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ABSTRACT

This paper discusses issues concerning inclusion of children with special health care needs in the regular classroom. Six categories of health conditions are discussed in terms of their implications for the educational setting. These are: (1) "hidden" conditions (e.g., juvenile rheumatoid arthritis, sickle cell anemia, asthma, and cystic fibrosis); (2) infectious conditions (e.g., Acquired Immune Deficiency Syndrome [AIDS], hepatitis B and cytomegalovirus); (3) conditions which cause the child to be medically fragile (e.g., children in the final stages of AIDS, cancer, and renal failure); (4) conditions that require technology assistance (such as ventilators, gastrostomy tubes, tracheostomy tubes, and catheterization tubes); (5) neurological conditions (e.g., seizure disorders, meningitis, and brain tumors); and (6) body and skin deformities (amputations, craniofacial conditions, burns). Aspects of these conditions discussed include the health care plan, the emergency plan, educational team communications, the educational plan, developing independence in health care, school absence, environmental factors, student placement considerations, orientation and technical assistance, transition, and transportation. Attached are handouts addressing screening and assessment, training for educators of students who are ventilator assisted, and peer orientation. (DB)

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# *Inclusive Education for Children with Special Health Care Needs*

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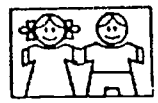


# INCLUSIVE EDUCATION FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

*Jan Janz, Jacqueline Harrison, Terry Caldwell, Carole McCutcheon-Goodwin*

The National MCH Resource Center is a grant program funded by the Bureau of Maternal and Child Health. The focus of the program is to train persons in the community who provide care to children who have special health care needs. The impetus for this training program grew out of a change that occurred in the 1980's. It was at this time that medical professionals became aware of the many benefits of home care for children with health conditions. The children's nutritional intake improved, they were exposed to fewer infections and a more normal environment which contributed to their psychosocial development to mention but a few of the benefits. The insurance companies were also excited about these findings because it meant that costly hospital stays were kept to a minimum. However, with deinstitutionalization/dehospitalization, the move to home care, a new set of concerns arose. Personnel at Children's Hospital in New Orleans asked the question, "Why can't children get services in the community?" The response was that the community (educators, community physicians and health clinics, and religious institutions, etc.) was not prepared to deal with children with health conditions of which they had limited exposure. The time was ripe for a team approach to the problem.

In 1983, personnel at Children's Hospital developed a collaborative system so that children supported by ventilation could return to their homes and also have access to community services such as schools. Two years later, MCH funded another

program to support children with chronic illness in their homes and community. In 1989, MCH funded our program, the National Center for Ensuring the Adequate Preparation of Careproviders. The focus of this program is the training of careproviders in the community, using a training of trainers model.

One agency that was significantly impacted by having children with health needs in the community was education. In some cases, children were denied access to school programs because some educators believed they did not belong in school. In some cases the children who were offered school placement, were placed in unnecessarily restrictive settings. It is no wonder that educators did not understand the needs of these children. Children who would have been in hospital settings ten years ago, were now attending a full day at school. However, over the years much has been accomplished. The rights of all children to an appropriate education are primarily contained in laws such as the Individuals with Disabilities Education Act, the Americans with Disabilities Act and Section 504 of the Rehabilitation Act. The full extent of these rights has been challenged over the years. Some of the better known cases include: Irving Independent School v. Tatro (1984), Timothy W. v. Rochester School District (1989) and the Detsel cases (Detsel v. Board of Education of the Enlarged Auburn School District (1987) Detsel v. Bowen (Dept. of Health and Human Services. 1988), and Detsel v. Sullivan (Dept. of Health and Human Services, 1990), Holland v. Sacramento City Unified School District (1992). The Tatro case set a precedent for the provision of

catheterization in the school setting. Timothy W. v. Rochester ruled that a child need not demonstrate that he/she would "benefit" from an educational program in order to receive educational services. The Detsel cases actually are a series of cases. In 1987, the Second Circuit Court ruled that the school district need not provide nursing support for Detsel. This was followed by a suit against the Dept. of Health and Human Services challenging the right to receive Medicaid funding for a private duty nurse for Melissa Detsel in the school setting. Prior to this Medicaid funding for such services was limited to home, hospital, or skilled nursing facility. Holland v. Sacramento is certainly a landmark case when considering the rights of all children, regardless of their disability, to be educated in the regular classroom. These cases have definite implications for inclusion of children with special health care needs in the school setting. Litigation over these issues is by no means static as old issues are rehashed and new issues emerge.

