements

To develop appropriate educational programs for children with special health care needs, a few basic guidelines should be understood by all persons involved in the process. The belief statements that follow form the basis for the recommendations and contents of this document and are provided as basic guidelines for local district personnel and parents:

- 1. Children with special health care needs can participate successfully in learning experiences.
- 2. All children with special health care needs do not require special education.
- 3. All children who qualify for special education services are placed in the least restrictive environment, so they can actively participate in activities with their nondisabled peers to the greatest extent possible. All educational programs are provided in learning environments that are safe and clean, minimizing health risks for all involved.
- 4. Educational placements are not based solely on the basis of the need for health care services, nor as a result of a category of handicapping condition or "label", or the configuration of the existing service delivery system. If placement outside the regular classroom is needed, provisions are made for frequent interactions with the child's nondisabled peers.
- 5. Educational placements for students who qualify for special education services are not made on the basis of availability or location of related services or support services, but on the most appropriate setting in the least restrictive environment for each individual student. Related services are clearly defined in terms of the type, nature and extent to which they will be provided and who will provide the services.
- 6. Each child with special health care needs is handled through the regular entrance and/or ARC processes, taking into account individual health care needs at each stage of the process.
- 7. Every child who has a special health care need requiring care, intervention, or supervision should have a written plan of care established as outlined in the IEP.



- 8. Families are full partners in the decision making process because they are often the best informed about their child's health history and current status.
- 9. Educational program decisions are made by an interdisciplinary team that includes: personnel knowledgeable about the student, the evaluation data, and placement options; the child's parents; and the school nurse or other licensed health care professional with input from the child's physician. Team decisions take into account the child's health care needs and educational needs, appropriateness of the educational setting, risks to the child, and training needs of unlicensed school personnel.
- Health care professionals currently providing services to children with special health care needs are recognized as valuable and necessary team members and participate in the decision-making process in the identification and interpretation of health information for the entire staff and should provide child specific training to nonlicensed personnel.
- 11. The provision of proper training and information about the provision of health care services and legal issues in regard to this population of students can promote attitudes that these children can be appropriately served in the schools.
- 12. School nurses or other licensed health care professionals are valuable members of the service delivery team who maintain responsibility direct or indirect service provision, and for training, delegating and supervising the performance of health care related procedures by unlicensed school personnel. In addition, they function as the designated qualified health care professional who is accountable for a) making appropriate delegatory decisions, b) assuring that appropriate training has been provided for each health care service provider/implementer, c) verifying the initial and on going competence of the service provider/implementer to insure safe, effective care, d) conducting periodic assessments of students to assure that proper health care services are being provided and e) providing appropriate supervision of unlicensed personnel who perform health related procedures.
- 13. Financial responsibility and reimbursement considerations are issues when serving children with special health care needs. Educational agencies are not required to assume financial responsibility for noneducationally related medical services and supplies.

These belief statements were adapted from those contained in *Recommendations:* Services for Children with Special Health Care Needs (lowa Department of Education, 1988) and *Report of the Council for Exceptional Children's Ad Hoc Committee on Medically Fragile Students* (1988). These statements formed the



basis for developing the content in this document. In addition, the subcommittee reviewed several other key documents including *Guidelines for the Delineation for Roles and Responsibilities for the Safe Delivery of Specialized Health Care in the Educational Setting* (The Joint Task Force for the Management of Children with Special Health Needs, 1990), *Issues in the Education of Students with Complex Health Care Needs* (Lehr & Noonan, 1989), and *Health Care for Students with Disabilities* (Graff, Ault, Guess, Taylor, & Thompson, 1990). Much of the information in this document is based on these previous works and the experience of professionals currently serving these children in school districts in Kentucky.

Placement and IEP Development

As previously stated, not all children with special health care needs require special education services. However, whether the child qualifies for special education services or not, schools must have information about the child's health care needs in advance of the child's entrance to school so that all required planning, provisions, and staff training can occur.

Ideally, the parent(s) or guardian of a child with a special health care need will notify appropriate school officials that their child needs special health care services. The school official should, in turn, contact the school nurse or designated licensed health care provider responsible for planning and training. Based on an educational assessment, the school system will determine if the child qualifies for special education services. Regardless of whether the student qualifies for special education services, a meeting is convened to review the health needs of the child. In cases where the child does qualify for special education services, the review may occur at the Admission and Release Committee (ARC) meeting. Persons present at this meeting include the chairperson (building principal), referring teacher or teachers, parents, the student (when appropriate), other persons providing input into the individual education program as requested by any member of the ARC, and personnel responsible for providing and interpreting evaluation information (707 KAR 1; 051). When a student has special health care needs a school nurse or other licensed health care provider should be present during the meeting. In addition, other persons that may be requested to attend the meeting may include other teachers involved with the student, school health coordinator, director of special pupil services, school guidance counselor, and other appropriate team members as needed (speech-language pathologist, physical therapist, occupational therapist, etc.). One of the primary purposes of this meeting is to determine the extent to which the student will require special health care services.

The following questions are answered during the meeting:

- 1. What are the types and nature of the services to be provided?
- 2. What is the extent and frequency of services to be provided?
- 3. Which agency has responsibility for specified health care services?



...16

- 4. What, if any, interagency agreements are required if an agency other than the school district is providing the health care services?
- 5. Where and under what conditions are the services to be provided?
- 6. Who will be the designated health care service provider/implementer (e.g., school nurse, other licensed health care provider, unlicensed school personnel)? If the designated health care service provider/implementer will be an unlicensed school staff member, how will they be trained and who will supervise and monitor the service delivery (see section entitled Training Unlicensed School Personnel to Perform Special Health Care Procedures)?
- 7. What transportation services are needed and will special health care services need to be provided during transport?
- 8. How will emergency situations be handled?
- 9. How often will the service delivery plan be reviewed?
- 10. What are the criteria for terminating services?
- 11. Who will coordinate the delivery of health related services or support services to assure that appropriate services are provided for the student (e.g., school nurse or other licensed health care provider)?
- 12. How will the student participate in the health care procedure? Can the student learn to perform all or parts of the procedure with training and monitoring? Does the health related procedure provide a context for instruction of basic skills (e.g. communication) or partial participation?

All discussions and recommendations regarding the special health care needs of the student are clearly documented. If the child has been placed in special education, much of the information obtained from the questions above is included in the Conference Summary Report, as well as in the student's Individual Education Program (IEP). For example, all health care interventions that will be conducted at school are documented in the IEP. Who will perform the service(s), where, and under what circumstances are also clearly stated. Appendix C contains examples of how health care services are documented on the IEP and how to develop IEP objectives that use these routines as valuable instructional opportunities instead of just care taking tasks.

All efforts focus on providing the student an appropriate educational program in the least restrictive environment, ideally in the child's neighborhood school. Health care needs alone or "labels" do not determine educational placement. The ARC must determine the types and levels of supports that would be necessary to provide an appropriate education in the least restrictive environment.



A critical component of planning for educational services for children with special health care needs is the information collected from sources and agencies outside the school system. Standard school medical information forms will not adequately elaborate the detailed information necessary for program design and implementation. It is critical to obtain information from the child's physician that pertains to care at school. In all instances, the parents must sign a release of information form to obtain any and all information from sources and agencies outside the school system.

Most physician's offices are very cooperative about sharing information about the child's needs and subsequent problems that might occur. In many cases, efforts may be required to establish a working relationship with the physician for the benefit of the child. Appendix D contains a sample cover letter and forms that may be used to obtain information from physicians. If a response to your information request is not received in a timely manner, follow the request with a telephone call. If necessary, forms can be hand delivered by the parents or guardian, or school personnel.

How much information is gathered and how to use the information gathered is not always easily ascertained. Sometimes, educators expect more information than is available or needed to make decisions in the realm of educational programming. Often, the best source of information is the parent or guardian and information gathered from the physician is used to confirm the information from the parents.

Information about etiology (cause) and other areas, while interesting, are not necessarily critical to our ability to provide services to the student. It is important to respect the confidentiality of medical and health related reports, while at the same time, gathering the information necessary for good educational planning and decision making. Any request for information made to an agency outside the school system is accompanied by a release of information form signed by the parents. Requests for medical and health related information are worded very specifically, rather than generally, stating questions so that they can be easily answered by the physician with the simplest answers possible. If we do not ask specific questions or provide parameters in our information requests, we may get information that is not pertinent and still not have the information we need.

A useful method of verifying and gathering additional information related to a specific health care procedure that a particular student requires is to have the parent meet with the school nurse or other licensed health care provider to list and explain the steps in the procedure in great detail. The school nurse or licensed health care provider verifies the accuracy of the detailed description of the procedure using the Program Plan and Training Form in Appendix E. The information contained in Appendix A on specific procedures may also be used to obtain additional pertinent information when talking with parents and completing the Program Planning and Training Form. If this information is clearly recorded and verified by the school nurse or other licensed health care provider, it can then be sent to the physician for verification and authorization. It is not recommended to ask the physician to complete detailed description (steps) in the procedure. The parents input is vital regarding individual adjustments in the procedure for their



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child and physicians may not be trained or experienced in the particular procedure. In addition, using this approach may greatly reduce the response time from the physician to obtain the authorization signature (See page one of the Program Planning and Training Form in Appendix E for physician's signature.). Once the physician has signed this completed form, it becomes the program plan for the student and is used as the training form by the school nurse or other licensed health care provider to train unlicensed school personnel who may be designated to be the health service provider/implementer and perform the health care procedure (see section entitled "Training Unlicensed School Personnel to Perform Special Health Care Procedures").

Provision of Related Services

Students who receive special education programs may require related services such as audiology, counseling services, identification, medical services (for diagnostic and evaluative purposes only), occupational therapy, parent counseling and training, physical therapy, psychological services, recreation, special health care services, social work services, speech pathology, and transportation. Students with special health care needs often require health care interventions during school hours in order to benefit from special education. Public Law 94-142 clearly states that medical services which have to be performed by physicians are not considered related services or support services unless they are solely for purposes of diagnosing or evaluating a student.

A precedent has been set for providing health related procedures during the school day. In Irving Independent School District vs. Tatro (1984), the United States Supreme Court ruled that clean intermittent catheterization was considered a related school health service that enabled a 3 1/2 year old child with spina bifida to benefit from special education. In the Department of Education, State of Hawaii vs. Dorr (1982) a similar decision was made. It was determined that reinsertion of a tracheostomy tube could be performed by a school nurse or other trained school personnel and was therefore considered a related school health service. It is worth noting that the procedure was considered a school health service as opposed to a medical service, which must be provided by a licensed physician. School health services may be provided by a school nurse or other trained school personnel.

In matters where the issue is one in which the school is asked to administer a particular procedure or provide a health care service, the courts appear to favor the plaintiff (child and family). However, when the issue is in regard to who pays for specific services, the courts are more likely to favor the school system. Thus, parents were responsible for supplying the equipment and supplies for health care procedures conducted at school. Two cases typify these circumstances. In Detsel by Detsel v. Board of Education of Auburn (1985) and Bevin H. by Michael H. vs. Wright (1986) parents asked the school system to pay for nursing services for their children upon entrance to public school. In both cases, procedures such as suctioning and administration of medications through a gastrostomy tube had previously been conducted by nursing services and paid for by outside funding sources. It was determined in both situations that the school system was not responsible for paying for nursing services to perform these procedures. In



summary, according to the outcomes of these cases, school systems are obligated to provide needed health care services (related or support services) or work with the family and other state agencies to obtain these services. However, parents supply needed equipment and other supplies, except for protective gloves, which the school system provides to school staff. However, these decisions were made in local judicial systems on a case by case basis and do not have the same precedence setting impact of the Tatro case.

In summary, the health related interventions commonly required of students with special health care needs can be considered related services or support services if they **do not** have to be performed by a physician. Referring to such procedures as school health services strengthens the position that the procedure is a related service that enables a student to benefit from special education.

Consideration is also given to that population of students with special health care needs who require special health care considerations or interventions during school but do not otherwise qualify for special education. Public Law 94-142 clearly states that students must qualify for special education before they are eligible to receive related services. A student with cystic fibrosis who requires daily percussion and who is placed full time in a regular class would fall into this category. While this student cannot receive the related service under P.L. 94-142, the student may receive the service under another federal law, Section 504 of the Rehabilitation Act of 1973 (P.L. 93-112). This law does not require that students be placed in Special Education to receive related services.

Training Unlicensed School Personnel to Perform Special Health Care Procedures

Appropriate training of school personnel is a critical component of service provision to children with special health care needs. Training focuses on the attainment of specific competencies by persons involved in working with the student. Three levels of competencies require consideration: a) general information, b) informational competencies, and c) performance competencies (Lyon & Lyon, 1980). It is recommended that information and resources in this document be incorporated into these three levels of training activities. It is recommended that all school personnel involved with a student's program and daily activities will require training in general information related to the student's particular health care needs. In addition, a number of these persons will require more intensive training focused on informational competencies related to the student's health care needs and interventions. When unlicensed school personnel are designated by the ARC as the health care service provider/implementer, the most intensive level of training is required so that personnel can attain the performance competencies required to provide the health care service.

General information (awareness) is provided to all persons involved with the student such as all the student's teachers and other key school personnel. This may include a description of the special health care need(s), the purpose of the procedure or service, who is responsible for administering the procedure/providing the service, where and when the procedure or service will be provided, and other



general information deemed pertinent, such as who to contact within the school setting in case of problems or emergencies.

Other examples of general information that should be provided to all school personnel include district policies and procedures related to documenting absences and illnesses, basic first aid, administering medications, and procedures to contact parent(s) when students become ill during school hours. All districts and schools have these basic procedures and all staff should be provided this information.

Informational competencies (knowledge) are those competencies that are needed to make a judgment about changes in a student's behavior or condition. These would include information such as the signs and symptoms of illness or problems. Persons trained in informational competencies are not required to take overt actions in implementing a procedure or intervention, but are trained to identify situations where the need for overt actions or intervention by trained personnel is needed and to seek appropriate means for intervention. All school personnel who work with the student require training in specific informational competencies in addition to the provision of training in general information, as previously described. These persons may include classroom teachers, special education teachers, teacher assistants, related services personnel involved with the child, school principal, librarian, physical education teacher, music teacher, etc., the child's peers and friends, and any others who need to know this information.

Performance competencies (skills) are those competencies where overt actions are being taught to and performed by trained personnel. These competencies refer to the actual administering of special health care procedures or interventions for a specific child. Training of district personnel and monitoring of their performance in implementing health care procedures must be provided by a licensed health care provider. Hence, the actual training of unlicensed school personnel may be provided by the child's physician, a school nurse, or districts may contract for the training through a home health care agency, hospital, or other health care facility. The training may be provided in the school or in a setting outside the school. In either case, the training must be conducted "hands on" with the actual student who requires the procedure. Parents cannot serve as primary trainers to train unlicensed school personnel to perform health care procedures. However, the parent is an integral part of the training since parents can provide a wealth of information on individual adjustments that can be included to make administering the procedure more efficient, effective, and more comfortable for their child

Training unlicensed school personnel in performance competencies must be provided by a qualified trainer, which is defined as a licensed health care professional who possesses the knowledge and skills necessary to teach the performance of the health care procedure or intervention to others. Do not assume that an individual with a health care discipline label (e.g., nurse, school nurse, physician, etc.) possesses the knowledge, skills, and experience in a particular health care procedure or intervention that a student may require. Thus, programs that do have a school



nurse may have to obtain additional training for the individual related to the health care procedure that is required. Programs that do not have a school nurse will need to locate a licensed health care professional who has the knowledge, skills, and experience in providing the required health care intervention and obtain the professional's services to make appropriate delegatory decisions, train unlicensed school personnel, verify their competency in performing the intervention(s) in a safe, effective manner, monitor the quality of the health care services provided for the student, and supervise the performance of the procedure. Part B funds may be used for provision of health care services for students who require the services as a direct result of the student's educational disability (qualify for special education services).

The Program Planning and Training Form contained in Appendix E can be used to document the steps in the procedure and is signed by both the physician and the parent(s) or guardian. This program plan then becomes the training form and used to document the individualized training (see Program Plan and Training Form in Appendix E). Quality training of unlicensed school personnel involves:

- 1. explanation and demonstration of the procedure by the trainer,
- 2. observation of the trainee performing the procedure,
- 3. feedback from the trainer to the trainee on his or her performance of the steps involved in the procedure,
- 4. verification by the trainer that trainee has reached criterion (defined as performance of 100% of the steps correctly without prompts or cues [hints or assistance] from the trainer over a specified number of training sessions),
- 5. monitoring the newly trained personnel periodically to insure that they continue to perform the procedure correctly, and verifying the trained personnel can identify when additional consultant, training and/or resources are needed in the provision of services,
- 6. conducting the training in a manner that preserves the student's privacy and dignity at all times during sessions and thereafter, particularly during the procedures of colostomy and ileostomy care, and catheterization.

When health care procedures must be performed at school, always train at least three persons in the school (building). If only one person is trained to perform the procedure, there is no back-up plan or substitute if the sole trained person is absent or unavailable. This rule also applies to training of transportation personnel or teacher assistants who accompany students on the school bus, if these procedures are required during transit (e.g. suctioning).

In some cases, parents have been employed by the school district to come to the school at a scheduled time during the day to perform the health care procedure (e.g. catheterization). If this is necessary, caution is taken to ensure that parents



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and children do not become overly dependent on each other or that a parent's presence at school does not further isolate or stigmatize the student. The same caution is taken when the child's parent is employed full time as an assistant for the student. In these cases, it is recommended that the parent would work with all the children in the class, not just their son or daughter. This would be true for any assistant or teacher's aide assigned to work with a student. The reasons for caution in these cases is that we want to a) promote healthy separation of child and parent from each other, b) increase the probability that the child learns to work with other adults and interact with children his or her own age, and c) reduce the possibility of further stigmatization that may occur because the child's parent (or any other specific adult) is always with them.

When school district personnel first encounter students who require special health care procedures, district staff are usually concerned with liability. However, liability is not the issue, because we are all liable for everything we do in the educational setting. The real issue is negligence. If districts follow appropriate planning and training procedures and regularly monitor the child's program, they have taken all known precautions. It is critical to note that negligence exists only if school personnel act in an unreasonable or imprudent manner.

Other training needs. It may prove prudent for a school district to train most or all its personnel in first aid, school health policies and procedures, universal precautions to prevent the spread of illnesses and communicable diseases. cardiopulmonary resuscitation (CPR), first aid, and such things as seizure monitoring, and other pertinent information related to the special health care needs of the children they serve. Education and training of staff can go a long way to diffuse very emotionally laden issues as they arise in the future. Unfortunately, the usual immediate response of most staff in dealing with students with special health care needs is fright and an attitude of "that's not within my job scope or responsibility". By providing some training of a general nature (in advance) to all staff before individual cases arise, we can prevent some of these fears and concerns from developing later on when the need for special health care arises. These types of trainings and staff development activities are excellent for all staff in terms of general knowledge and awareness. Appendices F through H include examples of general training information that should be provided to all school staff, and appendices I through L contain additional training materials, readings, and resources related to providing services to students with special health care needs.

