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ABSTRACT

This paper considers ways to help children with special health needs by utilizing the Individualized Education Program (IEP) and the Individualized Health Care Plan (IHCP). Results of a study which found a lack of necessary health information in school documents is summarized. The school nurse is seen as a pivotal person in the identification and coordination of student health needs. He/she conducts a health assessment and writes an Individualized Health Care Plan. This is followed by development of an Individualized Health Services Plan by a committee composed of the nurse, parent, student, teacher/s, school administrator, and others. This document specifically addresses goals and objectives leading to independence in self care. A sample checklist demonstrates how to assess levels of involvement in self care. A case example of a 9-year-old with diabetes demonstrates how to develop health care goals and objectives. Extensive attachments include health services plan forms and instructions; an outline of levels of care; case examples; training checklists for catheterization, gastrostomy, clean suctioning, and tracheostomy care; and fact sheets/emergency procedures for Type 1 diabetes, juvenile rheumatoid arthritis, mechanical ventilation, and spina bifida. (DB)

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CHILDREN WITH SPECIAL HEALTH NEEDS IN SCHOOL: DEVELOPING AN
INDIVIDUALIZED EDUCATIONAL PROGRAM (IEP)
AND AN INDIVIDUALIZED HEALTH CARE PLAN (IHCP)

Jan Janz, Jacqueline Harrison, Terry Caldwell

ED 367 126

The number of children with special health care needs in schools is increasing. Children with health conditions who may not have survived in the past are surviving and living beyond previous expectations. For a variety of reasons, home and community care have been identified as more desirable than hospital and institutional care for most children with health care needs. Laws and subsequent litigation have strengthened the responsibility of the school system to serve all children regardless of the disability. More parents and advocates are becoming increasingly aware of the rights of children in the educational system and have taken an active role in advocating for these rights.

Teachers at times may feel ill equipped to deal with the health needs some children present. Teachers often view these health needs as completely separate from the academic curriculum for a student. However, health needs of students can be incorporated into the child's education program. Goals leading to maximum independence in self-care can assist the child in feeling competent and somewhat in control of his/her body. This session is designed to assist school personnel in developing IEP goals and objectives for self-help skills specifically in the area of health care.

The National MCH Resource Center conducted a study in 1991. The purpose of the study was to determine the extent of health

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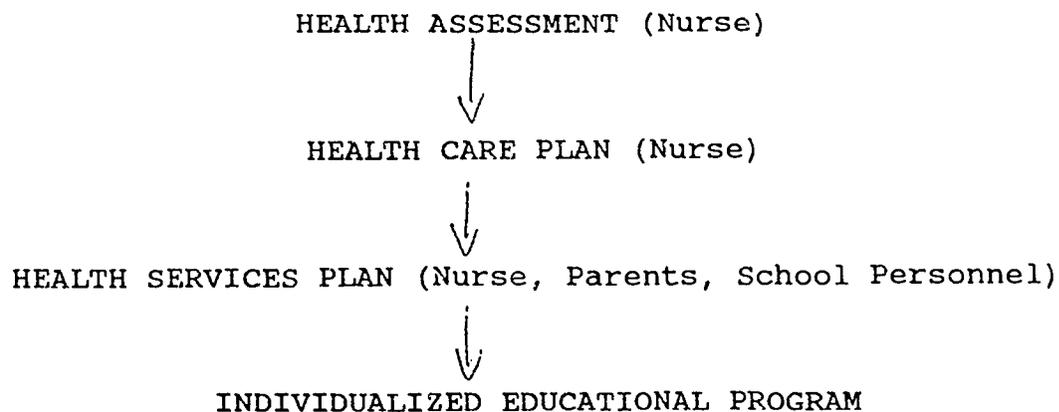
information for students with special health needs was documented in school records. The IEP, evaluation, and health care plans were the documents reviewed. The following are a few observations from this study:

1. No consistency in health records was found at the school. There was no evidence of written health care plans.
2. Only 82 percent of school documents stated primary diagnosis.
3. Only 23.5 percent of these documents contained warning signs and symptoms.
4. Few IEPs contained goals and objectives which addressed student involvement in self care.

This study demonstrated the lack of health information that was contained in documents at the school. More information on this study can be obtained by contacting the National Center (address on the handout) for those who are interested.