The stage is now set to discuss issues that surround inclusion of children with special health care needs in the regular classroom. The presentation will describe six categories of health conditions and implications for the educational setting. The six health conditions include children with: 1) "hidden" conditions, 2) infectious conditions, 3) conditions which cause the child to be medically fragile, 4) conditions that require technology assistance, 5) neurological conditions, and 6) body and skin deformities.

## 1. "HIDDEN" CONDITIONS

The first category concerns children with **"hidden"** conditions, that is, the child may have no visible signs of the condition. Conditions such as juvenile rheumatoid arthritis, sickle cell anemia, asthma, cystic fibrosis are included in this category.

**(Please refer to page #1 in the hand-out titled "Students with Special Health Needs: Screening and Assessment" as a guide for the discussion of educational considerations for each of the six categories.)**

*I. HEALTH CARE CONSIDERATIONS*

*A. HEALTH CARE PLAN:*

All children with a health need should have a health care plan and an emergency plan. The health care plan should be developed by the school nurse with support from physicians and other health care providers and shared with persons with whom the child will interact. The health care plan should include:

*1. Diagnosis and description of the condition*

e.g. Children with juvenile rheumatoid arthritis may not complain of pain but may have difficulty performing physical tasks or may tire easily.

*2. Treatment/Side Effects*

e.g. Children with cystic fibrosis may require a breathing treatment in the middle of the school day. Care should be taken to schedule the treatment at least 45 minutes prior to lunch.

*3. Special Nutritional Requirements*

e.g. Children with cystic fibrosis as well as diabetes may

require a special diet. In addition, conditions such as cystic fibrosis, sickle cell anemia, and asthma may require that children increase their fluid intake.

*4. Medication/Side Effects*

e.g. Children with severe asthma may be treated with steroids which may compromise their immune system and thus be more susceptible to infectious diseases. Parents may wish to be notified of an outbreak of communicable diseases in the school.

*B. EMERGENCY PLAN:*

*1. Warning Signs and Symptoms*

e.g. Children with insulin dependent diabetes may present the following warning signs and symptoms of hypoglycemia: headache, nausea, irritability, confusion, tremors, cold/moist skin. School personnel need to be familiar with these signs.

*2. Interaction/Intervention/Emergency Reaction Time*

e.g. A plan should be in place for the intervention that needs to take place when warning signs, such as the ones previously mentioned, indicate hypoglycemia. A possible response for a specific student may be to administer 1/2 cup orange juice immediately. Do not leave the child unattended until symptoms disappear. Contact the parent. Contact emergency room if the symptoms do not subside in 30 minutes.

*3. Emergency Contacts*

e.g. In urban communities that have more than one hospital, parents should be asked which hospital the child should be

transported in case of emergency. Dialing the emergency phone numbers prior to an actual emergency assures all concerned that the numbers have been recorded correctly and assists in preventing problems with accessing the services when an actual emergency occurs.

*4. Natural Disasters*

e.g. Fire drills, actual fires, floods, blizzards, etc. present problems for anyone. However, for children with health needs they offer additional concerns. What will happen if a child is unable to reach home at the usual time and the child is unable to receive treatment or medication? What are the alternatives? Are services like the Red Cross aware that there is a child who may need special consideration if evacuation is necessary?

**2. INFECTIOUS CONDITIONS**

The infectious condition that looms large in the minds of many people is HIV or AIDS. However, there are other diseases that pose a threat to the school community. These include hepatitis B, salmonella bacteria, cytomegalovirus as well as typical communicable diseases such as measles, mumps and chickenpox.

*II. EDUCATIONAL CONSIDERATIONS*

*A. TEAM COMMUNICATIONS:*

*1. Family*
*2. School*
*3. Community*

Team communication and decision making is most important when planning educational programs for children with infectious diseases. However, this may be problematic as some families are reluctant to disclose the fact that their child has an infectious disease for fear the child will be stigmatized. If in fact the family shares this information with school personnel, efforts toward developing trust among all parties need to be initiated. Trust will foster honesty which will greatly assist in the educational planning for the students.