Emergency Procedures

Two types of emergency procedures must be planned and documented when working with children with special health care needs. First, emergency procedures must be planned in case of illness, accident, or life-threatening situations. Parents must provide written instructions for how to deal with these situations. This includes what to do and who to notify in case of emergency including such information as physician's name and how to contact him or her, emergency medical assistance (emergency medical team, ambulance service, emergency room and what hospital), insurance type and policy number, at least two persons to contact and in what order to call them (e.g. parent(s), other family members,



neighbors), and what to do if no one on the contact list can be reached. This information is place on tile, located by the telephone for easy reference, and taken on off-campus school activities (e.g. community-based instruction, class trips). It is heipful to contact and alert the local emergency medical assistance (resue units) and the hospital of choice before their services are needed as part of the emergency plan.

The second type of emergency procedures relate to the occurrence of fire or natural disasters (e.g. tornados, earth quakes) and possible equipment problems due to power outage or failure (e.g. child requires operated equipment powered by electricity or batteries). Building escape routes and procedures are reviewed to determine if special evacuation procedures or emergency provisions are needed for the child with special health care needs. If the child uses equipment that is operated by electricity or batteries, is there a battery-operated or manual back-up device (e.g. suctioning machine, respirator)? If the child uses a wheelchair and attends a class on the second floor of the school, how will they be transported downstairs during fire drills when the elevator is inoperable? These are all questions that must be answered to develop plans to handle these situations safely and efficiently in the school environment.

Transportation Issues

Admissions and Release Committees need to consider the following transportation issues, document them on the IEP, and review them on a periodic basis:

- 1. mode of transportation to and from school (e.g. school bus, van, parent transport),
- 2. length of time on vehicle one way,
- 3. equipment and/or adaptations necessary for transportation,
- 4. evacuation procedures during transit in case of fire or accident,
- 5. need for bus aides,
- 6. driver and/or bus aid training, and
- 7. protocols for on-board health care procedures delivered during transit.

Depending on the specific health care need of the child, the school district may need to provide this service during transit. When intervention is required during transit (e.g. seizure monitoring, suctioning), the school bus staff must be well trained to deal with these situations. They may be trained in conjunction with other school staff being trained by the licensed health care professional consulting on the child's case. This training is documented and procedures monitored by the professional (Refer to the previous section on training). Always have more than one person trained who can provide services during transport. This back-up plan will be critical when trained staff are absent. The other person trained could be the



van driver, another teacher aid that could serve as the back-up transport staff, or the child's teacher could serve in this role.

There must be clearly written procedures for transportation personnel that include who has been trained to administer the procedure, what the procedure involves (including signs and symptoms of problems), guidelines for documenting the administration of procedures or incidents, and procedures to handle emergencies that may occur in transit including evacuation procedures. On going training and consultation between transportation staff and school staff is critical. On going communication between educational staff, parents, and transportation staff needs to be provided on a daily basis. One source of sharing information is the written record of procedures administered. Refer to the sections on training and emergency procedures for additional information pertinent to transportation issues. The same documentation procedures and training model used with teachers can be used for transportation personnel.

In some cases, a transportation aid or even a nurse may be needed to ride the vehicle. Special equipment, such as a suction machine, may need to be used on a transportation vehicle. Decisions about who provides and maintains the equipment, is documented on the IEP.

Length of time in transit is also considered. Information is obtained from the physician about the maximum length of time in transit that the child can tolerate comfortably and safely. Whenever possible, children with special health care needs can and do attend their neighborhood school (the school closest to their home). This reduces the amount of transportation time involved and thus, may reduce or eliminate the need for procedures to be administered by transportation staff during transit.

Summary and Recommendations

The purpose of this document was to provide school district personnel with guidance in providing services for students with special health care needs. Information regarding the definitions related Kentucky regulations, and results of the Kentucky survey of teachers has been included to further understand the related issues and needs in Kentucky. The belief statements included lay the foundation upon which quality services should be designed and implemented. The sections that address placement and IEP development, provision of related services, training unlicensed school personnel, emergency procedures, and transportation issues provide a discussion of the related issues and recommendations in regards to implementation.

We hope that this document is both informative and useful for administrators, service providers, parents, and persons involved in policy making and training. It is recommended that this document be used to design and provide quality services for students with special health care needs in local school districts. In addition, the information contained within should be incorporated into staff development plans and personnel preparation programs at Kentucky's colleges and universities. We encourage the duplication, dissemination, and use of the related training materials



and forms contained in the appendices section. Your reactions and suggestions related to the content of this document and accompanying materials are welcomed and appreciated.



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APPENDIX A

Recommendations for Dealing with Specific Health Care Procedures



SPECIFIC HEALTH CARE PROCEDURES

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The purpose of this section of the document is to provide school district personnel guidance in planning health care services and needed training for working with students with special health care needs. The information provided is general in nature and should not be viewed as a substitute for appropriate training. (See section entitled "Training Unlicensed School Personnel to Perform Special Health Care Procedures" in the narrative portion of this document for information related to training procedures.)

The specific health care procedures are acts generally considered nursing care activities which are provided by a nurse or provided only by a designated trained person(s) for an individual student as delegated by, and under the supervision of a nurse. (See section entitled "Related Kentucky Regulations" in the narrative portion of this document - Pg. 10).

Other licensed health care providers such as physicians, physical therapist, occupational therapist, or speech/language therapist may provide, delegate, teach and supervise others in the performance of procedures, when the procedures are within the scope of practice of the given licensee. The following health related procedures are included in this section:

Administering Medications

Cast Care and Monitoring

Catheterization

Gastrostomy Tube Feeding

Glucose Monitoring (Diabetes)

Ileostomy/Colostomy Care

Nasogastric Tube Feeding

Seizure Intervention and Monitoring

Tracheostomy Care and Suctioning (including oral suctioning)

Ventilator Dependent



ADMINISTERING MEDICATION

Description: Children may receive a variety of medications at school. Medications may be administered in a variety of ways including orally, rectally, etc. Students may need to take medications for both acute illnesses and chronic conditions. Acute illnesses result in medication being given for an illness that will last only a few days or weeks. Children with chronic conditions such as epilepsy will possibly have to take medication on a continual basis.

Recommendations

- * All medications given via any injection route should be given by a licensed health care professional. Additionally, medications given via nasogastric tube must also be administered by a licensed health care professional.
- * Consult with the physician and parents about the type of medication that must be administered and a complete description including:
 - dosage,
 - when the medication must be given,
 - how the medication will be given (e.g., oral, rectal, NG tube, injection, etc.).
 - special considerations in administering the medication (e.g., medication given with or without food),
 - potential side-effects of the medication,
 - the length of time the child has been on the medication before returning to school and how long the child will be on the medication, and
 - how the medication will be prepared (e.g. crushed, mixed with food, etc.).
- * If the method of the administering the medication requires any unusual procedures, the teaching staff should be trained by qualified licensed health care professional to administer the medication.
- * Know signs and symptoms of side effects of medications and make plans in advance to deal with any complications.
- * Consult with parents to design a plan for emergencies that may result from both the direct side effects of the medication or emergencies related to the administration of the drug. These may include:
 - physical or behavioral side effects of the medication,
 - physical or behavioral symptoms that indicate that the medication is not
 - being properly absorbed into the child's bloodstream.
 - entire dosage of medication was not ingested by the child,
 - the child received the incorrect medication, and
 - the child choked while being administered the medication.



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Documentation

- * Document treatment recommendations as specified by the physician with the parental consent.
- * Document emergency procedures as planned in conjunction with parents.
- * Document training by qualified licensed health care professional for school personnel who administer the medication (where applicable).
- * Review and/or develop district policies that include a checklist of procedures for the prevention of giving the wrong medication to a student including:
 - medication was delivered in original container,
 - medication was properly labeled with student's name, and
 - medication was stored properly (in a locked storage cabinet) so that it is not accessible to other students.
- * Daily record of medication administration (copy sent to parents daily) that includes:
 - time medication was given,
 - method of administration,
 - dosage of medication,
 - any side effect from the medication, and
 - responses to medication(s) (e.g., drowsiness, hyperactivity, nausea).
- * Use Authorization to Give Medication form and Medication Administration Record in Appendix D.

Precautions

- * One person should be responsible for the entire process of administering the medication to a given student to reduce the risk of improper dosages or wrong medications being given. In other words, if one person retrieves the medication from storage and measures the dosage, that person should also administer the medication.
- * The first dosage of a new medication or a change in dosage of a current medication should not be given at school.
- * Medicine spoons should be used to assure that the dosage of liquid medications given to the student is as accurate as possible.
- * Students with oral motor and feeding difficulties will also have difficulty taking oral medications. The students are at a greater risk or choking during the administration of the medication



- * The administration of improper medications should be reported immediately to the student's physician and the parents.
- * School staff who are unsure of the side effects of a particular medication should consult a nurse, pharmacist, or physician.

Recommended Readings and Resources

Physician's Desk Reference or Nurse's Drug Book

Gadow, K. D. (1979). <u>Children on medication: A primer for school personnel</u>. Reston, VA: Council for Exceptional Children.

Graff, J. C., Ault, M. M., Guess, D., Taylor, M., & Thompson, B. (1990). <u>Health care for students with disabilities: An illustrated medical guide for the classroom.</u>
Baltimore, MD: Paul H. Brookes. (see Chapter 3: Medication Administration)

P.D. Smith & J. L. Leatherby (1991) Services for Children with Special Health Care Needs Kentucky Systems Change Project May be reproduced for program or training purposes.



CAST CARE

Description: Casts are generally made of plaster of Paris. Students most often wear casts to immobilize a broken or fractured bone. Students with physical disabilities may wear casts due to joint dislocations or to prevent or correct body deformities such as scoliosis.

Recommendations

- * Consult with the physician and parents about the type of cast and complete description including:
 - type of cast (may be plaster of Paris or fiberglass),
 - how long the student will have to wear the cast before the injury heals,
 - the reason the child is wearing the cast (e.g. orthopedic surgery or bone fracture),
 - how long the child has had the cast, and
 - special positions needed due to cast (i.e., leg elevation).
- * Know the signs and symptoms of complications that might arise and make plans in advance to deal with these.
- * Know the signs, symptoms, and complaints that may indicate cast problems including swelling, blueness of extremities (fingers, toes), complaints of pain, and complaint of burning sensation.
- * Consult with parents to design a plan for conditions or emergencies that may result from wearing cast. These may include:
 - indentations in a new cast,
 - skin breakdown around or under the cast, and
 - conditions that indicate that the cast is too tight or rubbing (redness).

Documentation

- Document emergency procedures as planned with parents
- * Document treatment recommendations as specified by the physician with parental consent. Physical and occupational therapists can also provide assistance in interpreting and implementing cast care recommendations. These may include:
 - cleaning the cast.
 - assisting the student with a cast in toileting activities,
 - checking the condition of the skin around and underneath the cast, and
 - checking for the continued correct positioning of the cast.



- * Documented training by qualified licensed health care professional for school personnel who perform cast care (e.g. nurse, physical or occupational therapist).
- * Maintain daily treatment record (sent to parents) for the duration that the cast is applied, particularly during the first two to three weeks that includes:
 - documentation that cast was checked for pressure sores or skin
 - breakdown during day,
 - record of any skin irritation that was discovered and treatment method,
 - time of elimination, if relevant to type of cast, and
 - documentation of any sign of poor circulation.
- Use or adapt for use Health Care Services Record form in Appendix D.

Precautions

- * Care should be given to protect the cast from the following:
 - indentations (especially when the cast is new),
 - soiling from food, drink, urine, or feces, and
 - dropping small objects or pieces of food down in the cast.
- Prevent pressure sores and skin breakdowns can be reduced by repositioning the student at regular intervals, per physician and/or therpist's recommendations.
- * Closely observe the student's skin condition and circulation during the time the student is wearing the cast. Repeated complaints of discomfort by the student should be reported to the child's parents and the school nurse or other licensed health care provider, and/or the child's physician.

Recommended Reading

Graff, J. C., Ault, M. M., Guess, D., Taylor, M., & Thompson, B. (1990). <u>Health care for students with disabilities: An illustrated medical guide for the classroom</u>. Baltimore, MD: Paul H. Brookes. (see Chapter 10: Cast Care)

P.D. Smith & J. L. Leatherby (1991) Services for Children with Special Health Care Needs Kentucky Systems Change Project May be reproduced for program or training purposes.



CATHETERIZATION

Description: The purpose of catheterization is to drain urine from the bladder via insertion of a catheter (flexible tube). Catheterization may be necessary for reasons such as injury to the bladder, paralysis of bladder functioning, and acquired disease. Types of catheter systems include indwelling catheters with external collection bag and clean intermittent catheterization.

Indwelling Catheters: Indwelling catheters are the type that are frequently used in hospitals for patients receiving surgery. The catheter is inserted and remains in the bladder. Urine drains into a collection bag. Condom catheters are one type of catheter used by males that fit over the penis and urine drains into a collection bag strapped to the leg. Indwelling catheters are usually used as a temporary solution for bladder control since their presence over time increases the likelihood of urinary infections.

Clean Intermittent Catheterization: This catheterization method involves draining the urine from the bladder on a specified schedule (e.g., every 2 to 4 hours, or sometimes every 6 to 8 hours). The catheter does not remain indwelling, but is inserted each time the bladder is drained. (Sterile intermittent catheterization should be administered by licensed health care professional.)

Recommendations

- * All catheterization should take place in a private area. Students who can stand over or sit unassisted on a toilet may learn to catheterize themselves and do this in the regular restroom. Other students will require a room or private area to provide optimal privacy for the student. A high degree of sensitivity is demonstrated by the person performing the procedure due to the possibility of embarrassment to the student. Ideally, the room should contain a sink so that hand washing facilities are available. Always have supplies organized prior to performing the procedure.
- * Obtain training to perform procedure from qualified licensed health care professional working directly with the student during training sessions.
- * Consult with the child's physician regarding frequency (schedule) of intermittent catheterization and to determine if urine amount is to be recorded.
- * Know signs and symptoms of urinary tract infections and problems (e.g. unusual color or odor of urine, presence of blood in the urine, fever, pain or burning in students without paralysis).
- * Encourage adequate intake of fluids and monitor fluid intake and implement recommendations as specified by physician.



- * Document treatment recommendations as specified by the physician with parental consent including:
 - authorization form signed by parents and physician (see Appendix D),
 - specifications about type of catheterization (clean or sterile techniques),
 - schedule of times to be conducted, and
 - amount of urine eliminated if required to be measured.
- * Maintain daily treatment record (sent to parents) that includes:
 - times catheterization occurred,
 - amount of urine (if required),
 - who conducted,
 - evidence of urinary tract infection, and
 - amounts of liquids given.
- Document emergency procedures as planned in conjunction with parents.
- * Document training by a qualified licensed health care professional for unlicensed school personnel who perform catheterizations (use Program Plan and Training Form in Appendix E)
- * Use Authorization for Treatment form and Special Health Care Services Record in Appendix D.

Precautions

- * Wear vinyl or latex gloves when performing catheterization. However, many children with spina bifida are allergic to latex and require the use of vinyl gloves during catheterization or any other procedure where they are required. Consult with the physician regarding the type of gloves to use.
- * Regular testing of nitrates in urine may be required for some students.
- * Follow appropriate procedures for the disposal of body fluids (urine) as specified in Appendix G.

Recommended Reading

Graff, J. C., Ault, M. M., Guess, D., Taylor, M., & Thompson, B. (1990). <u>Health care for students with disabilities: An illustrated medical guide for the classroom</u>. Baltimore, MD: Paul H. Brookes. (see Chapter 15: Clean Intermittent Catheterization)



GASTROSTOMY TUBE FEEDING

Description: Used to provide supplemental or total nutrition via a tube surgically placed into the stomach called a gastrostomy tube (G-tube). There are three types of feeding methods: 1) bolus (formula is allowed to flow through the G-tube within a few minutes, 2) drip method with external feeding bag (formula drips slowly over a specified period of time), and 3) drip method with external feeding bag on a time regulated pump (formula drips slowly throughout the day and/or night, regulated by pump).

Recommendations

- * Consult with physician and parents about type of method used and complete description including:
 - amount of feeding,
 - name of liquid formula.
 - rate of delivery of formula,
 - positioning of student during feeding.
 - length of time after feeding before child can be placed in a reclined position, and
 - any special considerations.
- * Be trained by qualified licensed health care professional to perform the specified G-tube feeding for an individual student. This includes aspiration procedures if required.
- * Know oral stimulation or oral feeding procedures and/or contradictors (see Feeding Disorders in Appendix B).
- * Know signs and symptoms of problems that might arise and make plans in advance to deal with these.
- * Consult with parents to design a plan if and when G-tube comes out or is accidentally pulled out. The student's parents or a licensed health care professional must reinsert the tube. Unlicensed school personnel should not be trained to perform this function.

Documentation

- * Document treatments and recommendations as specified by the physician with parental consent.
- * Document emergency procedures as planned in conjunction with the parents.
- * Maintain daily treatment record for each student (copy sent to parents daily) including:



- time and date feeding was given,
- type and amount of formula,
- amount of water given,
- physical reactions (e.g. vomiting), and
- initials and identifying signature of person completing record.
- * Document training by qualified licensed health care professional for unlicensed school personnel who perform procedure (use Program Plan and Training Form in Appendix E).
- * See Authorization for Treatment form and Special Health Care Services Record in Appendix D.

Precautions

- * Wear latex gloves when coming in direct contact with G-tube and stoma area.
- * Have plan in the event the G-tube becomes displaced. Only a nurse or the idd's parents can reinsert the tube.
- * Consult with the physician to clarify positioning of the student while feeding and after feeding takes place.
- * Obtain release and recommendations from the physician for positioning any student with a G-tube in a prone position (lying on stomach).
- * Observe the student closely during feeding and discontinue if the child displays excessive sweating, begins to vomit, coughs or chokes, or appears uncomfortable.
- * The nutritional value of some formulas may be altered by adding certain medications. Be aware of what medications are permissible to be mixed with the particular formula being used.
- * Watch for signs that the student is not tolerating the formula, such as, vomiting, diarrhea, and excessive gas; and report these to the parents and/or health care professional.
- * Watch for signs of skin irritation around the stoma.