The results of this study are disconcerting when we consider the safety and well-being of the child. In addition, documentation of health needs on the IEP is one way of insuring that health services for students will be delivered.

The IEP not only serves as a contract between the school and family for service delivery but is designed to be the work plan for school personnel in educating the child. How are health needs written on IEPs and how do IEP committees write goals and objectives for health care needs? The following flow chart illustrates the preliminary steps leading to the development of those goals and objectives.



As one can see, the school nurse is an important player in this process. It is advisable for the school nurse to be involved even before the child enters/reenters school. Educators may wonder why is the nurse's involvement so important? Often a complete evaluation has been conducted and contains health information. The parent can provide additional health information. However, the nurse can conduct a health assessment of the child and determine specific needs. In addition, the evaluation may lack some of the necessary health information or the status of the child's health may have changed. The nurse may be able to identify necessary information that is missing and formulate questions that need to be answered. The nurse is also often aware of the routines of the school day as well as the set up of the physical plant and facilities. The coordination of health needs to the educational environment is beneficial in planning for a smooth transition into the school setting.

The first phase of the child's entry/reentry to school is the **Health Assessment** is conducted by the school nurse. The assessment

includes physical findings, strengths, social and emotional relationships, coping strategies, family issues and resources available. This stage may involve data collection from a variety of means such as telephone calls to providers and families, reports, interview with the child, etc.

An **Individualized Health Care Plan (IHCP)** is written by the nurse and is based on the information gathered during the Health Assessment. The IHCP may include areas such as health needs, emergency plans, communication between home, school, health care provider, school absences, environmental concerns, etc. (Bulletin 1909, 1993).

The **Individualized Health Services Plan (IHSP)** is developed by a committee composed of the nurse, parent, student when appropriate, teacher(s), school administrator, and others when appropriate. Information from the preceding two steps is incorporated into the daily school activities attending to details such as what is required, and who is responsible. Goals and objectives leading to independence in self-care are addressed. This document can now serve as the plan for students who do not qualify for special education services under IDEA or it can be used in the development the Individualized Educational Program (IEP) for a child who qualifies for special education services (see handout for Individualized Health Services Plan).

DEVELOPING GOALS FOR INDEPENDENCE IN SELF-CARE

The ability of students to provide for their own health care

can allow them greater freedom in school and the community. It can also make the difference between whether they can live independently as adults or will need to be placed in restrictive settings.

Objectives for achieving maximum independence in self care can be developed whether or not a student will eventually be independent. Caldwell, Gates and Todaro (1989) distinguish three tiers of student involvement: 1) improved tolerance of care, 2) direction of care, and 3) independence in care. (See handout Levels of Care)

Some children may never be able to participate in their own care due to the extent of their cognitive and or physical involvement. Improvement for these children will be based on increasing their tolerance of care. For instance, a student who does not tolerate catheterization may be soothed by listening to music during this time.

Other students may have physical limitations which prevent them from actually completing procedures. These students can often provide directions to the caregiver or assist in actually performing the procedure. For instance, a student who has quadriplegia and has limited use of his arms may direct the careprovider on when it is time for his/her gastrostomy feeding as well as assuming the correct position for the feeding.

Other students will be able to learn to perform the procedure independently. Degree of supervision will depend on their level of maturity.

Following is a quiz to assess knowledge of levels of involvement in self care.

T = Tolerance (student is only able to cooperate or tolerate care due to physical or cognitive disabilities)

D = Directs or assists (student is able to assist with care but unable to complete care independently)

I = Independent (student is able to complete care independently)

_____ Lynn will be fed 175 cc of Ensure at 11:00 a.m. every day

_____ Chris will document the times when he has administered Intol using his inhaler.

_____ Gus will name the equipment used for gastrostomy tube feeding.

_____ Melissa will demonstrate the correct procedure for gastrostomy tube feeding on a doll.

_____ Rhonda will open mouth in preparation for medication.

_____ Rhonda's parents will report any changes in Rhonda's health status.

_____ Melinda will prick her finger and place the strip in the DIASCAN meter.

_____ Gary will identify the warning signs of his fluid retention.

_____ Given a prompt, Terry will report to the nurses's office to receive medication.

Handout "Case Examples"

(see handout)

Case Example #1

Mary is a 9 year old female who was diagnosed with diabetes mellitus at the age of 6 years. Her urine glucose level must be checked daily before lunch and at other times during the day when specific symptoms occur. Snacks must be eaten throughout the day. Mary performs adequately in all academic subjects as long as glucose levels are maintained at normal levels.