The team should involve school personnel, family, and health care provider. Lines of communication need to be established and opportunities for future meetings arranged if there is a change in the health status of the student. The team should discuss the possibility of informing others of the child's condition.

In addition, school personnel, family members and community health providers should be made aware of the various infectious conditions, characteristics, modes of transmission, incubation period, and methods of prevention. All care providers would benefit from information regarding the importance of handwashing and the use of universal precaustions when dealing with blood and body fluids.

## 3. CONDITIONS WHICH CAUSE THE CHILD TO BE MEDICALLY FRAGILE

Children whose health status is unpredictable or who have the possibility of experiencing an emergency that is difficult to manage are considered medically fragile. Some examples of these

conditions are children who are in the final stages of AIDS, various forms of cancer, and renal failure.

*B. EDUCATION PLAN:*

*1. Level of Developmental/Educational/Vocational Function*

e.g. This information can be gleaned from input from the family, appraisal personnel, occupational therapist, physical therapist, and school nurse. The family's input is critical in planning goals for the child. Many children have outlived a discouraging prognosis. School work may offer hope for the future as well as enhance the child's feeling of well-being.

*2. Physical Ability to Participate*

e.g. It is important for the family, teacher, and school nurse to discuss the daily activities that occur in school. This will provide an opportunity to discuss the child's level of participation in each of the activities. Information about the times during the day when the child is most alert would be valuable to school personnel.

*3. Classroom modifications*

Numerous suggestions are found in the handout

*4. Educational/Communication Equipment Needs*

e.g. What equipment is needed for the child in the classroom? Who is responsible for securing the equipment?

*C. INDEPENDENCE IN HEALTH CARE:*
(see handout titled "IEP Development")

*1. Present Level of Functioning*
*2. Potential*

e.g. What is the child's level of involvement in self-care? What is the child's potential in this area? Independence is a natural growing up process. Independence in self care can add to the child's dignity and feeling of competence. Goals and objectives can be written which promote maximum independence in self-care. Three levels of involvement are described as follows: 1) tolerating the procedure or the positioning required for the procedure, 2) assisting or guiding the caregiver in performing the procedure, 3) performing the procedure independently with or without supervision.

**4. CONDITIONS WHICH REQUIRE "TECHNOLOGY ASSISTANCE"**

The Office of Technology Assessment (1987) defines students supported by technology as those who "require the routine use of a medical device to compensate for the loss of a life-sustaining body function and require daily and ongoing care and/or monitoring by trained personnel". Medical devices include ventilators, gastrostomy tubes, tracheostomy tubes, catheterization tubes, etc.

*D. SCHOOL ABSENCE:*

*1. Reduced Vitality*

e.g. It is important to plan instructional time during peak periods. Some students may be able to execute written exercises in the morning but may not have the strength to do so in the afternoon. Teachers may want to plan ways to conserve the child's energy in the morning. There have been

known instances when children have received regular instruction in the morning and homebound services in the afternoon.

*2. Time Factors Influencing Absences*

e.g. There have been instances when the child has been asked to stay home from school when the assigned careprovider is absent. This is not acceptable. However, there may be other instances that contribute to absences. A system could be developed to address the problem of missed instruction (tape recording, notes from another student, use of NCR paper, homebound teacher).

*3. Program Accommodations*

e.g. Children who require technology may miss school due to appointments or illnesses. Planning for missed work is important for continuity in the educational program.

*E. ENVIRONMENT:*

1. *Accessible*
2. *Temperature Control*
3. *Allergens*
4. *Environmental Hazards*
5. *Running Water*
6. *Electrical Requirements*
7. *Storage Area*
8. *Private Area to Complete Procedures*

Participants are asked to refer to two pages in the handout titled: "School Facility Assessment for Students Who Are Ventilator Assisted" and "Training and Technical Assistance Checklist for Schools Involved in Educating Students Who are Ventilator Assisted".

5. **BODY DEFORMITIES AND SKIN CONDITIONS**

Amputations, craniofacial conditions, burns, etc. are examples of conditions in this category. Children with these conditions may experience significant problems in the school setting.

***III. PLACEMENT CONSIDERATIONS***

*A. PERSONNEL/CONSUMER CONSIDERATIONS:*

*1. Need for Supplemental/Related Services*

e.g. What services are needed in order for the child to benefit from the instructional program at school? Does the child qualify for occupational therapy, physical therapy, health services? Will these services be delivered directly to the student or will the specialist consult with classroom personnel in planning the program for the child?