Recommended Reading

Graff, J. C., Ault, M. M., Guess, D., Taylor, M., & Thompson, B. (1990). <u>Health care for students with disabilities: An illustrated medical guide for the classroom.</u>
Baltimore, MD: Paul H. Brookes. (see Chapter 14: Gastrostomy Tube Feeding)

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GLUCOSE MONITORING (DIABETES)

Description: Students who are diabetic, meaning that they have an excess of glucose or sugar in their bloodstream, may require glucose monitoring during school hours. Glucose monitoring simply means testing the amount of sugar in the bloodstream at regular intervals. It may be accomplished by sampling urine or blood for its sugar content. According to Graff, et al. (1990), testing the blood is the method of choice. However, glucose monitoring may be accomplished by sampling either urine or blood for sugar content.

Recommendations

- * Consult with the physician and parents about the type of glucose monitoring procedure used (urine or blood) and obtain a complete description of the following:
 - what the ideal and acceptable blood sugar goals are and how that varies at certain times of day,
 - what the schedule is for glucose monitoring,
 - what method of glucose monitoring will be used,
 - how the amount of glucose in the blood or urine will be determined (i.e. visually or with a glucose monitoring device),
 - what signs and symptoms are of hypoglycemia (too little sugar) and hyperglycemia (too much sugar), and
 - any treatment recommendations related to hyperglycemia and hypoglycemia.
- * Be trained by qualified licensed health care professional to perform glucose monitoring.
- * Know signs and symptoms of complications that might arise and make plans in advance to deal with these.
- * Consult with parents to design a plan for emergencies that may become apparent as a result of insulin therapy. These may include:
 - trauma to the part of the body that is continually pricked for blood tests,
 - increased insulin in bloodstream.
 - decreased insulin in bloodstream, and
 - coma resulting from too much insulin (insulin coma) or too much sugar (diabetic coma).
- * Licensed health care professionals should periodically check and assure proper operation of glucose monitoring equipment.



- * Document treatment recommendations as specified by the physician with parental consent.
- * Document emergency procedures as planned in conjunction with the parents.
- * Document training by qualified licensed health care professional for unlicensed school personnel who perform procedures (see Program Plan and Training Form in Appendix E).
- * Use Authorization for Treatment form and Special Health Care Services Record in Appendix D.
- * Maintain daily treatment record (copy sent to parents daily)
 - time and date of glucose monitoring and the results,
 - who performed the glucose monitoring (child or school personnel),
 - any evidence of trauma to skin on area where blood was taken,
 - report signs and symptoms of hypoglycemia or hyperglycemia to parents and health care provider, and
 - administration of any emergency procedures for hypoglycemia or hyperglycemia.

Precautions

- * Signs of inadequate insulin coverage should be reported to the student's physician.
- * Teachers having students who are nonspeaking and diabetic should be especially aware of the behavioral symptoms of hypoglycemia and hyperglycemia and what to do in response to these conditions.

Recommended Readings and Resources

- Christiansen, R. O., & Hintz, R. L. (1982). Juvenile diabetes mellitus. In E. E. Bleck & D. A. Nagel (Eds.), <u>Physically handicapped children: A medical atlas for teachers</u> (2nd ed.) (pp.269-278). New York: Grune & Stratton.
- Graff, J. C., Ault, M. M., Guess, D., Taylor, M., & Thompson, B. (1990). <u>Health care for students with disabilities: An illustrated medical guide for the classroom.</u>
 Baltimore, MD: Paul H. Brookes. (see Chapter 11: Glucose Monitoring for the Student with Diabetes)



Winters, R. J. (1983). Childhood diabetes mellitus. In J. Umbreit (Ed.), <u>Physical disabilities and health impairments: An introduction</u> (pp.195-205). New York: Macmillan Publishing Co.

Juvenile Diabetes Foundation (see Appendix J)

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ILEOSTOMY AND COLOSTOMY

Description: Methods by which feces are eliminated when a person has an obstruction in the intestines which prevents normal flow of fecal matter. A colostomy results in some portion of the large intestine being brought through the abdominal wall. Fecal matter is irrigated through a stoma or opening in the abdomen. A portion of the small intestine is brought through the abdominal wall when the ileostomy is performed. A pouch is worn on the outside of the abdomen to collect the fecal matter.

Recommendations

- * Consult with the physician and parents about type of ostomy and complete description including:
 - location of the ileostomy or colostomy,
 - frequency of elimination.
 - special diet modifications,
 - consistency of the feces,
 - medications used on the ostomy,
 - type of collection pouch used,
 - procedures for changing pouch, and
 - supplies needed for changing pouch.
- * Unlicensed school personnel must be trained by qualified licensed health care professional to perform ostomy care.
- * Know signs and symptoms of complications that might arise and make plans in advance to deal with these.
- * Consult with parents to design a plan for emergencies that may result from ileostomy/colostomy care. These may include:
 - blockage of the intestine that may result in cramping, vomiting, etc.,
 - dehydration from persistent diarrhea,
 - bleeding from the stoma, and
 - skin breakdown around the stoma.

Documentation

- * Document treatment recommendation as specified by the physician with parental consent.
- * Document emergency procedures as planned in conjunction with the parents.
- * Document training by a qualified licensed health care professional for unlicensed school personnel who perform ostomy related care (use Program Plan and Training Form in Appendix E).



- Use Authorization for Treatment form and Special Health Care Services Record in Appendix D.
- * Maintain daily treatment record (copy sent parents daily) including:
 - time and date of elimination(s),
 - consistency/color of fecal matter,
 - variations in diet for the day,
 - unusual discharge from stoma,
 - skin irritations observed,
 - medications applied to skin irritations, and
 - note if collection bag had to be replaced and why.

Precautions

- * If collection bag is closed with a clamp, prevent child from lying on clamp which could result in injury.
- * An adequate supply of collection pouches and other materials should be kept on hand in case of leakage.
- * Care should be given to protect the student's privacy when providing ileostomy or colostomy care.
- * Wear vinyl or latex gloves when performing providing ileostomy/colostomy care or coming in contact with the stoma. However, many children with spina bifida are allergic to latex and require the use of vinyl gloves. Consult with the physician regarding the type of gloves to use.
- * Use appropriate sanitation practices when caring for ileostomy/colostomy including hand washing and use of deodorant sprays when changing collection bag.
- * In cases where the student has an excessive amount of gas, special diet considerations may be required.

Recommended Reading

Graff, J. C., Ault, M. M., Guess, D., Taylor, M., & Thompson, B. (1990). Health care for students with disabilities: An illustrated medical guide for the classroom. Baltimore, MD: Paul H. Brookes. (see Chapter 12: Colostomy or Ileostomy Care)



NASOGASTRIC TUBE FEEDING

Description: Used to provide supplemental or total nutrition via a tube that is inserted into the nose and leads to the stomach. Nasogastric (NG) tube feeding is intended to be a short-term intervention for children with feeding difficulties. There are four types of feeding methods: 1) bolus (formula is allowed to flow through the NG-tube within a few minutes), 2) intermittent gravity drip method (formula drips slowly from a hanging container in 20-30 minutes, 3) continuous gravity drip method (formula is dripped slowly over a period of 16-24 hours), and 4) continuous infusion by pump method (formula is dripped slowly throughout the day and/or night, regulated by pump).

Recommendations

- * Consult with the physician and parents about type of feeding method used and complete description including:
 - amount of feeding,
 - name of liquid formula,
 - rate of delivery of formula.
 - preferred method of checking tube placement,
 - daily care requirements of NG tube.
 - length of time after feeding before child can be placed in reclined position, and
 - any special considerations.
- * Only licensed health care professionals can provide NG tube feedings and administer medications via this route. The designated licensed health care professional should obtain training to perform the specified NG tube procedure for an individual student. This includes aspiration procedures, if required.
- * Know oral stimulation recommendations or oral feeding procedures and/or contradictions (see Feeding Disorders in Appendix B).
- * Know signs and symptoms of problems that might arise and make plans in advance to deal with these.
- * Consult with the parents to design a plan if and when the NG tube slips up or is accidentally pulled out from the stomach into the esophagus.
- * A nurse or parent should be responsible for inserting/reinserting the NG tube.



- * Document treatment and recommendations as specified by the physician with parental consent.
- * Document emergency procedures as planned in conjunction with the parents.
- * Maintain daily treatment record (copy sent to parents daily):
 - time and date feeding was given,
 - method of determining that tube is in place,
 - type and amount of formula given,
 - amount of water given,
 - physical reactions (e.g. vomiting), and
 - initials and identifying signature of person completing record.
- Use Authorization for Treatment form and Special Health Care Services Record in Appendix D.

Precautions

- * The nutritional value of some formulas may be altered by adding certain medications. Be aware of what medications are permissible to be mixed with the particular formula being used. (Only licensed health care professionals can perform NG tube feedings or administer medications via this route.)
- * Watch for signs that the student is not tolerating the formula such as vomiting, diarrhea, excessive gas, etc.
- * NG tubes may become plugged or clogged and not allow the formula to pass through the tube. Be aware of procedures for removing whatever is obstructing the tube.
- * Watch for signs of skin irritation where the tube is taped to the child's face or in the child's nostril.
- * Feeding should be discontinued if the NG tube slips up from the stomach into the esophagus.
- * Wear vinyl or latex gloves when having direct contact with the NG tube.

Recommended Reading

Graff, J. C., Ault, M. M., Guess, D., Taylor, M., & Thompson, B. (1990). <u>Health care for students with disabilities: An illustrated medical guide for the classroom</u>. Baltimore, MD: Paul H. Brookes. (see Chapter 13: Nasogastric Tube Feeding)



SEIZURES

Description: Seizures are characterized by involuntary motor activity or a change in consciousness. A seizure occurs when bursts of unorganized electrical impulses interfere with normal brain functioning. Epilepsy is a chronic condition of the nervous system and involves recurrent seizures. While recognizing the 1981 International Classification of Epileptic Seizures, types of seizures generally used in schools include: (a comparison may be found on Page 50.)

Petit Mal - may have a variety of small movements, momentary and partial loss of consciousness, sometimes difficult to observe, may appear to resemble inattentiveness or daydreaming, may have several in succession;

Psychomotor - repetitive motor act such as twisting button of shirt, clicking of tongue, partial loss of consciousness, confusion and disorientation;

Grand Mal - physical movements of the whole body (convulsions, tonicclonic), loss of consciousness, may be loss of bladder and/or bowel control, usually experience fatigue after seizure and may need to rest or sleep;

Akinetic or Drop - loss of consciousness, fall to floor, length of seizure varies.

Focal - rhythmic eye movement, some head turning, usually short in duration (less than 30 seconds), often seen in students who are very physically limited; and

Recommendations

- * Obtain information from parents about student's seizure activity including:
 - type(s) of seizures,
 - frequency,
 - typical behavior or signs prior to occurrence of seizure.
 - usual treatment during and after seizure,
 - name of medication(s) taken, dosage, times given (see section on administering medications),
 - name and telephone number of physician,
 - name, telephone number, and location of hospital in case of emergency, and
 - need for helmet for student to prevent injury in case of atonic or drop seizures and severe grand mal seizures.
- * Have knowledge of intervention practices for Grand Mal seizures:
 - Try to protect the student from injury by breaking fall or assisting student to floor and remove any furniture or objects that might fall on the student.
 - Do not restrain the student's physical movements.
 - Position the student on their side to allow any saliva or vomitus to drain out



to the side and to maintain an open airway.

- Do not place anything in the student's mouth.
- Stay with the student during the seizure.
- * After a seizure, the student may be tired and sleepy, confused, agitated or aggressive, and may require a change of clothing if incontinent. Reassure the student and try to dispel any anxiety they may be experiencing. Allow the student to rest or sleep, if needed.

Documentation

- * Maintain a seizure record for each student who has seizures and include the following information for each seizure record (see Appendix D):
 - duration of seizure.
 - conditions or behaviors that preceded the seizure (e.g. bright or flashing lights, sounds, student's facial expression or physical movements and behavior),
 - description of physical movements during seizure, (e.g. jerking extremities)
 - description of other behaviors during seizure (e.g. smacking of lips, behavioral changes, facial color or expression changes, any respiratory distress, incontinence, etc.),
 - intervention after the seizure (e.g. allowed to rest, changed clothing, etc.), and
 - if child went to hospital, document efforts to notify parents.
- * Document emergency procedures (if needed for an individual student) as planned in conjunction with the parents.
- * Use suggested Seizure Record in Appendix D or similar form that clearly documents symptomatology of seizure.

Precautions

- * Prolonged grand mal seizure activity is called status epilepticus and can be life threatening. If grand mal seizure activity continues for more than 10 minutes:
 - Summon an ambulance and have the student transported to the hospital for emergency treatment.
 - Notify the student's parents by phone and notify the hospital by phone so that they can anticipate the student's arrival.



International classification	Previous label
Generalized seizures	Generalized seizures
Absence	Petit mal
Myoclonic	Minor motor
Tonic-clonic	Grand mal
Atonic	Akinetic, drop attacks
Partial seizures	Focal seizures
Simple partial with more symptoms	Jacksonian seizures
Complex partial seizures	Psychomotor seizures
	Temporal lobe seizures

Source: Commission on Classification and Terminology of the International League Against Epilepsy (1981).

Recommended Readings and Resources

Graff, J. C., Ault, M. M., Guess, D., Taylor, M., & Thompson, B. (1990).

Health care for students with disabilities: An illustrated medical guide for the classroom. Baltimore, MD: Paul H. Brookes. (see Chapter 1: Seizure Monitoring)

Berg, B. O. (1982). Convulsive disorders. In E. E. Bleck & D. A. Nagel (Eds.), <u>Physically handicapped children: A medical atlas for teachers</u> (2nd ed.) (pp. 171-180). New York: Grune & Stratton.

Nealis, J. G. (1983). Epilepsy. In J. Umbreit (Ed.), <u>Physical disabilities and health impairments:</u> An introduction (pp.74-85). New York: Macmillan Publishing Co.

Epilepsy Foundation of America (see Appendix J)

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TRACHEOSTOMY CARE AND SUCTIONING (including oral suctioning)

Description: A tracheostomy is a surgical opening (stoma) made into the trachea (wind pipe, airway) to permit air movement in and out of the lungs. This may be needed for various reasons such as to bypass an area of obstruction, to relieve acute or chronic respiratory distress, as an adjunct to surgical procedures of the face and neck, and many other reasons. A plastic or metal tracheostomy tube is secured in place by cotton ties (string) around the neck. Student breathes through the tube instead of the mouth or nose. Suctioning is a procedure used to remove mucus from the tracheostomy tube or from the mouth and back of throat (oral suctioning). For oral suctioning, some students require this on a routine or regular basis during the day. Other students may require oral suctioning only in extreme emergencies (e.g. excessive vomiting after a seizure).

Recommendations

- * Consult with the physician and parents about the type of method used and the student's needs including the following:
 - frequency that suctioning is needed,
 - appropriate positioning of student during suctioning,
 - provision of suctioning machine for use at school (electric or battery-operated),
 - provision of DeLee suction catheter to be used during transport, in the community, and in case of power loss (nonelectric), and
 - responsibilities of and training for school personnel.
- * School personnel may require training in several or all of the following:
 - removal of secretions from the trachea (suctioning) or removal of secretions from the mouth and back of throat (oral suctioning),
 - cleaning the inner portion of the tracheostomy (needed at least 2 or 3 times per day including being done at home or more frequently),
 - cleaning and care of the skin around the stoma,
 - changing tracheostomy ties (done at least once per day and usually at home, may become soiled and need changing at school), and
 - reinserting and/or changing tracheostomy tube. (School personnel must know how to reinsert the tube. Changing of the tube is usually done at home at least weekly.)
- * All school staff who work directly with the student should be trained in how to suction (using suctioning machine and DeLee suction catheter) and how to reinsert the tracheostomy tube if it should accidentally be removed.
- * Each suctioning should take no longer than 10-15 seconds and be followed by at least a 60 second rest period to allow for reoxygenation.



- * Students may require more frequent suctioning if he or she has a cold other respiratory condition, and when respiratory rate is increased due to physical exertion or respiratory distress/problems.
- * Some students may require suctioning prior to eating/feeding. Follow recommendations of physician, nurse, and/or parent.
- * Signs that indicate a student's need for suctioning include (Perry, 1982):
 - restlessness and an inability to be calmed,
 - difficulty breathing and/or faster breathing,
 - a frightened expression,
 - flaring of the students nostrils,
 - pale or bluish color around the student's mouth, and/or
 - bubbles of mucus that are seen or heard at the opening of the tracheostomy tube.

- * Document treatment and recommendations from the physician and parents on how to suction student, frequency, and proper equipment use.
- * Document authorization from parents to perform suctioning and other related tasks as may be needed during the school day.
- * Maintain and record on daily treatment record including (copy sent to parents):
 - times suctioned.
 - amounts (scant, small, moderate, large, excessive),
 - color (note signs of infection),
 - blood in mucus.
 - saline instillation.
 - any other information related to the student's individual needs, special signs and symptoms, or individualized needs for transportation, and
 - need for replenishment of supplies at school.
- * Document staff training by qualified licensed health care professional (use Program Plan and Training Form in Appendix E).
- * Document emergency procedures as planned in conjunction with the parents.
- * Use Authorization for Treatment form and Special Health Care Services Record in Appendix D.

Precautions

- * Know symptoms of respiratory distress (indicates need for track or oral suctioning) including:
 - bluish or grayish color of fingernails or toenails,



- nasal flaring,
- retraction around ribs,
- facial color changes (see above under signs for need of suctioning),
- anxious look on face,
- restlessness.
- sounds of mucus in airway,
- increased respiratory and/or heart rate, and
- excessive choking, vomiting, or aspiration (oral suctioning).
- * Positioning requirements for track or oral suctioning are highly individualized for each student and should be recommended by the child's physician.
- * When performing oral suctioning, aim for the excess mucus or vomitas. Do not aim/suction too far back in the throat so that the student's gag reflex is stimulated. Continued stimulation of the gag reflex may cause the student to lose it.
- Use vinyl or latex gloves when suctioning and/or coming in contact with mucus secretions

Recommended Reading

Graff, J. C., Ault, M. M., Guess, D., Taylor, M., & Thompson, B. (1990). <u>Health care for students with disabilities: An illustrated medical guide for the classroom.</u>
Baltimore, MD: Paul H. Brookes. (see Chapter 16: Tracheostomy Care)

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VENTILATOR DEPENDENT

Description: Children are considered "ventilator dependent" if they require mechanical ventilation to sustain life. The student receives assistance with breathing through the ventilator via a tracheostomy tube. Reasons for why a child may be ventilator dependent include cardio vascular disorders, disorders of the nervous system including brain injuries and tumors, pulmonary disorders, metabolic disorders, and others including asthma, smoke inhalation and shock. The amount of time a person must remain on the ventilator each day varies from person to person.