What are the questions that need to be asked before goals and objectives can be written:

1. What is Mary's level of involvement in managing her care?
2. What are the areas that have to be considered?
3. Will Mary require injections?
4. Who will administer the injections?
5. What is the existing exercise regime?
6. How involved is she in monitoring urine glucose levels?
7. Is blood glucose monitoring ever indicated?
8. What time is lunch?
9. Are there any dietary considerations?

Turn to the three pages in the handout on Diabetes. This information sheet will assist in formulating the right questions to ask when developing goals and objectives.

What is Mary's current level of Performance?

Current Level of Performance

Mary is able to monitor her urine glucose level. She is inconsistent in documenting the levels. She needs to be reminded to eat snacks during the day. She is unable to self inject insulin.

Annual Goal

Mary will maintain healthy urine glucose levels. She will work toward independence in self care.

Objectives

Mary will list typical signs and symptoms of insulin reaction.

Mary will state the treatment for early insulin reaction symptoms (e.g. where snacks are stored, who to notify, etc.).

Mary will describe diet exchange selections.

Mary will write out a diet for 1 day.

Mary will document urine glucose levels.

Mary will report to the office to eat her snack at 10:30 a.m. and 2:30 p.m.

Mary will report signs of infection to the school nurse.

Mary will monitor her sugar and acetone levels in her urine 1 hour prior to lunch.

Persons Responsible

Student, parent and teacher, assistant, teacher.

The handout provides information that can be used to generate goals and objectives on the remaining four case studies.

Checklists used in healthcare settings are often useful in providing information on scope and sequence for some procedures. Existing literature helps teachers formulate useful questions. Participants are reminded that they are not expected to know everything about specific health conditions but rather to depend on the resources such as the family, school nurse, community providers and services.

Thursday, April 8, 1993

*Children with Special Health Needs in School: Developing
an Individualized Education Program (IEP)
and an Individualized Health Plan (IHP)*

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LOUISIANA DEPARTMENT OF EDUCATION
HEALTH SERVICES PLAN
for
STUDENTS WITH SPECIAL HEALTH CARE NEEDS

(Please attach forms if room is insufficient)

STUDENT IDENTIFICATION

Student Name _____ Date of Birth _____
School _____ Grade _____

BACKGROUND INFORMATION/NURSING ASSESSMENT (complete all applicable sections)

Brief Medical History/Specific Health Care _____ (additional information is attached)

Psychosocial Concerns _____ (additional information is attached) Family Concerns/Strengths _____ (additional information is attached)

GOALS AND ACTIONS

Attach physician's order and other standards for care.

1) Procedures and Interventions (student specific)

(1)	Procedure	Administered By	Equipment		Maintained By	Authorized/trained By
			List	Provided by		
(3)						

2) Medications _____ Attach medication guideline and administration log. 3) Diet _____ (additional information attached)

4) Transportation Needs _____ (additional information is attached) 5) Class/School Modifications _____ (additional information is attached)

6) List Supplies: _____ Provided By: _____ 7) Safety Measures _____ (additional information attached)

8) Student Participation in Procedures: No Yes (if yes, attach description of participation level) _____ (check if student is enrolled in special education)

CONTINGENCIES Emergency Plan Attached Training Plan Attached Possible Alerts _____

AUTHORIZATIONS I have participated in the development of the Health Services Plan and agree with the contents.

Parent(s) _____	Date _____ / /	Teacher(s) _____	Date _____ / /
School Nurse _____	Date _____ / /	Other _____	Date _____ / /
School Administrator _____	Date _____ / /	Other _____	Date _____ / /

Effective Beginning Date _____ Next Review Date _____

STUDENTS WITH SPECIAL HEALTH CARE NEEDS

INSTRUCTIONS FOR USE

STEP I

Following assessment, the school nurse will complete the following sections of the Health Services Plan:

- Student Identification
- Background Information/Nursing Assessment
- Goals and Actions
 - 1) *Procedures and Interventions* - the nurse must identify the special health procedures that must be performed in the educational setting, who will perform the procedure and the training required)
 - 2) *Medications*
 - 3) *Diet*