*2. Need for Direct Care Personnel*

*a. Licensure Required*
*b. Training and Supervision Required*

It is important to check with the professional organizations (Board of Nursing, Occupational Therapy, Respiratory Therapy, Physical Therapy) to determine what procedures may be performed by unlicensed care providers. Procedures which may appear to be relatively simple to perform but may in fact have serious health implications if something were to go wrong. In most states, Registered nurses in the school are the only professional group that can legally delegate noncomplex health procedures to nonlicensed care providers. Other professional groups can also delegate functions which come under their professional practice act.

If in fact the health procedures can be delegated to nonlicensed care providers training is necessary for the well being of the child as well as the level of comfort for the care provider. Table IX "Training Levels" provides a description of some componenets involved in training.

*B. ORIENTATION AND TECHNICAL ASSISTANCE:*

1. *Direct Care Personnel*
2. *Supplemental/Related Services Personnel*
3. *Administrators*
4. *School Personnel*
5. *Classmates*
6. *Schoolmates*
7. *PTA/Community*

Efforts should be made to prepare or orient faculty, staff and student body prior to a child entry/reentry to school. The student should be asked if he/she would like to be involved in the orientation. Some families have provided the school with a videotape of the child that can be used in the orientation training. Please refer to the handout titled "Orientation of Peers" and "Training."

**6. NEUROLOGICAL CONDITIONS**

The number of children in this category is growing. This is due in part to the improved medical response time to emergencies and advanced treatment and technology. Unfortunately, an increase in violent crimes has also contributed to this number. This category does not only consider those children affected with head injuries but other neurological conditions such as seizure disorders, meningitis, brain tumors, aneurysms, etc.

*C. TRANSITION:*

*1. More Restrictive Environment*

e.g. Children who have sustained a head injury require flexibility in programming. A student may be quite involved initially on his reentry to school but make significant progress throughout the year. Children who appear to fit into the programming for a student who has moderate mental disabilities may rapidly progress and be capable of more challenging programs. It is important to frequently monitor the appropriateness of these programs throughout the year.

*2. Personnel Resources*

e.g. Specialized personnel may not be indicated to work with some children with neurological problems. However, it is most beneficial to train current school personnel as well as establish contact with support personnel and community resources to supply information and services that meet changing needs. These resources may able to provide assistance to school personnel as situations arise.

*D. TRANSPORTATION:*

*1. Accessibility*
*2. Secure for Student*
*3. Secure for Equipment*
*4. Temperature Control*
*5. Trained Personnel*
*6. Emergency Plan*

Planning for the transportation needs of children with health needs requires many of the same considerations as planning for the child during the school day. Many transportation departments have very specific regulations for transporting a child in a wheelchair

or the equipment the child may need. Seizure activity may be triggered by heat requiring that a constant tolerable temperature be maintained on the school bus. Some children with head or spinal cord injury may also have problems with maintaining normal body temperature.

Attendants on buses transporting children with health needs may be indicated. The bus driver cannot be expected to keep a watchful eye on the road and respond to a child's emergency at the same time.

Emergency plans, such as to which hospital the child needs to be transported, what is the quickest route, necessary documents for emergency room staff, are just some of the considerations for community health care providers. Some systems have even provided cellular phones to the bus drivers in some situations.

During this presentation, we have outlined the six categories of children with health care needs and given some examples of implications for educational programming for these children. More and more literature is appearing on this population. Participants are referred to the bibliography for more information. Working with children with special health care needs requires preplanning and some modifications. However, the benefits to the child and society are innumerable.

# STUDENTS WITH SPECIAL HEALTH NEEDS: SCREENING AND ASSESSMENT

The following guidelines provide information areas to consider when developing individualized school plans. Not all areas will be relevant to consider for every student.