Recommendations

- * Consult with the physician and parents about the following:
 - length of time child must be on ventilator each day,
 - the reason the child requires mechanical ventilation.
 - the feeding method and schedule of the student,
 - appropriate positioning for the child, and
 - brand names of equipment used.
- * All school personnel working with a student who is ventilator dependent will require training in several or all of the following from qualified health care personnel:
 - ventilator operation.
 - tracheostomy care and suctioning (see previous section on tracheostomy care and suctioning),
 - use of humidification,
 - cardiopulmonary resuscitation from mouth to tracheostomy stoma,
 - positioning,
 - postural drainage,
 - feeding techniques,
 - special communication techniques and devices,
 - manual ventilation with a resuscitation bag, and
 - specific instructions for particular types of equipment (some brand names require specific training measures).
- * Consult with parents and medical personnel to design a plan for emergencies that may occur. These may include:
 - power outages (Back-up power sources should be identified. Power companies and fire departments should be notified there is a student on life sustaining equipment at the school so they can be prepared in the event of a power outage.),
 - how to protect/cover the tracheostomy when the child is taken outside,
 - what to do in the event that the tracheostomy site is obstructed,
 - what to do in the event that the tracheostomy tube becomes displaced,
 - recognize signs of respiratory distress including dyspnea, orthopnea,



- retractions, nasal flaring, tachypnea, and cyanosis (report to parents),
- what to do in the event of respiratory infections and recognize the symptoms of such infections, and
- what to do in the event that bleeding occurs.
- * Due to the complexity of the needs of students who are ventilator dependent, a nurse is required at school. This is considered a medical service (not a related service) and is usually paid for by the family's medical insurance or Medicaid.

- Document procedures as planned in conjunction with the parents and medical personnel.
- * Maintain daily observation records (copy sent to parents) including:
 - feeding records (see form in Appendix D)
 - any emergencies that occur including tracheostomy obstruction or displacement, power outage, respiratory difficulties, blood in mucus, and
 - record of length of time mechanical ventilator is activated (if student does not need continuous ventilation).
- * Use Authorization for Treatment form and Special Health Care Services Record in Appendix D.

Precautions

- * The ventilator must be plugged in when not mobile.
- * An emergency generator must be available in the event of a power outage.
- * Emergency calling system should be available in the classroom of a student who is ventilator dependent.
- * Emergency numbers of the following people/agencies should be readily available: family members and friends (both home and work numbers); otolaryngologist, pediatrician, local hospital; local police, fire, or rescue squad; and utility company.
- * A system should be developed for the child, whenever possible, to signal when in distress. If the child does not have the ability to signal, it is more imperative for caregivers to be aware of signs and symptoms of distress.
- * Avoid clothing that may obstruct the tracheostomy or shed fibers should be avoided.
- * Avoid getting anything in the tracheostomy.
- * Not all students who are ventilator dependent are mentally handicapped. For



that reason, placement in programs for students with mental handicaps should not automatically occur simply because those programs may have health care personnel readily available. The Admissions and Release Committee determines the appropriate placement for the student.

Recommended Reading

- Graff, J. C., Ault, M. M., Guess, D., Taylor, M., & Thompson, B. (1990). <u>Health care for students with disabilities:</u> An illustrated medical guide for the classroom. Baltimore, MD: Paul H. Brookes. (see Chapter 16: Tracheostomy Care)
- Newton, L., Chambers, H., Ruben, R. J., Jornsay, D., Liquori, J., Stein, R., & Lawrence, C. (1982). Home care of the pediatric patient with a tracheostomy. <u>Ann Otol Rhinol Laryngol</u>, 91, 633-640.

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APPENDIX B

Recommendations for Dealing with Other Health Care Concerns



OTHER HEALTH CARE CONCERNS

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The purpose of this section of the document is to provide school district personnel guidance in planning health care services and needed training for working with students with special health care needs. The information provided is general in nature and should not be viewed as a substitute for appropriate training. (See section entitled "Training Unlicensed School Personnel to Perform Special Health Care Procedures" in the narrative portion of this document for information related to training procedures.) The following health related concerns are included in this section:

The specific health care procedures are acts generally considered nursing care activities which are provided by a nurse or provided only by a designated trained person(s) for an individual student as delegated by, and under the supervision of a nurse. (See section entitled "Related Kentucky Regulations" in the narrative portion of this document - Pg. 10).

Other licensed health care providers such as physicians, physical therapist, occupational therapist, or speech/language therapist may provide, delegate, teach and supervise others in the performance of procedures, when the procedures are within the scope of practice of the given licensee. The following health related procedures are included in this section:

Bone and Joint Deformities

Bowel Care

Congenital Heart Disease

Feeding Disorders

Nutrition

Orthotics Care (Braces and Splints)

Prosthetics Care (Artificial Limbs)

Shunt Monitoring

Skin Care



BONE AND JOINT DEFORMITIES

Description: Bone and joint deformities may result from restriction of movement of the muscles surrounding the bones and joints. Muscles surrounding joints, that do not maintain adequate range of motion, eventually shorten so that full range of motion is not possible. Permanent shortening of these muscles results in **contractures** of the joints. Inability to participate in normal movement activities can also lead to bone deformities due to the fact that bones become softer and less dense as a result of lack of movement. Lack of movement may also adversely effect other systems of the body including the respiratory system, urinary tract, the gastrointestinal system, and condition of the skin.

Recommendations

- * Consult with a physical or occupational therapist and the student's orthopedic specialist about the types of therapeutic management techniques needed to prevent bone and joint deformities including a description of the following:
 - oint range of motion exercises.
 - joint range of motion techniques to integrate throughout the day,
 - variety of positions to place student in for educational activities,
 - handling techniques including specialized physical assistance, and
 - adaptive equipment.
- * All personnel working with a student with bone and joint deformities are trained to perform therapeutic management techniques. Training is done by a qualified physical or occupational therapist who has experience working with students with physical and motor disabilities.
- * Visual reminders (pictures) of appropriate handling and positioning techniques are obtained from the therapist(s) for school personnel to refer to at all times
- Know signs and symptoms of complications that might arise and make plans in advance to deal with these.
- * Consult with the student's parents to design a plan for associated problems or emergencies that may occur. These may include:
 - pressur€ sores,
 - bone fractures, and
 - swelling or inflammation of joints.



- * Document treatment recommendations as specified by the physician and/or physical therapist with parental consent
- Document emergency procedures as planned in conjunction with parents.
- * Document training by qualified personnel (e.g. physical therapist) for school personnel who perform positioning and physical management techniques.
- * Document on going communication between physical therapist and school personnel in regard to changes in therapeutic management techniques.
- * Weekly treatment record including:
 - frequency of range of motion exercises,
 - frequency of positioning changes as well as variations,
 - presence of redness, blanching, swelling, or bruising, and
 - any recommended changes in therapeutic management procedures by physical therapist.
- * Use Positioning Requirements form in Appendix D to document positioning recommendations.

Precautions

- * Obtain training from a physical therapist in the use of proper body mechanics when lifting, handling, or carrying students with physical disabilities.
- * Range of motion exercises, handling techniques, and positioning are not, in and of themselves, educational goals for students with physical or motor disabilities. They are physical management techniques and should be included in all instructional activities in which the student participates.
- * Equipment should be maintained for safety and proper fit for each individual student.
- * Fractures and joint dislocations can occur during range of motion exercises. School personnel should be aware of the signs of this occurring.
- * Signs of joint contractures should be reported to the physical or occupational therapist.



Recommended Readings

- Campbell, P. H. (1987). Physical management and handling: Procedures for students with movement dysfunction. In M. E. Snell (Ed.), <u>Systematic instruction of persons with severe handicaps</u> (3rd ed.) (pp. 174-187). New York: Macmillan Publishing Co.
- Graff, J. C., Ault, M. M., Guess, D., Taylor, M., & Thompson, B. (1990). <u>Health care for students with disabilities: An illustrated medical guide for the classroom.</u>
 Baltimore, MD: Paul H. Brookes. (see Chapter 7: Therapeutic Management)
- Lough, L. K. (1990). Positioning and handling. In J. A. Blackmon (Ed.), <u>Medical aspects of developmentally disabilities in children birth to three</u> (2nd ed.) (pp. 25-44). Rockville, MD: Aspen Publishers.
- Word, D. E. (1984). <u>Positioning the handicapped child for function</u> (2nd ed.). Phoenix, AZ: Phoenix Press.

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BOWEL CARE

Description: Children with certain medical conditions and/or motor disabilities may have problems with bowel regularity and elimination.

Recommendations

- * Consult with the student's parent/guardian to obtain history of child's regular bowel habits.
- * Know signs and symptoms of bowel problems (e.g. constipation, diarrhea, dehydration, hemorrhoids).
- * Implement nutritional and fluid intake recommendations, and the use of laxatives, stool softeners, suppositories, or enemas as specified by physician.
- * Promote practices that prevent bowel problems including ample fluid intake, and adequate fiber in diet.
- * Determine if the child requires special positioning devices for toileting or the use of relaxation techniques to promote elimination. Consult with physical and/or occupational therapists for recommendations and/or training if needed.

Documentation

- * Document treatments and recommendations as specified by the physician with parental consent.
- * Maintain daily treatment record (copy sent to parents) including:
 - supplements given (if prescribed),
 - amount and frequency of fluid intake,
 - laxatives given (if prescribed), and
 - date and time of bowel movement

Precautions

- * Use vinyl or latex gloves when toileting children. (see Appendix G Preventing Transmission of Communicable Diseases)
- * Students with motor disabilities may have impacted bowels, which require medical intervention.



Recommended Readings

- Graff, J. C., Ault, M. M., Guess, D., Taylor, M., & Thompson, B. (1990). <u>Health care for students with disabilities: An illustrated medical guide for the classroom</u>. Baltimore, MD: Paul H. Brookes. (see Chapter 5: Bowel Care)
- Shaddix, T. (1986). <u>Nutritional care for the child with developmental disabilities:</u> <u>Management of constipation</u>. Birmingham, AL: United Cerebral Palsy of Greater Birmingham.
- Sullivan-Bolyai, S. (1986). Practical aspects of toilet training in the child with a physical disability. <u>Issues in Comprehensive Pediatric Nursing</u>, 9, 79-96.

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CONGENITAL HEART DISEASE

Description: Children with disabilities may have one of two types of heart disease. The first type occurs before birth and is called congenital heart disease. A congenital heart defect generally occurs prior to the eighth week of gestation. Factors that may result in an infant acquiring a congenital heart defect include improper prenatal care, German measles, and genetic anomalies. Children with Down's Syndrome are especially at risk for congenital heart defects. Acquired heart disease is less common in children. A child is most likely to develop an acquired heart disease as a result of Rhuematic Fever which may cause permanent heart damage. Hypertension (high blood pressure) is another acquired heart disease, but it is generally not seen in children. Children may also have heart murmurs which may or may not be the result of some type of heart disease.

Recommendations

- * Consult with the child's parents and the heart specialist (if possible) about the type of heart disease and a description of the following:
 - what caused the heart disease (congenital or acquired),
 - safety precautions for working with the child,
 - diagnostic measures that were taken to determine the existence of the heart disease,
 - surgery the child may have had to correct the heart defect,
 - medications the child has to take for the heart disease,
 - length of hospital stay for surgery (may impact development),
 - any restrictions on physical or strenuous activities, and
 - medications required during school hours.
- * Know signs and symptoms of complications that may result from the heart defect (these will be different for each type of heart disease).
- * All personnel working with a student with any type of heart disease should be trained to perform any type of special care (e.g. positioning) that may be needed if symptoms of distress occur at school. Training should be done by qualified health care personnel. In addition, all school personnel who work with the student should be trained in Cardiopulmonary Resuscitation (CPR) (specific to age of child).



- Consult with the parents to design a plan for associated problems or emergencies that may occur. These may include:
 - "hypoxic spells" caused by lack of oxygen, which are "characterized by hyperventilation, increasing cyanosis, and fainting" (Baum, 1982, p. 318),
 - any other signs of heart distress.

- Document treatment recommendations as specified by the physician.
- Document emergency procedures as planned in conjunction with the parents and physicians.
- Document training by qualified personnel for school personnel who perform any type of specialized treatment including CPR.
- Maintain incident reports (as needed) and send to parents that include:
 - observance of any type of behavior indicative of distress, and
 - use of any type of emergency technique.
- Document the administration of medications related to heart disease (use the Authorization to Administer Medications form and the Medication Record form in Appendix D). Review the section on administering medications in Appendix A.

Precautions

- Know signs and signals of heart distress in all children who may be at risk for heart disease. These include "shortness of breath, chest pain, faintness, cyanosis, very rapid heart beat and unusual fatigue" (Baum, 1982, p.324).
- Since a majority of congenital heart defects manifest themselves within the first two years of life, it is recommended that early interventionists be especially aware of the signs and symptoms of various congenital heart defects.
- Teachers should be aware of any physical activity restrictions which may prohibit a student from competing in certain athletic events and obtaining strenuous jobs.



Recommended Readings

- Baum, D. (1982). Heart disease in children. In E. E. Bleck & D. A. Nagel (Eds.), <u>Physically handicapped children: A medical atlas for teachers</u> (2nd ed.) (pp. 313-324). New York: Grune & Stratton.
- Bricker, J. T., & McNamara, D. G. (1983). Heart disorders. In J. Umbreit (Ed.), <u>Physical disabilities and health impairments: An introduction</u> (pp.222-232). New York: Macmillan Publishing Co.

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FEEDING DISORDERS

Description: Some students with motor disabilities (e.g. cerebral palsy) and many students with severe/profound mental disabilities have significant feeding problems. These may include poor lip closure, tongue thrust, tonic bite reflex, poor chewing, a passive swallow, insufficient gag reflex, poor dental health, and others.

Recommendations

- * Proper positioning is a key factor in minimizing feeding problems as well as facilitating digestion. Overall body positioning includes positioning the students body in alignment and facilitating symmetry in both sides of the body. Use supports when needed to maintain the student's trunk and head upright and in midline (not leaning to the side or forward). The student's arms and hands are placed in a midline position (together and to the center of the body) and are supported by a lap tray or table surface. The student's feet are well supported on the wheelchair foot rests, on the floor, or by placing a bolster or box under the student's feet. Consult with occupational and physical therapists for specific recommendations about positioning and related equipment for individual students.
- * Special feeding techniques or utensils may be required for some students. These may include techniques such as oral stimulation activities, jaw control, placement of food and liquids in the mouth, special cups and utensils, and others. Work closely with occupational therapists and speech therapists who have special training in prespeech and feeding techniques to learn and use appropriate feeding techniques for individual students.
- * Obtain input from occupational therapists and speech therapists who have special training in prespeech and feeding techniques to vary and broaden students' abilities to consume foods of various temperatures and textures. Students who continue to eat pureed foods without consideration of systematically increasing food textures will not learn to handle (eat/drink) a variety of types of foods.
- * Students with poor chewing or swallowing abilities may need foods blended in a food processor. Blend each food individually so that students are exposed to different tastes, smells, and textures. Do not blend all the students food together.
- * General feeding guidelines include proper positioning of the head/neck, provision of a small amount of food on the spoon and/or cut food in small bites, and provision of liquids in small sips, making sure that the student receives adequate fluid intake throughout the day.



- * Know signs and symptoms of distress while feeding:
 - change in facial expressions (e.g. look of anxiety or stress on student's face, facial color changes, perspiration on face),
 - excessive increase in muscle tone or stiffening of the student's limbs or whole body (spasticity),
 - excessive movements of arms and legs,
 - nasal flaring or increased rate of respiration.
 - frequent coughing and/or choking while eating,
 - turning head away from food offered, and
 - excessive fatigue.
- * Feeding problems require a team approach for assessment and instructional programming. Team members may include occupational therapist, speech therapist, nutritionist, physician, nurse, educator, and physical therapist. School psychologists and behavior specialists may be needed for some students.
- * To evaluate the possibility of feeding disorders, refer parents to their family physician. A medically prescribed test called a videofluroscopy can be conducted to determine the presence or absence of a swallowing disorder.
- * Obtain information regarding food types and textures, solids vs. liquids, amount of food and liquids for mealtimes and snacks during the school day, rate of eating/drinking, and foods to avoid due to allergies or risk of choking.
- * Obtain training in first aid for choking and CPR from certified instructor.
- * Obtain training from qualified therapists to perform special oral motor and feeding techniques.

- * Obtain a written description of correct positioning for feeding (from physical or occupational therapists) and all special oral motor and feeding techniques and/or special equipment used during feeding (from an occupational therapist or a speech therapist who has had training in feeding).
- * Document recommendations from the student's physician and parents regarding nutritional requirements, amount and rate of feeding, and foods to avoid.
- Use Feeding/Eating Record in Appendix D.



Precautions

- * Avoid foods such as hard candy, nuts, and other foods that break up into small pieces and may be hard to handle and cause choking (whole kernel corn, raw vegetables such as carrots, popcorn, hard cookies, etc.).
- * When cutting foods, dice or cut lengthwise (i.e. hot dog weiner).
- * Obtain training in first aid for choking and CPR in case of emergency.
- * Wash hands before and after feeding students.
- * Use disposable napkins for clean ups or use one wash cloth for each student.
- * Feed one student at a time to prevent the spread of communicable diseases (see Appendix G).
- * Wear vinyl or latex gloves when feeding students with known highly contagious conditions (see Appendix H) or if you have an open wound or sore on your hands. If gloves are required, wear a different set of gloves for each student to prevent the spread of known communicable diseases.

Recommended Readings & Resources

- Crump, M. (Ed.) (1987). <u>Nutrition and feeding of the handicapped child</u>. San Diego: College-Hill Press.
- Morris, S. E., Kein, M. D. (1987). <u>Pre-feeding skills: A comprehensive resource for feeding development</u>. Tucson, AZ: Communication Skill Builders.
- Alexander, R. (1991). Prespeech and feeding. In J. L. Bigge (Ed.), <u>Teaching individuals with physical and multiple disabilities</u> (3rd ed.) (pp. 175-198). New York: Macmillan Publishing Co.

United Cerebral Palsy (see Appendix J)

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NUTRITION

Description: Students with certain medical conditions and/or feeding disorders may not receive adequate nutritional intake. This includes students who have either inadequate or excessive intake.

Recommendations

- * Know signs and symptoms of poor nutrition including:
 - excessively underweight or overweight,
 - poor condition of skin such as no elasticity, presence of open sores, changes in skin color, dry or itchy skin, swelling of hands or feet,
 - poor condition of hair such as dry hair, dull hair, loss of hair,
 - cracked or peeling lips or corners of the mouth,
 - coating of the tongue, presence of cracks in the tongue,
 - abdominal distention (swollen or protruding),
 - poor muscle tone or muscle weakness,
 - poor dental hygiene, bleeding or swollen gums, dental cavities or decay,
 - lack of facial expression, and
 - irritability and other behavioral signs/changes.
- * Know elements of balanced diet and basic nutritional requirements. The daily requirements for children include 3 milk servings, 2 meat or protein servings, 4 vegetable and fruit servings, and 4 grain or bread servings.
- * Be aware of socioeconomic and cultural differences that influence students' dietary intake.
- * If over or under nourishment is suspected, seek consultation from a nurse, nutritionist, or physician. These persons can obtain a dietary history from the family and determine if nutritional intervention is needed.
- * Monitor students dietary intake and follow recommendations from health care personnel regarding nutritional needs and/or supplements.
- * Measure, record, and monitor weight and height/length. A health care worker can assist in interpreting these data to determine if problems exist and recommend referral to the physician and/or nutritionist if needed.