STEP II

With the assistance of the nurse, the student's health care team (parent(s), teacher(s), school administrator, and others when appropriate) will complete the remaining sections of the Health Services Plan:

- Goals and actions
 - 4) *Special Transportation (if applicable)*
 - 5) *Classroom/School Modifications* - a description of any modifications that must be made in the classroom or on the school grounds to accommodate the student.
 - 6) *Equipment and Supplies* - a description of the equipment and supplies needed to safely conduct the procedure.
 - 7) *Student Participation* - a description of the level of student participation expected to be accomplished by the instructional staff, the nurse and the parents.
 - 8) *Safety Measures*
- Contingencies
Plans for emergencies, plans for training of personnel, and possible alerts.
- Authorizations
Signatures of all parties and the date of implementation.

STEP III

Implementation of the special health services plan will begin.

BEST COPY AVAILABLE

Levels of Care

- I. Tolerance
 - A. Tolerate position
 - B. Tolerate procedure

- II. Assistance
 - A. Position
 - 1. Maintain position
 - 2. Assume/describe position
 - B. Awareness of need of schedule
 - 1. Respond to verbal or physical cue related to physical signs of need or schedule
 - 2. Respond independently to physical sign of need or schedule
 - C. Equipment
 - 1. Recognize equipment
 - 2. Name equipment
 - 3. Hand equipment during procedure
 - 4. Gather equipment
 - 5. Maintain equipment
 - D. Procedure
 - 1. Identify area to be dealt with
 - 2. Assist with preparing (cleaning) area
 - 3. Increase assistance with procedure, i.e., holding container, disposing of urine, hand-over-hand insertion
 - 4. Supervise/outline procedure

- NOTE: Objective in 1 through 4 may be dealt with concurrently.

- III. Independence
 - A. With supervision
 - B. Without supervision

Note. From *Community Provider's Guide: An Information Outline for Working with Children with Special Health Needs* by T. C. Terry Caldwell, A. W. Todaro and A. J. Gates, 1989.

National MCH Resource Center
at Children's Hospital, New Orleans, LA
4/2/93

Quiz Level of Care

- | | | |
|----------|---|---|
| T | = | Tolerance (student is totally dependent in care) |
| D | = | Directs or assists (student is able to assist with care but unable to complete care independently) |
| I | = | Independent (student is able to complete care independently) |

- _____ Lynn will be fed 175 cc of Ensure at 11:00 a.m. every day.
- _____ Chris will document the times when he has administered Ental using his inhaler.
- _____ Gus will name the equipment used for gastrostomy tube feeding.
- _____ Melissa will demonstrate the correct procedure for gastrostomy tube feeding on a doll.
- _____ Rhonda will open her mouth in preparation for medication.
- _____ Rhonda's parents will report any changes in Rhonda's health status.
- _____ Melinda will prick her finger and place the strip in the DIASCAN meter.
- _____ Gary will identify the warning signs of his fluid retention.
- _____ Given a prompt, Terry will report to the nurse's office to receive medication.

CASE EXAMPLES

- I. Mary is a nine-year-old female who was diagnosed with diabetes mellitus at the age of six years. Her urine glucose level must be checked daily before lunch and at other times during the day when specific symptoms occur. Snacks must be eaten throughout the day. Mary performs adequately in all academic subjects as long as glucose levels are maintained at normal levels.

- II. Paula was diagnosed with juvenile rheumatoid arthritis at the age of nine. She is now twelve and in the seventh grade at school. On days when she has flare ups, she has difficulty getting dressed as well as walking. It is important that Paula be allowed to flex her joints frequently throughout the day. She may also need assistance carry her lunch tray, books, etc. She receives aspirin twice a day at 10:00 a.m. and 2:00 p.m.

- III. Kelly is a six-year-old female who was born with spina bifida. As a result of this condition she is paraplegic and is dependent on a wheelchair for mobility. She has mild deficits in the area of fine motor skills. She requires catheterization at 9:00 a.m. and 12:00 p.m. during the school day.

- IV. Roger is a fourteen-year-old student who is quadriplegic as a result of a recent spinal cord injury. He is in need of ventilation 24 hours a day. He requires tracheal suctioning and trach care as needed. He is able to communicate verbally. He is physically dependent in self care but has the potential to direct his care.