## I. HEALTH CONSIDERATIONS

A. Health Care Plan:
   1. Diagnosis and Description of Condition
   2. Treatments/Side Effects
   3. Special Nutritional Requirements
   4. Medication/Side Effects

B. Emergency Plan:
   1. Warning Signs and Symptoms
   2. Interaction/Intervention/Emergency Reaction Time
   3. Emergency Contacts
   4. Natural Disasters

## II. EDUCATIONAL CONSIDERATIONS

A. Team Communication:
   1. Family
   2. School
   3. Community

B. Education Plan:
   1. Level of Developmental/Educational/Vocational Function
   2. Physical Ability to Participate in Classroom Activity
   3. Classroom Modifications
   4. Educational/Communication Equipment Needs

C. Independence in Health Care:
   1. Present Level of Function
   2. Potential

D. School Absence:
   1. Reduced Vitality
   2. Time Factors Influencing Absence
   3. Program Accommodations

E. Environment:
   1. Accessible
   2. Temperature Control
   3. Allergens
   4. Environmental Hazards
   5. Running Water
   6. Electrical Requirements
   7. Storage Area
   8. Private Area to Complete Procedures

## III. PLACEMENT CONSIDERATIONS

A. Personnel/Consumer Considerations:
   1. Need for Supplemental/Related Services
   2. Need for Direct Care Personnel
      a. Licensure Required
      b. Training and Supervision Required

B. Orientation & Technical Assistance:
   1. Direct Care Personnel
   2. Supplemental/Related Services Personnel
   3. Administrators
   4. School Personnel
   5. Classmates
   6. Schoolmates
   7. PTA/Community

C. Transition
   1 More Restrictive Environment
   2. Personnel Resources

D. Transportation:
   1. Accessible
   2. Secure for Student
   3. Secure for Equipment
   4. Temperature Control
   5. Trained Personnel
   6. Emergency Plan

## Table III

### IEP DEVELOPMENT

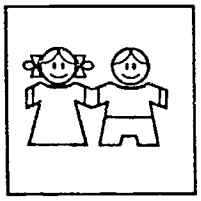
I. Tolerance
   1. Tolerate Position
   2. Tolerate Procedure

II. Assistance/Direction
   1. Position
      a. Maintain Position
      b. Assume/Describe Position
   2. Awareness of Need Schedule
      a. Respond to Verbal or Physical Cues Related to Physical Signs of Need or according to schedule
      b. Respond Independently to Physical Signs of Need or according to Schedule
   3. Equipment
      a. Recognize Equipment
      b. Name Equipment
      c. Hand Equipment During Procedure
      d. Gather Equipment
      e. Maintain Equipment
   4. Procedure
      a. Identify Area to be Dealt With
      b. Assist with Preparing (Cleaning) Area
      c. Increase Assistance with Procedure, e.g., holding container, disposing of urine, hand-over-hand insertion
      d. Supervise/Outline Procedure

      Note: Objectives 1 through 4 may be dealt with concurrently.

III. Independence
   1. With Supervision
   2. Without Supervision

Note. From *Community Provider's Guide: An Information Outline for Working with Children with Special Health Care Needs* (p. 172) by T. H. Caldwell, A. W. Todaro, A. J. Gates, 1989, New Orleans, LA: Children's Hospital. Reprinted by permission.



Children's Hospital

# Training and Technical Assistance Checklist for Schools Involved in Educating Students Who Are Ventilator Assisted

| Schedule Location Participants | |
|---|---|
| | In preparation for receiving a student who needs ventilator assistance, an IEP committee is convened to discuss the specific educational needs of a student. Hospital personnel are available to assist with providing general student information, establishing goals and objectives for maximizing independence in health care routines at school, and to assist with identifying needs for staff training. The IEP committee also determines whether or not a child specific aide will be needed to conduct routine health procedures throughout the school day, and whether or not a student will need health services as a related service. |
| | The next step in preparing to receive a student who is ventilator assisted is to identify a school site which meets the needs of the child, and conduct a facility assessment. A facility assessment is conducted to evaluate accessibility as well as identify specifications and requirements unique to students needing high tech equipment. |
| | The school nurse will conduct a health assessment including a determination of the health procedures that will be done during school hours as well as needs for staff training. |
| | Training procedures for school personnel begin with a general orientation of all faculty and staff which includes an equipment demonstration, a description of a student's condition and needs and open discussion addressing general questions and concerns. General faculty and staff orientation takes about one hour. |
| | Before child specific orientation begins, school administrators, the school nurse and VACP staff will meet to discuss and determine responsibilities for specific training steps and tasks as indicated on Attachment A "Child Specific Training Requirements". |
| | Next is a child specific orientation for school personnel involved in providing direct and related services to a student. Included in the 2-3 hour program is a more detailed discussion of a student's educational and health needs as well as mapping out emergency procedures and protocols. |
| | The child specific training based on a physician's prescription includes training for all health related procedures which will be conducted at school. The training may include tracheostomy suctioning, ventilator maintenance and care, emergency signs and symptoms and how to respond to them. Our trainers will maintain documentation of competencies related to each skill taught and the school system will be provided copies of all completed training checklists. The school nurse who is ultimately responsible for health in assigned schools collaborates with the trainer to insure that trainees are competent to perform health care procedures independently. Training time varies depending upon the skills and background of the person(s) being trained. Participants in the child specific training include teachers' aides and school nurses. |
| | The next area relates to the preparation of the student body and classmates. Students are often very curious about wheelchairs, tracheostomies and ventilator equipment. Presenting information about special health needs prior to the arrival of a student can facilitate the entry and adjustment into the school environment. |
| | The initial school trial is an optional and final component in the training process. It involves one or two trainers from Children's Hospital or caregivers from the students home accompanying the aide and student from home to school and back on the first day. The reason for a school trial is to navigate through a student's daily schedule and environment to identify any problems that may arise and make adjustments when necessary. |
| | Describe additional training needs. |