Documentation

- * Maintain daily record of student's dietary intake. Use or modify and use the Eating/Feeding Record in Appendix D.
- * Obtain written instructions from the child's physician or nurse regarding special dietary concerns including:
 - amounts and schedule of dietary supplements, and
 - record of weight and height/length recorded as part of student's permanent record.

Recommended Readings & Resources

- Crump, M. (Ed.) (1987). <u>Nutrition and feeding of the handicapped c'ni-d</u>. San Diego: College-Hill Press.
- Graff, J. C., Ault, M. M., Guess, D., Taylor, M., & Thompson, B. (1990). <u>Health care for students with disabilities: An illustrated medical guide for the classroom</u>. Baltimore, MD: Paul H. Brookes. (see Chapter 5: Nutrition Monitoring and Supplementation)
- Shaddix, T. (1986). <u>Nutritional care for the child with developmental disabilities:</u>
 <u>Management of constipation</u>. Birmingham, AL: United Cerebral Palsy of Greater Birmingham.

National Center for Nutrition and Dietetics (see Appendix J)

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ORTHOTIC CARE

Description: Orthoses, commonly referred to as braces or splints, are devices used to prevent joint contractures and bone deformities and also to facilitate proper joint alignment to assist in weight bearing and walking. Braces are made of either metal or plastic that is molded to fit the child. There is a wide variety of braces from those that support the child from the chest to the feet (e.g. reciprocating gait orthosis) to those that support only the ankle and foot (e.g. ankle-foot orthoses). Braces may also be used to prevent joint contractures in the upper extremities (arms and hands).

Recommendations

- * Consult with the student's orthopedic specialist, physical therapist or occupational therapist (hand splints), and parents about the type of orthotic device and a complete description of the following:
 - why the orthotic device is needed,
 - how to place the brace on the child.
 - how long each day the child is to wear the brace,
 - activity restrictions while the brace is being worn,
 - movement patterns that are being promoted while the brace is worn, and
 - other treatment techniques used to prevent the orthopedic problem.
- * Obtain training from a qualified physical therapist to put the braces on the child. All school personnel working with the student should receive this training.
- * Know signs and symptoms of complications that might arise and make plans in advance to deal with these.
- * Consult with parents to design a plan for complications that may arise as result of wearing orthotic devices. These may include:
 - metal, plastic, or strapping that maintains contact with skin, and
 - any skin irritation resulting from new or improperly fitting braces.

Documentation

- * Document treatment recommendations as specified by the physician and/or physical therapist with parental consent.
- * Document procedures for dealing with complications as planned in conjunction with the parents.



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- * Document training by qualified personnel (e.g. physical therapist) for school personnel who monitor the fit and function of othotic devices.
- * Document that periodic checks have been made to assure that the orthotic device fits properly (by physical therapist).
- * Maintain weekly treatment record (sent to parents) including:
 - length of time orthotic device was worn each day,
 - movement pattens that are being encouraged during time orthotic device is being worn,
 - -signs of skin irritation, and
 - -recommendations by physical therapist to have braces changed for appropriate fit.

Precautions

- * Improperly placing an orthotic device on a student can cause orthopedic problems including bone fractures.
- * Orthotic devices that fit improperly **can** cause serious skin irritation. Do not disregard a student's behavioral signs of discomfort or unwillingness to wear the device as simply an intolerance for the device.
- * Pressure points (red marks) that do not disappear in 20 minutes are reported to the parents and physical or occupational therapist (hand/arm splints). This condition can lead to pressure sores.
- * Students should not wear orthotic devices for extended periods of time upon initial receipt of the device. Likewise, the length of time the student wears the device should be reduced following extend periods of time when the device was not worn (e.g. vacation).
- * Training should not exclude other tasks involved in the use of orthotic devices including ambulation and movement transitions.

Recommended Reading

Lough, L. K. (1990). Bracing. In J. A. Blackmon (Ed.), <u>Medical aspects of developmentally disabilities in children birth to three</u> (2nd ed.) (pp. 25-44). Rockville, MD: Aspen Publishers.

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PROSTHETIC CARE

Description: A prosthesis replaces a missing body part. The information contained in this section refers to artificial limbs which replace the function of missing arms and/or legs. Prostheses are custom molded for the individual and are held on with straps or a harness.

Recommendations

- * Consult with the student's physician, prosthetist, physical or occupational therapist, and parents to obtain a complete description of the following:
 - type of prosthesis and how it operates,
 - type of training the child needs to become functional with the prosthesis and who will do the training,
 - abilities of student with prosthesis,
 - potential dangers to other students that could be caused by prosthesis,
 - the schedule for wearing the prosthesis.
 - indications that the prosthesis is not functioning properly,
 - activities that should be avoided while the child is wearing the prosthesis,
 - assistance the child needs while wearing the prosthesis, and
 - how to apply the prosthesis.
- * Know the signs and symptoms that indicate that the prosthesis does not fit properly.
- * Design a plan for explaining to other children in the classroom about the prosthesis.

Documentation

* Record as needed any signs of skin irritation including bruising, rashes, or abrasions that result from wearing the prosthesis and report these to the parents and appropriate ancillary personnel (occupational therapist for upper extremities or physical therapist for lower extremities).

Precautions

- * Poor hygiene can cause skin irritations. Teachers should be aware of such situations and alert parents if they notice this.
- * Be sensitive to the emotional needs of the student wearing the prosthesis. Avoid teasing by other students by explaining or having the child explain the device.
- * Consider the physical education needs of the student. Students wearing artificial limbs are encouraged to participate in physical education as much as possible, but may require adapted physical education and/or consultation from



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- an adapted physical educator.
- * Consideration should be given to the fact that the child with absent limbs may perspire more than a typical child. Therefore, their underclothing may need to be changed more frequently. Also, children with absent limbs may run extremely high temperatures during minor infections such as a cold.

Recommended Readings

- Frederick, J., & Flether, D. (1985). Facilitating children's adjustment to orthotic and prosthetic appliances. <u>Teaching Exceptional Children</u>, <u>17</u> (3), 228-230.
- Setoguchi, Y. (1982). Amputations in children. In E. E. Bleck & D. A. Nagel (Eds.), <u>Physically handicapped children: A medical atlas for teachers</u> (2nd ed.) (pp. 17-26). New York: Grune & Stratton, Inc.
- Brooks, M. (1983). Limb deficiences. In J. Umbreit (Ed.), <u>Physical disabilities and health impairments:</u> An introduction (pp. 93-99). New York: Macmillan Publishing Co.

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SHUNT MONITORING

Description: A shunt is a plastic tube placed into the ventricle of the brain to drain excess cerebrospinal fluid. Children with an excess of cerebrospinal fluid are said to be hydrocephalic (enlarged head due to excess fluid). The shunt leads from the brain to a particular cavity of the body where the excess fluid is received and processes or eliminated from the body. The shunt may drain the cerebrospinal fluid into either the heart chamber or the abdominal cavity (most common, ventricular peritoneal).

Recommendations

- * Consult with the student's physician and/or neurologist and parents about the type of shunt and a complete description including:
 - child's typical behavior and how it may differ if the shunt is malfunctioning,
 - knowledge of signs and symptoms of malfunctioning shunt, and
 - when the shunt was inserted and any warning signs that may result during the first weeks following insertion.
- * Know signs and symptoms of complications that might arise and make plans in advance to deal with these.
- * Consult with parents to design a plan for emergencies that may result from the shunt. These may include:
 - behavioral symptoms including irritability, restlessness, personality change, lethargy, drowsiness, inability to follow simple commands, and decreased orientation to time and place; and
 - physical symptoms including headache, nausea, vomiting, double or blurred vision, seizures, soft spot becomes full, and changes in reaction to light

Documentation

- * Document emergency procedures as planned in conjunction with parents.
- * Maintain weekly observation records (copy sent to parents) that include:
 - any changes in behavior or physical symptoms as described above,
 - level of activity, and
 - response to and awareness of environment.
- * Document occurance of seizures and any other emergencies that require medical attention at school.



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Precautions

- * Physical and behavioral symptoms of shunt malfunction are reported to the child's parents immediately. Any rapid increase in pressure in the brain can result in serious complications and death.
- * If school health care workers are not available, the Emergency Medical Team (EMT) should be notified in the event of an emergency situation. The student's parents should be also be notified immediately if the student is showing signs of shunt malfunction.

Recommended Readings

- Graff, J. C., Ault, M. M., Guess, D., Taylor, M., & Thompson, B. (1990). <u>Health care for students with disabilities:</u> An illustrated medical guide for the classroom. Baltimore, MD: Paul H. Brookes. (see Chapter 9: Monitoring a Shunt)
- Wolraich, M. L. (1990). Hydrocephalus. In J. A. Blackmon (Ed.), <u>Medical aspects of developmentally disabilities in children birth to three</u> (2nd ed.) (pp. 175-180). Rockville, MD: Aspen Publishers.

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SKIN CARE

Description: Children who have limited movement or mobility, may require special skin care to prevent the development of skin breakdown and pressure sores.

Recommendations

- * Know signs and symptoms of developing skin problems including:
 - pressure points (red marks) that do not disappear in 20 minutes can lead to pressure sores and are reported to the parents, and
 - signs of skin irritation including swelling, redness, tenderness, bruising, rashes, abrasion, or other signs of problems.
- * Apply topical treatments or dressing changes as specified by physician.
 Unlicensed school personnel may change simple nonsterile dressings.
 Complex dressings requiring a sterile technique should be performed by a qualified licensed health care professional.
- * Promote practices that prevent skin problems including keeping the skin clean and dry, proper nutrition and fluid intake, frequent position changes, and activities to promote circulation.

Documentation

- * Document treatments and recommendations as specified by the physician with parental consent (use the Authorization for Treatment form in Appendix D).
- * Document topical medications and treatment applications when required (use the Authorization to Administer Medication form and the Medication Administration Record in Appendix D).
- * Record as needed any signs of skin irritation including swelling, redness, tenderness, bruising, rashes, abrasion, or other signs of problems and report these to the parents.

Precautions

* Wear vinyl or latex gloves if applying topical treatments, changing dressings, or dealing with open sores or injuries.



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Recommended Reading

Graff, J. C., Ault, M. M., Guess, D., Taylor, M., & Thompson, B. (1990). <u>Health care for students with disabilities: An illustrated medical guide for the classroom</u>. Baltimore, MD: Paul H. Brookes. (see Chapter 4: Skin Care)

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APPENDIX C

Developing Appropriate Individual Education
Programs for Students with Special Health Care Needs



DEVELOPING APPROPRIATE INDIVIDUAL EDUCATION PROGRAMS FOR STUDENTS WITH SPECIAL HEALTH CARE NEEDS

Historically, Individual Education Programs (IEPs) for students with complex health care needs have often contained objectives that indicated what would be done to the student and not what the student will learn. For example, the IEP may have contained **inappropriate or noninstructional objectives** such as:

The student will be fed three times a day with a gastro-intestinal feeding tube.

or

The student will be positioned in 5 different positions throughout the school day.

Objectives such as these can be referred to as "staff directives" as opposed to student objectives. The content of "objectives" such as these refers to related services the students requires during the school day. As with other related services, such as physical therapy, procedures requiring support from school health services are included in the student's IEP. The IEP also contains information about how often the related service will be provided. With related services such as physical therapy, the skills the physical therapist wants included in the IEP will be written on the document in the form of instructional objectives. However, when the related service is school health services, the process is somewhat different in that health procedures are not in and of themselves skills the student will learn.

Thus, it is suggested that teachers include information about health care procedures on a separate page of the IEP. Information that is provided on this page includes a) a description of the required procedures, b) the person who is primarily responsible for carrying out the procedures, c) the back-up person(s) who will carry out the procedures in the absence of the primary person, and d) when the procedures will be initiated, reviewed, and end. An example of how this might look is shown below:



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REQUIRED PROCEDURE	PERSON(S)	DATE	=
DATE	will Teacher dication (Primary) per day Teacher	BEGIN	END
The student will receive medication three times per day each day he is at school.	(Primary) Teacher Assistant	Aug 1991	June 1992

Once the procedure has been included in the IEP, a program plan is developed for each procedure. The plan includes the student's name, name and description of procedure, the primary and back-up person(s) responsible for carrying out the procedure, the rationale for why the procedure must be conducted, the steps required to perform the procedure as outlined by a qualified medical personnel (e.g. physician, nurse), materials needed to perform the procedure, and documentation required. See Appendix E for Program Plan and Training Form and Appendix D for School Health Care Services Record form.

The teacher will also need to write instructional objectives related to instruction that will occur during the health care routine. The reader is referred to Hudson and Leatherby (1991) for a detailed summary of how to write instructional objectives within activities and/or routines. Health care procedures are routines that are required on a daily basis. Again, they are not skills for the student to learn. However, health care routines may take a significant portion of the student's day, and are viewed as opportunities for instruction as would any other activity. Health care routines can be utilized for instruction by embedding instruction in basic skills (e.g. communication, motor, sensory) into these routines. Following the format for writing instructional objectives by Hudson and Leatherby (1991), an objective which includes the health care procedure of gastro-intestinal tube feeding might look like this:



When involved in an activity (described below) and given a verbal cue to "reach for _____" and when the item is placed 2-4" in front of the student, he will extend his right forearm from the elbow to make contact with the item within 15 seconds, 4 of 5 opportunities (for 3 consecutive days).

Examples of activities in which the student will practice reaching are:

- 1. reaching for switch to operate appliance during snack
- 2. reaching for switch to operate video game during leisure time
- 3. reaching for coat hook to hang up coat during arrival time
- 4. reaching for switch to operate electric can opener to open can of formula for G-tube feeding.
- 5. reaching for the supplies during G-tube feeding to assist with feeding during lunch

The health care routine can then be added to the activity matrix to as an activity occurring during the student's daily schedule (see Hudson & Leatherby, 1991).

Although, it has been stated that health care procedures are not in and of themselves instructional objectives for the child, there is one exception to that fact. For certain procedures, it is possible, that some students might eventually perform them independently. Catheterization is one example. Students with adequate cognitive and physical abilities can be taught to catheterize themselves, and are encouraged to do so. With procedures such as these, instructional objectives are written to reflect independence as the criterion. An example is shown below:

When given the materials needed for catheterization and given the verbal command to do so, the student will catheterize himself by independently performing 100% of the steps of catheterization 2 of 2 times per day each day of the school year.

Self catheterization falls within the independent living domain and certainly would be considered a functional skill to teach. For programming planning purposes, the teacher develops a task analysis of the steps required to perform catheterization and identifies an appropriate instructional strategy for teaching the procedure. Making both of the these decisions requires input from the student's physician or school nurse. The Program Plan and Training Form may be used or adapted for the purpose of direct instruction of the student.



As with other related services, health care procedures need to be addressed on the IEP. Teachers and other members of the Admissions and Release Committee should remember the following when including these procedures:

- 1. If the procedure has to be performed by an adult, it should not be included as an instructional objective for the child. (see #2)
- 2. Administering health care procedures is considered a related service and is included on the IEP, but not written as an instructional objective. (see #1)
- Health care procedures are considered routines in which instruction can occur. Basic skills taught within these routines are included on the IEP noting that the routine provides an additional context for instruction of these skills.
- 4. Some students may be able to independently perform certain health care procedures themselves. Systematic instruction is planned with input from appropriate medical personnel.



APPENDIX D

Sample Letters and Forms for Health Related Procedures and Concerns

Authorization to Give Medication

Medication Administration Record

Authorization for Treatment

Special Health Care Services Record

Seizure Record

Feeding/Eating Record

Positioning Requirements Form



SUGGESTED USE OF SAMPLE LETTERS AND FORMS

Authorization To Give Medication (sample letter and form): Use to obtain permission from parents/guardian if medication must be administered by school personnel. Adapt cover letter for district use and put on district/school letterhead. Use or adapt form on bottom half of page and put on school district letterhead. Must be completed/on file before any medications can be given by school personnel. See Appendix A for additional information.

Medication Administration Record (sample form): Use to document administration of medication by school personnel. The top portion of the form (matrix/boxes) is used to document each medication that is given at school including the name of the medication, dosage, time(s) to be given, pharmacy, prescription number (shown on label), and other comments or possible (and known) side effects. The bottom portion of the form is used to document each any medication is given including the date, time, medication type and dosage, the initials of the person who administered the medication, and any comments or problems and to whom these were reported. Use one form for each student. See Appendix A for additional information.

Authorization For Treatment (sample letter and form): Use to obtain permission from parents/guardian to provide treatment/perform health-related procedures during the school day. This is required whether the procedure is done by a licensed health care provider (e.g. nurse) or by a trained teacher or teacher assistant. Use this form for all the procedures described in Appendix A <u>unless</u> a specific form is described in this section for the procedure.

Special Health Care Services Record (sample form): Use this form to record when health-related procedures are performed by school personnel (both licensed health care staff or teaching staff). Complete the top portion then use the bottom portion to record each time the procedure is performed. Record the date, time(s) of day the procedure was done, the initials of the person who performed it (must be the trained person(s) listed on top portion), and any comments or problems that occurred and to whom these were reported. See Appendix A for information on specific procedures. Use one form for each student and each different procedure.



Seizure Record (sample form): Use this form to record seizures. Complete the informational section at the top and obtain the physician's signature. Based on information from the parent and/or physician, complete the baseline section with information regarding student's typical seizure behavior. Record the date; start/stop time; the initials of the person who observed the seizure and completed the forms; behaviors student exhibited based on the given checklist and any comments including intervention or problems and to whom these were reported. Use one form for each student. See Appendix A for additional information on seizures.

Feeding/Eating Record (sample form): Use this form to record feeding/eating recommendations or interventions used. Complete the top portion of the form for the student and use the bottom portion to record feeding/eating interventions and/or problems. Record the date, initials of the person trained in feeding the student/using special feeding procedures; and any comments or problems that occurred and to whom these were reported. Use one form for each student. See Appendix B for additional information on feeding/eating.

Positioning Requirements (sample form): Use to document recommendations about positioning provided by a licensed physical and/or occupational therapist. The team leader (usually the special education teacher) should complete with the therapist and share with the parents. Complete one form for each student. See Appendix B for more information on positioning.