- V. Tony is a seven-year-old male with a diagnosis of spina bifida. He achieved above average scores on academic tests. He is dependent on a wheelchair for mobility. He requires positioning every two hours. He is able to feed himself independently but depends on gastrostomy feedings for the majority of his nutritional needs.

F A C T S

DIABETES

(Type I: Insulin Dependent)

WHAT IS IT?

Insulin dependent diabetes, also known as Type 1 or juvenile diabetes, is a condition that prevents the body from utilizing food (glucose) normally. When this form of diabetes occurs, the body no longer produces insulin. Insulin is a hormone produced by the pancreas and released in response to blood sugar levels. For children who have insulin dependent diabetes, daily injections of insulin must be taken in order to stabilize blood sugar levels. Diagnosis can occur any time.

Common Symptoms of insulin dependent diabetes are excessive urination, thirst and hunger. Other symptoms include weight loss, abdominal pain, muscle weakness and visual disturbance.

CAUSE

The cause of insulin dependent diabetes is uncertain at this time, but present studies suggest that there is an inherited susceptibility to develop diabetes.

TREATMENT

Treatment involves daily injections of insulin, a modified diet and an exercise program. Blood glucose (blood sugar) levels must be routinely monitored. Insulin dependent diabetes is currently irreversible, but it can be controlled. Most children, as they grow older, have little trouble learning to inject the insulin and monitor blood sugar levels.

PROGNOSIS

Prognosis is good with proper control. Children with diabetes grow up to be functioning, productive adults. Management of diabetes at the present time is lifelong.

PROBLEMS FOR CHILDREN

The daily management of insulin dependent diabetes is a constant reminder to the child of a chronic health condition. Insulin injections, blood glucose monitoring, diet modifications and an exercise program are all required daily. The treatment regimen that must be followed can sometimes cause resentment in a child. A feeling of being different from peers can also be a source of stress for the child. Learning to live with diabetes can be difficult, but can be accomplished.

PROBLEMS FOR FAMILIES

Acceptance of the child's condition, which requires daily management, can be stressful for many families. Treatment is expensive. Families need to promote independence for the child by teaching the child to be responsible for all aspects of daily management. Encouragement of peer support, such as summer camps for children with diabetes, can be helpful.

DIABETES

(Type 1: Insulin Dependent)

INFORMATION NEEDS

1. Routine Treatment Regimen
2. Diet Requirements
3. Normal Glucose Levels
4. Exercise Considerations (Balance between food and exercise)
5. Medications and Side Effects
6. Signs and Symptoms of Hypoglycemia and Hyperglycemia
7. Emergency Procedures, Including Physician and Emergency Room Numbers (Forms attached)
8. Signs and Symptoms of Complications
9. Good Control May Help Prevent Long Term Problems

SKILL NEEDS

1. Measurement of Blood Glucose Levels
(This procedure may be completed at home or independently by child at school)
2. Monitor Proper Diet Intake
3. Administration of Medication
4. Recognition of Signs and Symptoms of Hyperglycemia or Hypoglycemia and Implementation of Emergency Procedures

COMMON EDUCATIONAL IMPLICATIONS

1. Frequent Urination
2. Frequent Snacks
3. Consistent Availability of Sugar Product
4. Variability in Participation when Blood Sugar Levels are Inconsistent

PHYSICAL EDUCATION ACTIVITY CONSIDERATIONS

Physical education activity and sports should be encouraged, as exercise is necessary to help manage diabetes. Exercise allows insulin to work more effectively, thus helping lower blood sugar levels. Ideally, exercise should be performed for 30-45 minutes a day approximately at same time of day and same intensity each day. The best time for gym is soon after breakfast or lunch. Supplemental snacks should be available before, during, or after periods of extra activity, in order to prevent exercise-induced hypoglycemia. Field trips or other prolonged exercise activities require preplanning in order to accommodate food needs.