# School Facility Assessment for Students Who Are Ventilator Assisted

When a school site has been identified, a "Facility Assessment" should be conducted to evaluate accessibility and to determine needs for modification of space, environment, programs, and routines.

Facility assessment includes an inspection of electrical outlets to determine whether or not there are adequate 10-15 AMP circuits in classroom(s) and other areas in which a student may be located. Electrical outlets should be grounded and conveniently located to a student's desk or wheelchair. If extension cords are used, they must be grounded and able to handle the current load. Ventilators and suction machines should be plugged into wall circuits whenever possible to preserve batteries for moving from place to place, riding the bus, and power outages.

Another area to be assessed is environment. Is air conditioning and heating available on buses and in classrooms? Many children needing ventilation are unable to tolerate extremes in temperature without serious health consequences. A temperature controlled environment will help insure the manageability of a student's health needs in a school setting. Recommended temperature ranges are 68°-72°.

Space and accessibility are also important considerations. A student should be able to navigate freely on the school campus including the bus loading area, classrooms, cafeteria, bathrooms, library, etc. Students should have access to the same subjects and classes as their non-handicapped counterparts. If a class is offered only on upper floors of a school building and there is no way for that student to get to upper floors, arrangements must be made to provide that class in a location accessible to the student. Storage space in a locked cabinet may be needed for medical supplies and equipment. Private space should be made available for students who need diaper changing or catheterization. Staff and students may need access to a water source for routine hand washing and cleaning equipment.

Methods of communication in case of emergency are also important. How does a classroom teacher notify the office of an emergency? Is there a telephone, intercom, or student runner available to alert the office. Some school systems also provide bus drivers with a method of communicating with the school in an emergency. Most commonly used methods are radio and mobile telephone. If communication devices are not available, what contingency plans have been made to handle such situations?

Another school facility consideration is what procedures exist for evacuation during fire or natural disasters. Are multiple exits ramped and accessible in case some are blocked by fire or flooding? What alternate arrangements can be made for students needing electric current for equipment in case of a prolonged power outage. Have the power and phone company been notified regarding the need for priority reinstatement in case of power or phone outages?

A final area of consideration is establishment of an emergency plan which includes a telephone list, contacts with a local physician and hospital emergency room who are familiar with a student's condition and are prepared to take responsibility for a medical emergency, and notification of EMS or ambulance service, Red Cross, the telephone and power companies, to assist in transporting or giving priority reinstatement of service during phone or power failure.

Source: Ventilator Assisted Care Program and
National MCH Resource Center
at Children's Hospital, New Orleans, LA
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Table VII

## ORIENTATION OF PEERS

There are a few standard guidelines that can be helpful to consider when designing student-orientation plans.