AUTHORIZATION TO GIVE MEDICATION*

Dear Parent or Guardian:

In order for school personnel to administer any type of medicine to your child at school, we must have on file a signed affidavit giving your permission for us to do so. The medicine should be sent to school with complete instructions and in its original container which must have the prescription label attached. Please be sure to complete all information that is listed on the form below before returning it to school.

		Sincerely,	
		Principal	
		School Nurse (if a	applicable)
— Date			
child,	eby request school personnel of This medicing This medicing winose address is	ine has been prescri	bed for my child by
	e instructions should be followed in giving my		
1.	Type of medicine:		
2.	Dosage:		
3.	Time of day the medication is to be given a	t school:	
4.	Reason medication is to be given:		
5.	Reason medication is to be given: Reactions or side effects: Please list potent	ial reactions the chi	ld might have to medication:
6.	Physician's telephone number:		
7.	Physician's Signature:		
8.	Parent's telephone number: Home	Work	Emergency
	I give my permission for medication for my child during school.	School System to	administer the above
	Signature of Parent or Guardian		

*NOTE: Use school letterhead. Obtain information for each medication. Adapted from School Health Services Manual (1990), Kentucky Department of Education.



MEDICATION ADMINISTRATION RECORD

Student School F	Name _ Personn	el Trained	to Perform F	Proced	C	lass	
Medic	ation	Dosage	Time(s)	Ph	armacy	Prescription #	Comments/Side Effects
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Date	Tim	e Medi	cation & Do	sage	Initials	Comments or Pro	blems (Reported to Whom)
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Additional Comments:

A = Absent from School

C = Change in Dosage

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AUTHORIZATION FOR TREATMENT*

Dear Parent(s) and/or Guardian:			
If your child requires a specific the following information, as we purpose of this is to make sure y	ell as signed pe	ermission from you and yo	our child's physician. The
Student's name:			
Duration of this form: Describe the treatment procedure			
Times to be administered:			
During the school hours of or trained school personnel will above instruction of the physici			ing that the school nurse and/ procedure according to the
	S	incerely.	
	P	Principal	
	S	school Nurse (if applicable	e)
Authorization Signatures			
Parent	Date	Physician	Date

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Physician's Address

*NOTE: Use school letterhead. Adapted from Kenton County Schools Independence, Kentucky

Telephone Number



City/State

Zip

SPECIAL HEALTH CARE SERVICES RECORD*

Special Considerations Signs and Symptoms of Problems Note: Gloves are required. Proper Disposal of Waste: Date Time(s) Initials Comments/Problems (Reported to Whom)	Procedu	re		
Note: Gloves are required. Proper Disposal of Waste: Date Time(s) Initials Comments/Problems (Reported to Whom)			ions	
Date Time(s) Initials Comments/Problems (Reported to Whom)	Signs ar	nd Symptor		
	ProcedureSchool Personnel Trained to Perform ProcedureSpecial Considerations	Proper Disposal of Waste:		
	Date	Time(s)	Initials	Comments/Problems (Reported to Whom)
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^{*}Note: Refer to Program Plan & Training Form (see Appendix E) for instruction per procedure.

Jefferson County Public Schools PHYSICIAN'S AUTHORIZATION/SEIZURE RECORD FORM

Please return to:	

Stuc	dent's Name:									_					
raic	ant Signature														
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Physi	cran's Signature Date			SCHOOL P	ERSO	NNEL:	Pleas	e checi	c obser	ved ch	unicter	138662 0	(seizu	re activ	ity
TYPE	OF SEIZURE:														
PHYS	SICIAN: Please specify by commenting	on each													
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	Staring Straight Ahead				# ip (Ì									
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	Looking to Right				الأثار										
	Drawn to the Left				<u> </u>								<u> </u>		
МОГЛІ	Drawn to the Right				- i.21										
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	Teeth Clenched				. 41.4										
[Noisy Breathing				٠.٠										
BKEATHING	Heavy Breathing														
KI:A	Change in Skin Color				:										
	Not Breathing								·						
	Incontinent of Urine				į.										
SI E	Incontinent of Stool														
ē [Vomiting														
MIN	Description of seizures including movements, change it behavior or skin color. (Attach additional comments as needed).														
VINTOR	If symptoms persust after physician's recommendations have been followed: 1. Notify parents 2. Call 911, using Emergency information(Appendix p. 89				1. CP 2 Cal	thing start of the control of the co	od staff ing Em				Append	rx b 89'	;	_	

FEEDING/EATING RECORD

Student		School/Class
School I	Personnel T	School/Class Trained in Special Oral Motor or Feeding Techniques
Feeding	/Oral Moto	r Needs/Interventions
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Position	ing for Fee	ding/Eating:
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Food Ty	mes/Amou	t:nts/Textures:
1000 1	pes/rimou	its/Textures.
Recomr	nended/Tra	ined by:
Precauti	ions:	
Date	Initials	Comments or Problems (Reported to Whom)
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POSITIONING REQUIREMENTS*

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ositioning Options:	Complete all that apply.		Personnel Trained in Positioning	
			Ç .	
Position	Purpose	Equipment	Proper Use & Precautions	Amount Time
Prone				
Supine				
Sidelying				
Sitting				
9 0				
Standing				
Other Positioning Reco	ommendations:			

APPENDIX E

Sample Program Plan/Training Form



SUGGESTED USE OF SAMPLE PROGRAM PLAN/TRAINING FORM

Purpose: Use this form as both a program plan form (child and procedure specific) and a training form when training unlicensed or untrained school personnel. The form is used when training school personnel to perform the health-related procedures described in Appendix A. The form should also be used when training school personnel to perform any other procedures that unless performed correctly might cause harm to the student. (e.g. other health-related concerns such as positioning, lifting, transfers, special oral motor and feeding techniques described in Appendix B.) All training or unlicensed school personnel must be provided by appropriate licensed health care personnel or related services personnel (e.g. nurse, physical therapist, occupational therapist, speech-language pathologist, etc.)

In the left column, list the 1) materials and terms Instruction: involved in the procedure (e.g. identify the g-tube, and type of formula, etc.) 2) steps involved in the procedure (task analysis), and 3) other critical information related to performing the procedure (e.g. amount of formula, length of time or speed to give, signs or symptoms of problems, emergency procedures). If the procedure is one of those described in Appendix A, these "steps" must be approved by the student's parents and physician (see space for physician's signature on top portion of form, parents signature on page two). In some cases the physician may complete the form. However in most cases, the designated licensed health care provider completes the form with students parents/guardian and sends it to the physician for approval and authorizing signature. Remember, you must also have a completed Authorization for Treatment Form signed by the student's parents/guardian (see Appendix D).

The grid or matrix to the right of the "steps" column is used by the trainer to record if the trainee (unlicensed school personnel) can perform each "step" by recording "+" to indicate that the step was done incorrectly. The trainee must "pass" by performing 100% of the steps correctly over three training sessions. Then the trainee can be allowed to perform the procedure. However, their performance is monitored periodically by the designated licensed health provider or trainer. The signature lines for the instructor on page two of the form should be



completed by the trainer to document that raining has occurred. Review (as many times as needed) the section entitled "Training Unlicensed School Personnel to Perform Special Health Care Procedures" contained in the from portion of this document.



PROGRAM PLAN & TRAINING FORM*

Student			_ Sch	001/	Cla	ss _									
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Consider this a prescription for the above n Perform the procedure as outlined in this ch	amed stud	ent's	s												
Perform the procedure as outlined in this ch	ecklist.				(<u>[</u>	rocs	dure))							
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Special Considerations (e.g., position	ing)														
Signs and Symptoms of Problems					_										
(Code each step "+" or "-")		(Date	Tra	ine	d)	(Recommended Recheck)									
nstructor	D	Date							Date	?		_	_		
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Checklist content approved by:															
Parent Signature	Da	ite				-									
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Adapted from: Ventilator-Assisted Care Program Children's Hospital, New Orleans, LA.

APPENDIX F

Related School Health Information

Recommended School Health Policies
Health Requirements for School Admittance



RECOMMENDED SCHOOL HEALTH POLICIES

The focus of this document has been on providing health care services to students with special health care needs. However, school health services exist for all students. Teachers should make themselves aware of these services in order to assure that a healthy school environment is maintained. The Kentucky Department of Education has developed a manual outlining guidelines and regulations for health services in schools. Below is a summary of some of those guidelines and regulations as well as some additional suggestions for a healthy school environment. Teachers should acquire this manual entitled *School Health Services Manual* for complete information on this topic. If a manual is not available at your school, one can be attained from the Division of School Health Services, Kentucky Department of Education.

School Health Coordinator

Each school system is required to employ a school health coordinator to work with school personnel to coordinate health services. Some of the job responsibilities of the school health coordinator include a) coordination of health screening programs, b) supervision of first aid, and c) follow-up of a student after a prolonged illness, injury, or hospitalization. Teachers should be aware of who the school health coordinator is in their school district and become familiar with all the services they provide.

First Aid Policy

Schools are required to take measures to prepare for medical emergencies that occur at school. Some of these emergencies include treatment for abrasions, insect stings, cessation of breathing, fractures, frost bite, and nose bleeds. In order to treat such emergencies schools are required to have the following: a) a first aid room or suite to deal with such emergencies, b) a minimum of two (2) persons in the school who are certified in first aid training, and c) a first aid kit with supplies for at least 50 children. Having someone at the school who is certified in CPR is also highly recommended. The School Health Services Manual has information on recommended supplies for a first aid kit as well as information on treating medical emergencies such as those listed above. Teachers should make themselves aware of where the first aid kit is located and who in the school is certified in first aid and/or CPR. It is also recommended that teachers always take a first aid kit on field trips and during any community based instruction activities. The School Health Services Manual also recommends that schools post emergency numbers such as ambulance service and police departments.



Health Screenings

The School Health Services Manual states that the purpose of health screening "is to detect previously undiagnosed health problems that may, by health intervention, be more readily corrected" (p. 16). Below is a list of health screenings that occur at school along with a summary of when these screenings should occur.

Vision Screening: Vision screening is recommended for students in kindergarten, first, third, and fifth grades and for students who presently have diagnosed visual difficulties. In addition, teachers may recommend that a student's vision be screened in any grade if they feel the student is having difficulty.

Hearing Screening: A student's hearing is screened in kindergarten, first, third, and fifth grades. Other students who should have their hearing screened on a regular basis include students in special education classes, students with known hearing problems, and students who have chronic ear infections. In addition, transfer students should have their hearing screened.

Scoliosis Screening: The purpose of scoliosis screening is to determine if a student has a spinal abnormality which manifests itself in a curvature of the spine. The Kentucky Department of Education recommends that scoliosis screening occur during sixth and eighth grades and if possible during the ninth grade.

Head Lice Screening: Screening for head lice is conducted on an "as needed" basis when a break-out occurs.

Height and Weight Screening: The Kentucky Department of Education recommends that height and weight be measured during each of the elementary grades and at least once during both middle and high school years.

Dental Health Education and Flouride Mouthrinse Program

While screening for tooth decay is not a requirement of school systems, the Department of Education recommends that teachers educate students about healthy dental habits to prevent tooth decay. In addition, it is recommended that schools implement a weekly flouride mouthrinse program. Such a program can be implemented through the health department at no charge to the school. If schools have not implemented such a program, it is recommended that teachers approach their principal about the possibility of doing so.



HEALTH REQUIREMENTS FOR SCHOOL ADMITTANCE

Children entering school in Kentucky for the first time (grades K - 12) are required to present evidence of medical intervention not conducted by the school.

Medical Examinations

According to the Kentucky School Health Services Manual:

"All students must have a medical examination within six months prior to or 30 days after initial admission to school. The examination must be reported on the prescribed Kentucky Department of Education (KDE) form and should include a medical history, assessment of growth and development and general appearance, physical assessment including hearing and vision screening, and any recommendations to the school regarding health problems that may require special attention in the classroom or during P.E. activities. Children transferring into a district must comply with the above requirements." (p. 43)

Tuberculosis Testing

All children entering school in Kentucky for the first time must have a tuberculosis test. Children transferring from one school to another in the state are not required to have the test retaken, however, students transferring from other states must have be tested in Kentucky. A student can attend school for 30 days before showing proof that they have been tested. After that time they may be expelled if proof is not provided. Proof of the tuberculosis test is generally shown on the medical examination form or is documented on "Tuberculin Test Certificate".

Immunization Certificate

All children entering Kentucky schools for the first time are required to present an immunization certificate from a physician on the first day of classes, demonstrating that immunizations are up to date. It is recommended that immunization certificates be monitored bi-annually to assure that they have not expired. Page 103 of the *School Health Services Manual* outlines the exclusion policy for students not presenting a valid immunization certificate. There are exemptions for not having a valid immunization certificate and not having a tuberculosis test. These include medical exemptions and religious exemptions and are discussed in detail on page 102 of the manual.



School Health Records

In addition to the medical examination form and the immunization form, there are additional forms related to a student's health that are kept in the student's cumulative folder.

Cumulative Health Record Form: This form is used to record results of a) all health screenings, b) record weight and height, c) provide evidence of immunization certificate, and d) record health care given at school.

Emergency Information Form: All children enrolled in school should have an emergency information form completed which provides information to school personnel regarding who should be contacted in case of an emergency, including who should be contacted if the parents can not be reached. In addition, the form asks for information regarding medication and special health conditions including allergies and seizures. Often a version of the emergency information form is used to obtain permission from parents for students to take field trips. These forms should accompany the child on any out of school trips, including community-based instruction, in case there is an emergency.

Accident/Incident Form: This form is to be completed when a student is injured at school. Treatment information is included on the form, as well as a detailed summary of how the incident occurred. Accident/incident forms are kept in each student's cumulative record.

Authorization to Give Medication and Daily Log for Medication: Prior to dispensing medication to a student, permission is obtained from parents to do so. Information contained in this permission form includes a) the type of medication, b) the dosage, c) time of day for dosage, d) reason for medication, e) side-effects, and f) physician's phone number.

A daily log for dispensing medication is required. Information included in the log includes student's name, type of medication, dosages, and times it was given. A sample of both the Authorization to Give Medication Form and the Medication Administration Record Form are contained in Appendix D.



104 107

General Guidelines

In addition to the required health services mentioned above, there are additional guidelines school personnel should follow in order to assure that a healthy school environment exists. These include:

- 1. Develop a parent handbook outlining the school's policies in regard to health care. For example, parents should know the policy for leaving sick students at school and what the expulsion policy is for students with head lice. Information such as this will prevent misunderstandings from parents who may think school personnel are merely trying to prevent their child from attending school.
- 2. Make parents aware when there is an outbreak of a particular illness. For example, if there is an outbreak of head lice, send a note home to all parents in the class or even in the entire school. Explain to parents how to detect the problem and how to treat it.
- Provide training for school personnel in health related needs and include information on preventing the spread of communicable diseases (see Appendix G).
- 4. Make health records available to teachers. There is an abundance of valuable information in a child's cumulative health record. As children move through grades, each teacher should spent time familiarizing themselves with the health needs of their students. For example, they should know if they have students with particular allergies or students who have seizures.
- 5. An essential part of a healthy school environment is school sanitation. There are specific regulations regarding school sanitation (902 KAR 45:150) and teachers should be aware of these regulations. The sanitation regulations relate to, among other things, restroom facilities, lighting, and safety. These regulations are monitored twice yearly by the Cabinet for Human Resources. Teachers should do their part to assure that their students go to school in a safe, clean environment. While there are not specific regulations regarding safety within individual classrooms, teachers should consider safety factors when arranging their classroom. In situations where a student in the class or school has either a physical or sensory disability, environmental safety considerations become even more critical.



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APPENDIX G

Preventing Transmission of Communicable Diseases

Daily Practices to Prevent Transmission of Communicable Diseases

Universal Precautions



DAILY PRACTICES TO PREVENT TRANSMISSION OF COMMUNICABLE DISEASES

All school personnel should be aware of practices to prevent transmission of communicable diseases. Using these practices can prevent the spread of any and all childhood diseases and illnesses in schools. School personnel should receive training in these procedures and processes should be developed to conduct periodic follow-ups to ensure that procedures are being followed, including conducting site visits and annual reviews of prevention information. This section describes information regarding hand washing, feeding/eating, diapering/toileting, cleaning, and universal precautions (references).

Hand Washing

The best way to prevent the spread of illnesses and communicable diseases is to practice frequent hand washing. Use the following method to make sure your hands are free of germs:

Use soap and running water.

Rub your hands vigorously as you wash them.

Wash all surfaces including backs of hands, wrist, between fingers, and under fingernails.

Rinse your hands well. Leave the water running.

Dry your hands with a paper towel.

Turn off the water using the paper towel instead of your bare hands.

Hand washing should be done when arriving at school in the morning, before eating, before preparing and/or serving food, after feeding students, after performing any medically related procedure, after toileting or diapering a student, after wiping a student's nose or cleaning up messes, and after toileting.

Feeding/Eating

In addition to washing hands before and after feeding a student, other precautions should be taken. All students hands should be washed before and after eating. In addition, after meals all messes should be cleaned (e.g. wiping mouth and face areas, change clothing if soiled, cleaning and wiping of chairs or wheelchairs and tables if food is present). Use disposable towels for wiping and cleaning up messes. If towels are used, use one per student and wash these immediately after use in hot water using chlorine bleach. All eating utensils should be washed immediately after use in the school's commercial dishwasher to sterilize or in hot water using chlorine bleach in conjunction with detergent.



Diapering/Toileting

When changing diapers, change diapers directly on paper towels, roll paper, or other disposable covering. Place the disposable cover on a surface that is smooth, nonabsorbent, and easily cleaned (e.g. formica, plastic, vinyl, metal, enamel, or diapering pad). The diapering area should be a out of reach of other children, separate from food preparation areas, and within easy reach of a sink not used for food preparation. When diapering or dealing with toileting accidents, use disposable cleaning materials only (e.g. towelettes, paper towels). Dispose of cleaning supplies, changing towels/paper, and soiled diapers in a plastic bag or plastic lined receptacle. Clean and disinfect the diapering area and equipment or supplies touched. If the child has to be washed completely, use running water and disinfect the sink immediately after. If soiled clothes are involved, place them in a plastic bag and send them home for laundering.

Cleaning

Be sure all facilities (e.g. tables, mats, etc.) and supplies are washed with soap and water, then disinfected with either a bleach solution (1 cup bleach per gallon of water or 1/4 cup bleach per quart) or a commercial disinfectant that kills bacteria, viruses, and parasites. Cleaning should be done daily. A spray bottle is easy to use and handy for storage. If bleach solution is used, it should be made fresh daily. Use washable teaching materials and wash these weekly using bleach solution or disinfectant. Daily washing of materials may be necessary if they are mouthed by students who have communicable diseases. Carpeted areas should be vacuumed daily.

Children who take naps should have individual mats or mattress covers and linens labeled with their own names for consistent use. These mats should be cleaned at least weekly or daily if students have communicable diseases.