DIABETES: (Type 1: Insulin Dependent) EMERGENCY PROCEDURES

WARNING SIGNS & SYMPTOMS—HYPOGLYCEMIA

COMMON SYMPTOMS

1. Headache
2. Nausea/Vomiting
3. Irritability/Crying/Confusion
4. Tremors/Shaky Body Parts
5. Cold/Moist Skin

CHILD'S NORMAL SYMPTOMS

TREATMENT

1. Administer a Food or Beverage that Contains a Sugar *Immediately* (e.g., ½ cup juice or soda). Child may need coaxing.
2. Do Not Leave Child Alone until Symptoms Disappear
3. Additional Foods May Need to be Eaten to Prevent Reoccurrence of the Reaction
4. Contact Parent
5. Contact Emergency Room if Symptoms Do Not Disappear within _____ minutes

WARNING SIGNS & SYMPTOMS—HYPERGLYCEMIA (Slow Onset)

COMMON SYMPTOMS

1. Tired/Drowsy/Weak
2. Increased Thirst
3. Increased Need to Go to the Bathroom (Increased urination)
4. Warm/Dry Skin or Flushed Skin
5. Abdominal Pain

CHILD'S NORMAL SYMPTOMS

TREATMENT

1. Contact Parent

IMMEDIATE DANGER: KETOACIDOSIS (Medical Emergency)

SYMPTOMS

1. High Blood Sugar Level (Blood Glucose Greater Than _____)
2. Severe Nausea and Vomiting
3. Severe Abdominal Pain
4. Rapid, Shallow Breathing

CHILD'S NORMAL SYMPTOMS

TREATMENT

1. Contact Parent
2. Contact Emergency Room

Form was individualized by:

Parent's Signature _____

Provider's Signature _____

Date _____

EMERGENCY INFORMATION

AMBULANCE SERVICE _____

NAME

NUMBER

EMERGENCY ROOM _____

NAME

NUMBER

PHYSICIAN _____

NAME

NUMBER

PARENT OR GUARDIAN _____

NAME

home number

work number

ALTERNATE CONTACT _____

NAME

home number

work number

I am aware that if my child has an emergency in school and I am not available, the school principal or alternate will have my child transported to the emergency room.

Signature Parent/Guardian _____

Date _____

Original: School Nursing Copy: Principal Teacher

Chronic Illness Program at Children's Hospital
New Orleans, Louisiana

7-89

F A C T S

JUVENILE RHEUMATOID ARTHRITIS

WHAT IS IT?

JRA is a chronic inflammatory disease of the joints. Arthritis refers to joint swelling and loss of function due to pain and swelling. Despite some similar signs and symptoms, JRA is not a childhood version of adult rheumatoid arthritis. Characteristics of JRA include: fever, skin rash, pericarditis and variation in lab test results.

Children with JRA are at risk of developing iridocyclitis (inflammation of the eye, which develops without warning), and if not detected leads to blindness. Other related problems which may occur without treatment are permanent joint deformities and reduced motor function.

CAUSE

The cause of JRA is not clearly understood, although it has been suggested that an infection or defect in the body's immune system may be responsible. There is also evidence that heredity plays a role in some JRA subgroups.

TREATMENT

Treatment for children with JRA should be individualized and family centered. The number of health professionals working with the family makes it imperative that care be coordinated.

Medical treatment includes the use of anti-inflammatory drugs to control the arthritis and move toward disease remission and a prescribed exercise regimen. Without an appropriate exercise program, rapid muscle atrophy and permanent loss of joint movement can occur. Splints may also be used. The splint maintains joints in good functional position. Splints are most often worn at night, although they may also be worn at school.

PROGNOSIS

Most children with JRA go into remission by the time they reach adulthood.

PROBLEMS FOR CHILDREN

Children with some forms of JRA may miss school frequently. The fevers and rashes associated with JRA are not contagious but may cause irritability and fatigue and prevent the child from being able to attend school. If a child misses more than 3 or 4 days of school due to his or her disease, hospitalization may be necessary.

Other school problems include:

1. Difficulty with speed and quantity of writing.
2. Difficulty using scissors or completing other fine motor activities.
3. Difficulty carrying books.
4. Difficulty with fast movement required between classes or stair climbing.
5. Difficulty staying in one position, i.e., sitting in chair, because of stiffness.
6. Difficulty keeping up in physical education.
7. Difficulty getting dressed or undressed.
8. Difficulty using eating utensils.

PROBLEMS FOR FAMILIES

Chronic illness can be a heavy burden for a family to carry, particularly when the affected member is a child. Everyone in the family may experience some degree of troubling emotions when told that the child has JRA.