1. Involve the child with special health needs in decision making and planning.
2. Allow the child to decide whether he/she will participate or whether he/she wants to be identified as the child with the condition being discussed.
3. Keep in mind the age of the child and child's peers when designing interventions. The complexity and type of materials used will vary depending on the age of the child.
4. Use pictures, drawings and audiovisuals. Whenever possible, provide the opportunity for hands-on experiences.
5. Compare "normal" anatomy so that they can compare special functioning to their functioning, e.g., compare a tracheostomy to a nose.
6. Prepare the child with special health needs ahead of time. Some questions may be difficult to answer. Make sure to include some of the more difficult questions in your preparation, e.g., Will you die soon? Let the child know that he/she may choose to answer or not answer difficult questions.
7. Prepare classmates for the presentation by providing background information and encouraging open communication regarding the health condition.
8. Training plans should include the opportunity for children to gain specific information, to relate the disability to their own experiences, e.g., "My grandmother has arthritis," and to discuss their experiences and feelings about the topic being discussed.
9. Answer questions simply and without a lot of detail. Give simple answers and ask if more clarification is needed.
10. Treat the child and peers with respect and answer questions as openly as possible.

Note. From *Community Provider's Guide: An Information Outline for Working with Children with Special Health Care Needs, 1991 Addendum* (p. 24) by T. H. Caldwell, A. W. Todaro, A. J. Gates, S. Failla, and K. Kirkhart, 1991, New Orleans, LA: Children's Hospital. Reprinted by permission.

## Table IX

### TRAINING LEVELS:

Orientation - Introduce current practice/technology and affect attitudes;

Diagnostic Specific Training - Provide detailed information about a specific condition or procedure and associated care;

Child-Specific Training - Assess and teach, daily and emergency care and implications of the child's function in the community; and

Trainer's Training - Teach licensed professionals how to train other care providers.

### RECOMMENDATIONS FOR TRAINING IN COMMUNITY SETTINGS:

1. Secure individualized prescriptions and protocols including warning signs and symptoms. Develop these in collaboration with parents and health care providers.
2. Begin training prior to the child's return to his/her community. Have parent observe and/or participate in the training.
3. Train at least two people so that back-up is available. Delivery of care by a consistent provider(s) is important to the child's health.
4. Train all personnel who will work with the child to deal with emergency situations, i.e., bus drive, adapted physical education teacher or anyone else who will be teaching the child. Recommend that the program administrator and/or secretary learn emergency procedures.
5. Provide back-up for a designated period, an expert (i.e., qualified professional, trained parent caregiver) should be present for continued training and on-site back-up. Length of back-up is determined by care provider's competency and comfort. It is recommended that at least five trials of procedures and emergencies with 100 percent accuracy be documented before care provider works independently.
6. Document training using an individualized checklist. The trainer and parent sign the checklist after training is completed.
7. Provide supervision. Re-checks are recommended by the trainer, with timelines based on complexity of procedures and competency of care provider.
8. Include recognition and implementation of emergency procedures as part of training and re-checks.

Note. From *Community Provider's Guide: An Information Outline for Working with Children with Special Health Care Needs* (p. 93) by T. H. Caldwell, A. W. Todaro, A. J. Gates, S. Failla, and K. Kirkhart, 1989, New Orleans, LA: Children's Hospital. Reprinted by permission.

Table IX *(cont.)*

## BARRIERS AND SOLUTIONS:

The following is a list of major barriers encountered by program staff and the approaches that have been successful in overcoming these barriers.

Barrier: Lack of Communication

Approaches:

- Linkage Committee (multi-agency systems planning including hospital, school and community providers)
- Multi-agency staffings
- Clarify and interpret information from multiple disciplines
- Use protocols and other tools for communication
- Include educators in discharge planning

Barrier: Attitudes including fear, uncertainty and resistance to change among professionals, providers and parents

Approaches:

- Assess individual and community needs and orientation
- Focus on child, transition plans, support and individual training

Barrier: Territorial Issues

Approaches:

- Exemplify a model of interdisciplinary collaboration and network through interactions of program personnel
- Encourage collaboration among disciplines, agencies and individuals (consumers, educators, social and health services personnel, and funding agents)
- Provide forums to discuss issues

Barrier: Liability Issues

Approaches:

- Involve families in planning, implementation and evaluation
- Document training of routine and emergency care
- Promote systematic monitoring and evaluation

Barrier: Interpretation of professionals' roles and regulations

Approaches:

- Work closely with the governing body of each profession to provide information and education
- Advocate for professional involvement and growth

Note. From *Community Provider's Guide: An Information Outline for Working with Children with Special Health Care Needs* (p. 94) by T. H. Caldwell, A. W. Todaro, A. J. Gates, S. Failla, and K. Kirkhart, 1989, New Orleans, LA: Children's Hospital. Reprinted by permission.