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UNIVERSAL PRECAUTIONS

In addition to the hygiene and cleaning practices previously described, the Centers for Disease Control (1987) and the Children's Hospital in Boston have recommended a list of universal precautions to prevent the transmission of communicable diseases. These universal precautions are recommended to be used by all persons who have contact with blood or body fluids, perform specialized health care procedures, and/or feed or toilet students. These persons are particularly at high risk for contracting communicable diseases and should follow these universal precautions:

- * Utilize frequent hand washing using the method described in the previous section. This is the best prevention against the spread of infections and cannot be over emphasized.
- * Wear vinyl or latex gloves when touching blood or body fluids, mucus membranes, or open skin areas. (Appropriate vinyl or latex gloves are available from any medical supply company.)
- * Avoid contact with and injuries from needles or other sharp instruments that have come in contact with body fluids.
- * Make sure that all needles are disposed of in appropriate sharps/infectious waste containers.
- * Dispose of waste and soiled supplies or clothing in the proper manner. Flush body fluids/waste down the toilet. Place soiled clothing in a plastic bag and send home with the student. Please discuss these practices with parents and explain why they are needed in the school setting.

Specific information on precautions and waste disposal for specific health care procedures and concerns is presented in Appendices A and B.



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APPENDIX H

Communicable Diseases



COMMUNICABLE DISEASES

HIV-positive (AIDS): Children who are HIV-positive should be admitted freely to all school activities. This virus is transmitted through blood, breast milk, semen, and vaginal secretions. Precautions include following hand washing recommendations previously described, and avoiding direct contact with blood. No vaccine is available. The primary means of contracting the virus is vaginal and anal intercourse with an infected partner, sharing needles for intravaneous medicine or drug use with another person infected with the virus, and obtaining a transfusion with blood that contains the virus. One case has been documented where a woman contracted the virus from her infected dentist who had an open wound on his hand and was not wearing latex gloves.

Hepatitis B Virus: Hepatitis B Virus is an inflammation of the liver and is highly contagious. The virus may be transmitted through contact with any and all body fluids including blood, urine, saliva, and other body fluids. Hepatitus B infection can become a chronic condition in some cases and the infected person becomes a carrier. A carrier does not appear ill with the disease, but does shed the virus in body fluids and is capable of transmitting it to others. In educational settings, precautions include following hand washing recommendations previously described, avoid direct contact with blood and all other body fluids, and wear aloves if feeding or toileting these children, and when performing medically related procedures. Students with known Hepatitis B virus should eat from disposable utensils and trays. Soiled clothing should be placed in a plastic bag and sent home for laundering. Soiled surfaces can be cleaned following the guidelines in Appendix G. If a student is identified as a chronic carrier of Hepatitus B, it is recommended that persons in the educational setting who come in close contact with the student and are at high risk of contracting the virus receive the vaccine that is available to prevent contracting Hepatitis B virus.

Cytomegalovirus (CMV): Cytomegalovirus (CMV) is a herpes viral infection characterized by variable symptoms including a slight fever or inflammation of the liver. Most acquired CMV infections result in no visible symptoms. The virus can be found in urine, saliva, semen, or feces of infected individuals for months or even years. The most significant danger from CMV is the transmission of the virus to the fetus during pregnancy which can cause severe neurologic impairments, blindness, mental retardation, and other birth defects. However, CMV can be present in the mother and not be transmitted to the fetus. Pregnant women should



be careful to avoid contact with known CMV carriers. However, since most CMV carriers are unknown, general precautions should be observed at all times. These precautions include hand washing and universal precautions as described in Appendix G.

A very heipful chart entitled "Communicable Diseases in Child Care Settings" is available from the Kentucky Cabinet for Human Resources, Department for Health Services, Immunization Program, 275 East Main, Frankfort, Kentucky 40621-0001. Just write and request a copy of publication PAM-DHS-046 (3-86) with the above title. Every building and/or classroom should order the chart for this valuable information.



APPENDIX I

Local Health Department and Home Health Coordinators



LOCAL HEALTH DEPARTMENT HOME HEALTH AGENCIES & COORDINATORS

Joyce Mansfield, RN Home Health Coordinator Allen-Monroe Co Health Dept PO Box 128 Scottsville, KY 42164 502-237-4423

Ruth Syre, RN Home Health Coordinator Barren River Dist Health Dept PO Box 1157 Bowling Green, KY 42101 502-781-2956

Nancy Nichols, RN Home Health Coordinator Breathitt CO Health Dept 377 Broadway, PO Box 730 Jackson, KY 41339 606-666-2322

Elisa Price, RN Clark Co Health Dept Home Health Agency 400 Professional Ave Winchester, KY 40391 606-744-1488

Dottie Dunsil, RN Home Health Coordinator Cumberland Valley Dist Health Dept PO Box 250 McKee, KY 40447 606-287-8437

Helen Crider, RN Home Health Coordinator Floyd Co Health Dept PO Box 188 Prestonsburg, KY 41653 606-886-2788 Renee Blair, RN Home Health Coordinator Ky River Dist Health Dept 400 Gorman Hollow Rd Hazard, KY 41701-2316 606-439-2361 or 0870

Dale Moore, RN Home Health Coordinator Knox Co Health Dept PO Box 897 Barbourville, KY 40906-0897 502-546-6294

Susie Shelley, RN Home Health Coordinator Lincoln Trail Dist Health Dept 1222 Woodland Dr, PO Box 2609 Elizabethtown, KY 42701-6609 502-769-1601 or 1602

Mary Lou Whitt, Coordinator Mepco Home Health Agency Madison Co Health Dept Boggs Ln, PO Box 906 Richmond, KY 40475 606-623-3441

Mary Ann Bright, RN Home Health Coordinator North Central Dist Health Dept PO Box 358 New Castle, KY 40050 502-845-2761

Jeanetta Berry, RN Home Health Coordinator Purchase Dist Health Dept PO Box 2357 Paducah, KY 42001 502-444-9625



Ros Miklav ic, RN Home Health Coordinator Franklin Co Health Dept #5 Physician's Park Frankfort, KY 40601 502-564-7383

Maureen Kohl, RN Home Health Coordinator Green River Dist Health Dept PO Box 1674 Owensboro, KY 42302-2199 502-686-8123

Anna Bowen, RN Home Health Coordinator Johnson-Magoffin Co Health Dept PO Box 111, 2nd St Paintsville, KY 41240 606-789-2596 Sherry Stamper, RN
Home Health Coordinator
Three Rivers Dist Health Dept
N Main Park, Rt 5, Box 16A
Owenton, K 40359
502-484-3412 or 564-3238

Lynn Whitaker, RN Home Health Coordinator Wedco Dist Health Dept PO Box 218 Cynthiana, KY 41031 606-234-8750

Sheryll Jackson, RN Home Health Coordinator Whitley Co Health Dept PO Box 147 Williamsburg, KY 40769 606-549-3380 or 1454



APPENDIX J

Related Resources and Information Centers



RELATED RESOURCES & INFORMATION CENTERS

National Clearinghouses

ERIC Clearinghouse on Handicapped and Gifted Children Council for Exceptional Children (CEC) 1920 Association Drive Reston, VA 22091-1589 (703) 620-3660

National Clearinghouse for Professions in Special Education 2021 K Street NW Suite 315 Washington, D.C. 20006 (202) 296-1800

National Health Information Center Post Office Box 1133 Washington, D.C. 20^13-1133 (301) 565-4167 or (800) 336-4797

National Information Center on Handicapped Children and Youth (NICHCY)
Post Office Box 1492
Washington, D.C. 20013
(703) 893-6061
(800) 999-5599

National Maternal and Child Health Clearinghouse 38th and R Streets NW Washington, D.C. 20057 (202) 625-8410

National Rehabilitation Information Center (NARIC) 8455 Colesville Rd. Suite 935 Silver Spring, MD 20910-3319 (301) 588-9284 (800) 346-2742 [Voice/TDD]

Organizations and Resources

American Council of Rural Special Education (ACRES) Western Washington University 359 Miller Hall Bellingham, WA 98225 (206) 676-3576



Organizations and Resources (continued)

Association for the Care of Children's Health (ACCH) 7910 Woodmont Ave., Suite 300 Bethesda, MD 20814 (301) 654-6549

Association for Persons with Severe Handicaps (TASH) 11201 Greenwood Ave. North Seattle, WA 98133 (206) 361-8870

Association for Retarded Citizens of the United States (ARC) 2501 Avenue J
Post Office Box 6109
Arlington, TX 76005
(800) 640-5255

Children's Hospital Rehabilitation Center Ventilator Assisted Programs 200 Henry Clay Ave. New Orleans, LA 70118

Council for Exceptional Children (CEC) 1920 Association Drive Reston, VA 22091 (703) 620-3660

Cystic Fibrosis Foundation (Kentucky) 1941 Bishop Lane Louisville, KY 40218 (502) 452-6353 (call collect)

Directions Services Center Personal Assistance Resources for People with Special Needs 1450 Newtown Pike Lexington, KY 40511 (800) 234-04987 (606) 233-9370

Epilepsy Foundation of America (EFA) 4351 Garden City Dr. Suite 406 Landover, MD 20785 (301) 459-3700 (800) 332-1000

Kentucky Commission for Handicapped Children 982 Eastern Parkway Louisville, KY 40217 (502) 588-3264



Organizations and Resources (continued)

Kentucky Council for Retarded Citizens 1146 South 3rd St. Louisville, KY 40203 (502) 584-1239

Muscular Dystrophy Association (Kentucky) 2100 Gardinir Lane Louisville, KY 40205 (502) 451-8088 (Louisville) (502) 782-7481 (Bowling Green) (606) 278-2599 (Lexington)

Sickel Cell Disease Department for Health Services 275 E. Main St. Frankfort, KY 40621 (502) 564-2154

Spina Bifida Association of Kentucky Kosair Charity Center 982 Eastern Parkway Louisville, KY 40217 (502) 637-7363

United Cerebral Palsy Association, Inc. 7 Penn Plaza, Suite 804 New York, NY 1001 (800) 872-1827

Hotlines/Other Toll Free Numbers

Aids

National AIDS Clearinghouse (800) 458-5231

Nationally Sexually Transmitted Diseases Hotline (800) 227-8922

Public Health Service AIDS Hotline (800) 342-AIDS

Kentucky Aids Hotline (800) 654-AIDS



Diseases/Conditions

Centers for Disease Control (404) 639-3311 or (800) 342-AIDS

Epilepsy Foundation of America (EFA) (800) EFA-1000

Juvenile Diabetes Foundation Hotline (800) 233-1138

National Association for Sickle Cell Disease, Inc. (800) 421-8453

National Cystic Fibrosis Foundation (800) 344-4823

National Health Information Center (NHIC) (800) 336-4797

National Information Center for Orphan Drugs and Rare Diseases (NICODARD) (800) 456-3505

National Organization for Rare Disorders (NORD) (800) 447-NORD

Health Information

National Information System for Health Related Services (800) 922-9234

National Health Information Center (800) 336-4797

Nutrition

Beech-Nut Nutrition Hotline (800) 523-6633

Gerber Products Company (800) 443-7237

National Center for Nutrition and Dietetics (800) 366-1655



APPENDIX K

Related Statewide Training Projects & Training Materials



RELATED STATEWIDE TRAINING PROJECTS

SPLASH - Strategies for Programming Longitudinally for All Severely Handicapped: Inservice training project primarily designed for teachers of students with moderate and severe handicaps; Kentucky Department of Education - Division of Special Learning Needs and University of Kentucky; conducted annually in Fall, 30 participants; funds available for participant expenses, to purchase funtional instructional materials, some funds for release time for participants. Contact Preston Lewis at KDE (502) 564-4970.

SHIPP - Severe Handicaps Integrated Preschool Programming: Inservice training project designed for teachers and other professionals providing services to children 0-5 with severe and multiple handicaps; Kentucky Departmen of Education (KDE) - Division of Early Childhood Education, Cabinet for Human Resources (CHR), Kentucky Deaf-Blind Intervention Project and University of Kentucky; conducted in the Fall and Spring; 40 participants each session. Contact Debbie Schumacher at KDE (502) 564-4970 or Marge Allen at CHR (502) 564-7703.



RELATED TRAINING MATERIALS

Learner Managed Designs, Inc. 2201 K West 25th Street Lawrence, KS 66047 (913) 842-9088

	Length	Price	Rental
Positioning for Infants and Young Children With Motor Problems	30 Minutes	\$180	\$50
CPR and Emergency Choking Procedures for Infants and Young Children	37 Minutes	\$180	\$50
Home Oxygen for Infants and Young Children	30 Minutes	\$180	\$50
Clean Intermittent Catheterization	25 Minutes	\$180	\$50
Feeding Infants and Young Children with Special Needs	26 Minutes	\$180	\$50
Home Tracheostomy Care for Infants and Young Children	37 Minutes	\$1 80	\$50
Infection Control in Child Care Settings	26 Minutes	\$180	\$50
Home Gastrostomy Care for Infants and Young Children	25 Minutes	\$180	\$50

Video Press University of Maryland at Baltimore School of Medicine Suite 301 32 South Greene Street Baltimore, MD 21201 (301) 328-5497

	Length	Price	Rental
Pediatric AIDS	20 Minutes	\$300	\$100
Therapist to Teacher	19 Minutes	\$200	\$100
Therapist to Therapist	25 Minutes	\$200	\$100
Rachael's Team (Documentary)	22 Minutes	\$300	\$100
Rachael, Being Five (Documentary)	28 Minutes	\$400	\$100



APPENDIX L

Related Documents and Readings



RECOMMENDED DOCUMENTS AND READINGS

American Academy of Pediatrics, Committee on Bioethics. (1983). Treatment of critically ill newborns. <u>Pediatrics</u>, <u>72</u>(4), 565-566.

This official policy regarding the treatment of critically ill newborns was developed in response to controversies surrounding the treatment of these infants. In recognition of the difficulties involved in determining the best interests of the infant, the Committee recommends a thorough review of the patient's situation before decisions are made regarding the withdrawal or withholding of treatment. This review should occur in consultation with other professionals, before institutional ethics committees developed within hospitals.

American Academy of Pediatrics (1991). Report of the committee on infectious diseases. Elk Grove Village, IL: Author.

Can be obtained by contacting the American Academy of Pediatrics, P. O. Box 927, Elk Grove Village, IL 60007.

Anderson, R., Bale, J., Blackman, J., Murph, J. (1986). <u>Infections in children: A sourcebook for educators and child care provider</u>. Rockville, MD: Aspen Publishers.

Information for educators about individual infectious agents, the conditions under which these agents can cause disease, and what measures can help prevent or resolve infection.

Batshaw, M., & Perret, Y. (1986). <u>Children with handicaps: A medical primer</u> (2nd ed.). Baltimore: Paul H. Brookes.

This book serves as a basic text for special education teachers, hearing and speech therapists and occupational therapists. A wide range of material is offered regarding handicapping conditions including fetal development, heredity, nutrition and special feeding problems of handicapped children.

Bergen, A. F., & Colangelo, C. (1983). <u>Positioning the client with central nervous system deficits:</u>
<u>The wheelchair and other adapted equipment</u> (2nd ed.). New York: Valhalla Rehabilitation Publications, Ltd.

Manual provides a guide for prescribing equipment which will allow maximum function.

Bigge, J. (1991) <u>Teaching individuals with physical and multiple disabilities</u> (3rd ed.). New York: Macmillan.

Text focuses on the academic and functional needs of the persons with physical and multiple disabilities. A chapter is included on children with special health care needs.



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Bilotti, G. (1984). <u>Getting children home: Hospitals to community</u>. Washington, D.C.: Georgetown University Child Development Center.

This volume provides a conceptual model for placing a chronically ill child in the home. The first section describes the three phases from initial planning to the placement in the home. The next section outlines the roles of various participants involved in the placement process, including parents, the physicians and the interdisciplinary team. The third section details the actual discharge plan and home care plan. The final section centers upon using the community resources which assist the placement effort. Throughout, the book incorporates checklists, charts, diagrams and sample documents to aid the parent planners.

Birenbaum, A., Guyot, D., & Cohen, H. J. (1990). <u>Health care financing for severe developmental disabilities</u>. Washington DC: American Association on Mental Retardation.

This monograph gives an up-to-date overview of current trends and controversies in the national health care crisis and reviews how they impact families caring for people with serious disabilities.

Black, G., & Porsch, T. (1981). School health services. In M.M. Esterson & L.F. Bluth. <u>Related</u> services for handicapped children (pp.103-111). Massachusetts: College-Hill Press.

Chapters include definition of school health services, relationship to special education and options in service delivery models.

Blackman, J. A. (1990). <u>Medical aspects of developmental disabilities in children birth to three</u> (2nd ed). Rockville, MD: Aspen Publications.

This book is a summary of health information related to developmental disabilities with special emphasis on aspects that affect day to day functioning.

Bleck, E., & Nagel, D. (1982). <u>Physically handicapped children</u> (2nd ed.). New York: Grune & Stratton.

This is a handbook of medical information for teachers of physically handicapped children and for college educators responsible for preparation of those teachers.

- .Braff, M. H. (1985). Dental treatment for developmentally disabled patients. <u>Special care in dentistry</u>, <u>5</u> (3), 109-111.
- Caldwell, T. H., Todaro, A. W., & Gates, A. J. (1991). Special health care needs. In J. L. Bigge (Ed.), <u>Teaching individuals with physical and multiple disabilities</u> (3rd ed.). New York: Macmillian.
- California State Department of Education (1980). <u>Guidelines and procedures for meeting the specialized physical health care needs of students</u>. Sacramento: Author.
- Campbell, M. S., Cohen, S. L., & Rich, M. (1987). <u>Guidelines for the management of health impaired students</u>. Portland: Providence Child Center.



Center for Community Integration (1988). Quality health care for people with developmental disabilities--a guide for parents and other caregivers. Minneapolis: University of Minnesota.

This health care guide is written for parents, advocates, helpers and friends who live and work with people with developmental disabilities. This guide contains four major sections: 1) being a more effective consumer advocate in selecting and working with health care providers, 2) managing routine health care and developing healthy lifestyles, 3) managing common illnesses and more complex problems; and 4) finding resource materials and organizations of potential help in obtaining appropriate health care. Basic information is presented on daily routines such as nutrition and hygiene, as well as on more complex considerations.