Many parents feel frustrated over their inability to relieve the child's pain. They may also find it difficult to coordinate the child's day to include time for doctor's appointments, daily exercises, taking medicine, etc.

JUVENILE RHEUMATOID ARTHRITIS (JRA)

INFORMATION NEEDS

1. Type and Severity (History) of Disease
2. Medications and Side Effects
3. Ambulation/Movement Implications
4. Fine Motor Manipulation (Consider ADL's & Writing)
5. Precautions/Activity Restrictions

SKILL NEEDS

1. Adapting Activities
2. Adapting Equipment for Activities of Daily Living
3. Administration of Medication

COMMON EDUCATIONAL IMPLICATIONS

1. Frequent School Absence
2. Fatigue
3. Activity Restrictions/Adaptation

PHYSICAL EDUCATION ACTIVITY CONSIDERATIONS

Activity restrictions are individualized. Contact sports and sports which stress joints (e.g., jump rope) should be avoided. Encourage regular physical activities that will assist in keeping joints mobile.

ATTACHMENT 2

SCHOOL ACTIVITIES CHECKLIST FOR STUDENTS¹

Please place an

A = always

S = sometimes

N = never

NA = does not apply to me

in the box next to each sentence to describe yourself. It is important that you answer as carefully as possible so that we can understand the problems kids have at school. This will help us make your school experience even better.

- The school system has been very helpful in meeting my needs at school

Getting Ready For School

- I can get out of bed without any help and without holding on to anything
 It takes me less than 30 minutes to feel good after I get up in the morning
 I must take a bath or shower to loosen up in the morning
 I can go up and down the stairs when I first get out of bed
 I can fully dress myself and put my shoes and socks on *quickly* in the morning
 I have a lot of pain in the morning before I go to school
 I do exercises before I go to school
 I need to bring splints, crutches, a cane or a wheelchair to school to help me during the day
 I go to school later in the day than the other kids because of my arthritis
 I take medication for my arthritis before I go to school

Getting to School

- I can *walk* to school or the school bus stop without any difficulty or help
 Waiting for the school bus is easy
 I can get into the school bus without any difficulty
 I need my parents to drive me to school or I take special transportation provided by the school

Activities At School

- I need help dressing and undressing at school
 I can go up and down the stairs quickly at school without any difficulty
 I can open and close the doors at school without any difficulty
 I can use the elevator at school by myself without any difficulty
 I need to get up and walk around in the classroom because of stiffness or pain
 I can carry my own lunch tray
 I need to take my arthritis medication at school
 I get embarrassed when I have to go to the school nurse
 I can use the bathroom by myself at school without any difficulty
 I find it easy to carry my own books at school *and* to and from school

¹ This questionnaire was developed by Diane M. Erlandson, RN, MS, MPH, and is used with permission. © Arthritis Foundation.

Note. From When Your Student has Arthritis: A Guide for Teachers. Reprinted with permission of American Juvenile Arthritis Organization (AJAO), A Council of the Arthritis Foundation.

- I can write at school without any pain or stiffness
- I find it difficult to write quickly
- I need more time than the other kids to take exams or complete homework because of my arthritis
- I find it hard to hold my pen or pencil
- I find writing on the chalkboard difficult
- I find it hard to use scissors to cut
- It is hard to raise my hand in class because of my arthritis
- I find coloring difficult
- I find painting difficult
- I get so tired at school, I want to rest
- I'm afraid that some of the other kids will knock me over
- I get frustrated because I can't always keep up with the other kids
- I find it difficult relating to the other kids at school
- I would like the other kids in my classroom to know I have arthritis as long as they don't treat me differently
- I find it difficult putting on or taking off my gym clothes
- I find it hard participating in regular gym activities
- I get physical therapy at school
- I get occupational therapy at school
- I take a rest period at school
- I get teased at school

I find it difficult to run jump hop skip
 and/or play: contact sports soccer basketball volleyball
 other (name) _____

After School Activities

- I need to take a nap or a rest period when I get home from school
- I can finish all of my homework every night without difficulty
- I can participate in after-school activities without difficulty
- I cannot get through the school day and must go home early

Please answer the following questions:

THE TYPE OF ARTHRITIS I HAVE IS:

- pauciarticular JRA polyarticular JRA Still's disease febrile onset JRA
- Systemic Lupus Erythematosus dermatomyositis scleroderma hypermobility
- other _____

I developed arthritis in 19__

I currently have an IEP (Individualized Education Plan) Yes No

I missed _____ days of school during the school year September ____ to June ____ because of my arthritis.