- Centers for Disease Control (1989). <u>Guidelines for prevention of transmission of human immunodeficiency virus and hepatitis B viris to health-care and public-safety workers</u>. Atlanta: Centers for Disease Control, U. S. Department of Health and Human Services.
- Centers for Disease Control (August, 1987). Recommendations for prevention of HIV transmission in health-care settings [Supplement]. Morbidity and Mortality Weekly Report, 36(2S).
- Children's Hospital (1990). The <u>Community provider's guide: An information outline for working with children with special health care needs in the community.</u> New Orleans: Author.
 - A 183 page guide with information relevant to children with specific health care needs including examples of IEP and school health plan goals and objectives.
- Claymon, C. (1988). Guide to prescription and over-the-counter drugs. New York: Random House.
- Contrucci, V. J., Holloway, N. F., & Taff, L. (1990). <u>Study of physical health care services in Wisconsin Public schools</u>. Madison: Wisconsin Department of Public Instruction.
 - Study offers a view of specialized physical health care services in Wisconsin public schools. Includes the number of pupils receiving care, types of care services provided and liability issues.
- Council for Administrators of Special Education, Inc. (1987). <u>1987 CASE Institutes: Medically related special education and related services</u>. (Conference proceedings). Indianapolis: Author.
- Council for Exceptional Children's Ad Hoc Committee on Medically Fragile Students (1988). Report of the council for exceptional children's ad hoc committee on medically fragile students. Reston, VA: Author.

This report proposed guidelines for the provision of education and related services for children with specialized health care needs. To order, write or call The Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091; (703) 620-3660.

- Crump, I. (1987). Nutrition and feeding of the handicapped child. Waltham, MA: College-Hill.
- Dreisbach, M., Ballard, M., Russo, D. C., & Schain, R. J. (1982). Education intervention for children with epilepsy: A challenge for collaborative service delivery. <u>The Journal of Special Education</u>, <u>16</u> (1), 111-121.
- Epstein, S. G., Taylor, A. B., Halberg, A. S., Gardner, J. D., Walker, D. K., & Crocker, A. C. (1989). Enhancing quality: Standards and indicators of quality care for children with special health care needs. Boston: New England SERVE, Massachusetts Health Research Institue.



Fithian, J. (Ed.) (1984). <u>Understanding the child with a chronic illness in the classroom</u>. Phoenix: Oryx Press.

This reference source contains practical information on thirteen of the most common chronic health disorders in children. Chapters provide information on how children can be expected to function in the classroom and what problems may arise. Disorders discussed are juvenile diabetes, hemophilia, sickle cell disease, juvenile rheumatoid arthritis, muscular dystrophy, cancer, lupus erythematosus, epilepsy, congenital heart disease, asthma, allergies, orthopedic problems and cystic fibrosis.

Fraser, B., & Hensigner, R. (1983). Managing physical handicaps. Maryland: Paul H. Brookes.

This book is intended as a practical guide for people who are involved on a day-to-day basis with children and young adults having serious physical handicaps, particularly those experienced by physically impaired students attending special education school programs.

- Fredrick, J., & Fletcher, D. (1985). Facilitating children's adjustment to orthotic and prosthetic appliances. <u>Teaching exceptional children</u>, <u>17</u> (3), 228-230.
- Gadow, K. (1979). <u>Children on medication: A primer for school personnel</u>. Reston, VA: Council of Exceptional Children.
- Gadow, K. D., & Kane, K. M. (1983). Administration of medication by school personnel. <u>The Journal of School Health</u>, <u>53</u> (3), 178-183.
- Gittler, J.D. & Colton, M. (1986). <u>Community-based care management programs for children with special health care needs</u>. lowa City, IA: National Maternal and Child Health Resource Center.

This publication provides detailed information about four case management programs which serve children with special health care needs and their families. Each program's organization, eligibility criteria and services, personnel and costs are described and related materials (e.g., assessment tools, case management guidelines) are included. The materials illustrates the complexity if the needs of many of these children and their families, the multidisciplinary nature of the services they mat require and the role of case management in facilitating the delivery appropriate services to families.

- Gittler, J. D., & Colton, M. (1986). <u>Future directions of services for children with special health care needs: Alternatives to hospitalization for technology dependent children</u> Washington, DC: National Maternal & Child Health Resource Center, U.S. Department of Health and Human Services.
- Goldfarb, L. A., Brotherson, M. J., et al. (1986). <u>Meeting the challenge of disability or chronic illness A family quide</u>. Baltimore: Paul H. Brookes.

Book focuses on the process of problem solving for parents to give them the skills to meet the challenges posed by having a child with a chronic illness or disability.

Graff, J. C., Ault, M. M., Guess, D., Taylor, M., & Thompson, B. (1990). <u>Health care for students with disabilities: An illustrated medical guide for the classroom</u>. Baltimore: Paul H. Brookes.

This book contains 16 chapters related to specific health care procedures. It is an excellent college text and reference for anyone working with children and youth with special health care needs.

Mulligan-Ault, M., Guess, D., Struth, L, & Thompson, B. (1988). The implementation of health-related procedures in classrooms for students with severe multiple impairments. The <u>Journal of the Association for Persons with Severe Handicaps</u>, 13(2), 100-109.



Healy, A. & Lewis-Beck, J.A. (1987). <u>Improving health care for children with chronic conditions:</u> <u>Guidelines for families</u>. lowa City, IA: University of Iowa, University Hospital School.

This manuscript presents guidelines, developed by parents of children with chronic health problems, which are designed to help families cope more effectively when a child becomes ill. These guidelines suggests means for maintaining a supportive home life for other children in the family; establishing collaborative relationships; identifying problems in health, cognitive, social, psycho-social, environmental, and developmental areas; determining strengths and needs in developing individualized plans; securing follow-up services to promote needed care; and participating in outreach and advocacy activities.

Healy, A. & Lewis-Beck, J.A. (1987). <u>Improving the health care for children with chronic conditions:</u>
<u>Guidelines for physicians</u>. lowa City, IA: University of lowa, University Hospital School.

These guidelines, developed by physicians, are designed to assist physicians work more effectively with families and children with chronic illness. Like the guidelines these authors designed for families, major areas requiring intervention are identified and specific activities targeted to each are described.

Heller, K. W., Alberto, P. A., Schwartzman, M. N., Shiplett, K., Pierce, J., Polokoff, J., Heller, E. J., Andrews, D. G., Briggs, A., & Kana, T. G. (1990). Monograph of Suggested physical health procedures for educators of students with special needs. Atlanta: Department of Special Education, Georgia State University.

Monograph contains suggested checklists, forms, and guidelines for eight physical health care concerns. Information on specific physical health care procedures and concerns is included.

Hobbs, N. & Perrin, J.M. (1985). <u>Issues in the care of children with chronic illness</u>. San Francisco: Jossey-Bass Publishers.

This comprehensive text examines a broad array of topics concerning children with chronic illness and their needs for services. In addition to introducing basic concepts concerning childhood chronic illnesses, the book provides a comprehensive orientation to epidemiological and demographic information concerning 11 different types of severe childhood chronic health conditions. In addition, contributors also discuss special populations and the unique characteristics of rural and inner-city children. The text also includes discussions concerning the involvement of children with chronic illnesses in the public education system and offers some suggestions for improving medical and social services for these children.

Hobbs, N., Perrin, J.M., & Ireys, H.T. (1985). <u>Chronically ill children and their families</u>. San Francisco: Jossey-Bass Publishers.

In presenting the results of a Vanderbilt University study concerning children with chronic illness, the authors present ways to develop a comprehensive system of care for these children. Current medical and social services, educational programs as well as training programs for health and social services professionals are evaluated. In conclusion, the authors make recommendations to improve the current organization and financing of services for these children and their families.

Holvoet, J. F., & Helmstetter, E. (1989). <u>Medical problems of students with special needs: A guide for educators</u>. Boston: College-Hill.



- Horsley, J. A. (1981). Preventing decubitus ulcers: CURN project. New York: Grune and Stratton.
- Hudson, M. E., & Leatherby, J. L. (1991). <u>Developing programs for students with severe handicaps using basic skills in the context of age-appropriate activities</u>. Lexington: Kentucky Systems Change Project, Interdisciplinary Human Development Institute, University of Kentucky.
- Jelm, J. M., (1990). Oral-motor/feeding rating scale. Tucson: Communication Skill Builders.

This book furnishes easy to use record keeping forms that will help screen and categorize the many varieties of oral-motor movements and note specific patterns for lip/cheek, tongue, and jaw movements.

- Johnson, V. S., Smith, M. H., Bittle, J. B., & Nuckolls, L. J. (1980). <u>Nutrition education for the retarded: A program for teachers</u>. Memphis, TN: Boling Center for Developmental Disabilities.
- Joint Task Force for the Management of Children with Special Health Needs of the American Federation of Teachers, Council for Exceptional Children, National Association of School Nurses, & National Education Association (1990). <u>Guidelines for the delineation of roles and responsibilities for the safe delivery of specialized health care in the educational setting</u>. Reston, VA: Council for Exceptional Children.

The guidelines in this manual delineate the roles and responsibilities of various personnel involved in the provision of specialized health care, from the perspective of professional practice. To order, write or call The Council for Exceptional Children, 1920 Association Drive, Foston, VA 22091; (703) 620-3660. Stock # R632 \$5.00

Jones, M.L. (1985). Home care for the chronically ill or disabled child. New York: Harper & Row.

This is a practical how-to guide for family members providing home care to children with chronic illnesses or disabilities. Written by the mother of a child who had a degenerative neurological condition, it provides detailed information about the daily care of a child's physical, educational, and social needs. The book is replete with drawings which illustrate specific techniques and equipment discussed in the text.

Katz, K. S., Pokomi, J. L., & Long, T. M. (1991). <u>Chronically ill and at risk infants: Family-centered intervention</u>. Palo Alto: VORT Corporation.

This book focuses on program design and implementation, and identifies steps for providing services to at risk infants. The text includes ways to maintain continuity in developmental intervention in spite of chronic medical needs, strategies for introducing a developmental intervention program into a NICU, and clarifies staff roles.

Kentucky Board of Nursing (1990). <u>Kentucky nursing laws</u>. Charlottesville, VA: The Michie Company.

Kentucky Department of Education (1990). School health services manual. Frankfort, KY: Author.



Kozlowski, B. & Wenner, B. (1982). <u>Nutritional implication of selected medications received by children with developmental disabilities</u>. Columbus, OH: Ohio State University Nisonger Center.

The potential of many drugs to alter nutritional status is increasingly being recognized. Persons with developmental disabilities are particularly vulnerable to these effects since use of multiple drugs is a life-long proposition for many who may, even without the drugs, exist under precarious nutritional circumstances. An extensive review of the scientific literature regarding this topic is presented, and implications for nutritional care are discussed.

- Larson, G. L. (1988). <u>Managing the student with a chronic condition:</u> A practical guide for school personnel. Minneapolis: DCIK Publishing.
- Lehr, D. H. (1990). Preparation of personnel to work with students with complex health care needs. In A.P. Kaiser & C.M. McWhorter (Eds.), <u>Preparing personnel to work with persons with severe disabilities</u>. Baltimore: Paul H. Brookes.
- Lehr, D. H., & Haubrich, P. (1986). Legal precedents for students with severe handicaps. Exceptional Children, 52, 358-365.

In this abstract the authors give their discussions around an example of a student with severe handicaps and present the effects of legal precedents on this child's free appropriate public education.

- Lehr, D. H., & Noonan, M. J. (1989). Issues in the education of students with complex health care needs. In F. Brown & D. H. Lehr (Eds.), *Persons with profound disabilities: Issues and practices* (pp. 139-160). Baltimore: Paul H. Brookes.
- Lyon, S., & Lyon, G. (1980). Team functioning and staff development: A role release approach to providing integrated educational services for severely handicapped students. *Journal of the Association for Persons with Severe Disabilities*, 5(3), 250-263.
- Martin, R. (1991). Medically fragile/technology dependent students: Drawing the line between education and medicine. Urbana, IL: Carle Center for Health Law and Ethics.

This publication is designed to provide accurate and authoritative information in regard to the medically fragile. Contents include separating medicine and education, questions on the IEP, school health procedures, liability, and risk management.

- McCublien, T. (1987). Routine and emergency medical procedures. In M.E. Snell (Ed.), <u>Systematic instruction of persons with severe handicaps</u> (3rd ed.)(pp. 152-172). Columbus: Charles E. Merrill.
- McInerney, W. F. (1989). The instruction of students with acquired immune deficiency syndrome (AIDS). <u>DPH Journal</u>, 10, 43-56.

This article provides information regarding the recent legal decisions and public school policies in reference to students with AIDS. Concerns related to instructional interaction with students with AIDS is also discussed.



McManus, M. A. (1988). <u>Understanding your health insurance options</u>: A guide for families who have children with special health care needs. Washington, DC: Association for the Care of Children's Health.

An insurance guide which details public and private insurance options, including Medicaid, Title V, traditional plans, HMO's, and preferred provider organizations. This "how-to" pamphlet provides answers to commonly asked questions, worksheets for comparing options, and suggestions on how to choose appropriate insurance coverage. A glossary of terms is also provided. (Available for \$2.75 plus \$1.00 postage and handling.)

Missouri Department of Elementary and Secondary Education (1990). <u>Guidelines for special health</u> care procedures in Missouri schools. St. Louis: Author.

The guidelines in this manual have been developed in order to assist school districts who serve students with complex medical conditions in making informed decisions regarding delivery of medical services at school.

Morris, S. E., & Klein, M. D. (1987). <u>Pre-feeding skills: A comprehensive resource for feeding development</u>. Tucson: Communication Skill Builders.

This compilation of theoretical and practical information gives a sound approach you can use every day. Chapters are included on normal development of pre-feeding skills, how to limit variations of feeding skills, assessment, treatment principles and perspectives, pre-feeding materials for assessment and treatment and self-study checklists and charts for tracking your client's progress.

- Mulligan-Ault, M., Guess, D., Struth, L., & Thompson, B. (1988). The implementation of health-related procedures in classrooms for students with severe multiple impairments. *Journal of the Association for Persons with Severe Disabilities*, 13(2), 100-109.
- Neisworth, J. T., & Garwood, S. G. (Eds.) (1986). Chronically ill children. <u>Topics in Early Childhood</u> <u>Special Education</u>, <u>4</u>(5).
- Orelove, F. P., & Sobsey, D. (1991). Educating children with multiple disabilities: A transdisciplinary approach (2nd ed.). Baltimore: Paul H. Brookes.

This text contains two excellent chapters on working with students with special health care needs, as well as content related to collaborative teamwork, physical management and positioning, and feeding.

- Pass, R. F., & Kinney, J. S. (1985). Child care workers and children with congenital cytomegalovirus infection. <u>Pediatrics</u>, 75.
- Peterson, N. (1987). Early intervention for handicapped and at-risk children.

Text delves into identifying at-risk children and defining handicapping conditions with a chapter on assessment and evaluation and then examines the actual delivery of services.

- Physician's desk reference. (1987). Oradell, NJ: Medical Economics Company, Inc.
- Policy Center for Children and Youth (1987). <u>Financial responsibilities of public agencies for providing handicapped children and youth with free appropriate public education: An introduction for state educational agencies to interagency financing of special education and related services. Washington, DC: Author.</u>



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- Project School Care (1989). <u>Children assisted by medical technology in educational settings:</u> <u>Guidelines for care</u>. Boston: Children's Hospital.
- Project Serve. (1985). New directions: Serving children with special health care needs in Massachusetts. Boston: Project Serve.

This volume reports the results of a tri-agency project directed at documenting and analyzing existing services for children with handicaps in Massachusetts. Quantitative and qualitative data were gathered regarding gaps in services or unmet needs, eligibility criteria, financing of services and linkage among systems.

Ruben, R. (1982). Home care of the pediatric patient with a tracheostomy. <u>Annal of Otolaryngology</u>. <u>Rhinoplasty</u>. <u>Laryngology</u>, <u>91</u>, 633-640.

This report is a retrospective study of all of the infants and children discharged from the hospital of the Albert Einstein College of Medicine. It presents information concerning epidemiology, mortality, home care management, and the implications of long-term tracheostomies.

- Shaddix, T. (1986). <u>Nutritional care for the child with developmental disabilities: Management of constination</u>. Birmingham, AL: United Cerebral Palsy of Greater Birmingham, Inc.
- Shelton, T. L. Jappson, E. S., & Johnson, B. H. (1987).. Family-centered care for children with special peak peaks. Washington, DC: Association for the Care of Children's Health.

This manual describes eight key elements of family-centered care, research, checklists for states, manual describes, training programs, hospitals and research projects, and other resources. (Purchase price is \$5.00 plus \$2.50 shipping and handling.)

- Students with special health care needs. <u>Teaching Exceptional Children</u>, <u>20</u>(4), 40-43.
- Smith, P. D., Leatherby, J. L., & Wasson, T. H. (1991). Delivery of health maintenance procedures to students with complex health care needs in Kentucky. Unpublished manuscript, University of Kentucky, Interdisciplinary Human Development Institute, Kentucky Systems Change Project, Lexington.
- Sullivan-Bolyai, S. (1986). Practical aspects of toilet training the child with a physical disability. <u>Issues in Comprehensive Pediatric Nursing</u>, <u>9</u>, 79-96.
- Task Force on Children with Special Health Care Needs (1988). Recommendations: Services for children with special health care needs. Des Moines: Iowa Department of Education.
- Todaro, & Caldwell (1989). An information outline for working with children with special health care needs.
- Trahms, C., Affleck, J., Lowenbraum, S., & Scranton, T. (1977). The special educator's role on the health service team. <u>Exceptional Children</u>, 43, 344.
- Umbreit, J. (Ed.) (1983). <u>Physical disabilities and health impairments</u>. Columbus, OH: Charles E. Merrill.

This book can serve both as a college text and as a reference book for anyone responsible for the education of children with physical disabilities and health impairments.

Vitello, S. (1986). The Tatro case: who gets what and why. Exceptional Children, 52, 353-356.



This abstract discusses the second special education case decided by the U. S. Supreme Court, Irving Independent School District v. Tatro.

Walker, D.K. (1986). Report of a national conference: School-age children with health impairments. Houston, Texas: Texas Children's Hospital.

The central focus of this conference was an examination of the role of the public schools in working with children who had health impairments. The presenters at the conference examined the key issues and areas that prevent children with a wide variety of chronic illnesses from fully participating in public education. Participants at the conference examined necessary supportive services, medical procedures and policies, life planning, transitional planning, and career preparation for teachers.

- Washington Department of Education (1989). <u>Medically fragile technical assistance manual</u>. Olympia, WA: Author, Office of the Superintendent of Public Instruction.
- Word, D. E. (1984). <u>Positioning the handicapped child for function</u> (2nd ed.). Phoenix: Phoenix Press.

This manual is written for occupational and physical therapists and discusses the current and popular practices used in positioning the bodies of severely handicapped children.

- Yard, G. J. (1980). Managing seizures in mainstream education. <u>The Journal for Special Educators</u>, <u>17</u> (1), 52-56.
- Yousef, J. M. (1985). Medical and educational aspects of epilepsy: A review. <u>DPH Journal</u>, 8, 3-15.

This article provides definitions and prevalence of the most common types, causes, diagnosis and treatment of epilepsy. The teacher's role in managing students with seizures is also discussed.