F A C T S

MECHANICAL VENTILATION

MECHANICAL VENTILATION

Ventilation is the movement of air into the lungs. It can be accomplished through two technologies. Air can be drawn into the lungs through negative pressure ventilation, using an iron lung or a portable pulmowrap. Through this process, the "abdomen and/or chest wall is pulled outward, lowering the diaphragm which pulls air into the lungs. Air is then passively exhaled." Air can also be pushed into the lungs through positive pressure ventilation. When this method is used, air is pushed into the lungs by a mechanical ventilator and then is passively exhaled. Positive pressure ventilation can be delivered through a nasal mask or oral/nasal mask but is most often applied through an artificial airway such as a tracheostomy tube, a hollow tube surgically inserted into the windpipe through a small incision made below the larynx (voice box). Positive pressure ventilators are machines that provide predetermined amounts of air, which enter the lungs in timed and measured numbers of breaths; sometimes the child can initiate the timing or number of breaths required. Some children will require 24-hour-a-day ventilation and others will require less. For instance, some children use their ventilators only at night. Use is determined by a physician and based on the needs of the child.

CAUSE

Mechanical ventilation is required because of the inability of a person to draw air into the lungs or the inability of the lungs to process air once it is there. Children who require ventilation usually fall into three categories: those with traumatic injuries such as spinal cord injuries and chest injuries, those with birth or genetic disorders; and those with neuromuscular diseases.

TREATMENT

Treatment needs will vary depending on the child's condition. Some will require humidification and others will require oxygen enrichment and/or respiratory treatments. Many will also require suctioning. Positive pressure ventilation may bypass the upper airway, including the nose and mouth. Because the nose warms air and acts as a filter, and because the child may not have the muscles necessary to cough independently, the child may need assistance "coughing up" mucus. Suctioning is the process by which mucus is drawn out through the tracheostomy tube using a suction catheter attached to a vacuum pump. Suctioning can also be used to clear mucus in the nose and mouth.

Some children who are ventilated will require other treatments such as bladder catheterization, pressure relief, and gastrostomy feeding for total replacement or supplementation of nutritional needs. The types of treatments the child requires depends on the child's condition.

PROGNOSIS

Prognosis is dependent on the primary condition requiring ventilation as well as other associated health problems. Some children will require ventilation their entire lives. Other children will have increasing or decreasing needs over time, or may be weaned entirely.

PROBLEMS FOR CHILDREN

Children will experience a variety of health problems depending on their primary condition. However, the major problems they face as a result of the ventilator are the effects of isolation. Many community, school and health care providers

overprotect children supported by ventilation and restrict them to protected settings such as hospitals, nursing homes, special education classes or centers. As a result, many children have limited access to their home and friends, community resources such as the grocery store and library, education, recreation and leisure, and vocational opportunities. However, attitude changes and the continued *positive, safe experience* of full inclusion for some children is increasing the availability of home and community settings.

PROBLEMS FOR FAMILIES

Problems for families can be difficult to manage. The financial burden, the medical uncertainty, home care needs, and the time required to coordinate and implement medical/health services can be overwhelming. In addition, families are faced with the shortage of resources, services, equipment, supplies and trained professionals in their home setting. A major support network available for parents of technology-assisted children is SKIP, Sick Kids (Need) Involved People.

Caldwell, T.H., Edaro, A.W., & Gates, A.J. (1991). Special health care needs. In L. Bigge (Ed.), *Teaching individuals with physical and multiple disabilities* (3rd ed., pp. 50-74). New York, NY: Macmillan Publishing Company.

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MECHANICAL VENTILATION

INFORMATION NEEDS

1. Routine treatment regimen (screening checklist attached)
2. Function of equipment and supplies
3. Diet requirements
4. Medications and side effects
5. Warning signs and symptoms of increasing distress and/or an emergency
6. Intervention to prevent an emergency or to handle one once it has occurred
7. Management of emergency backup equipment
8. Other related health information, such as heat and cold tolerance
9. How to access resources, services and technical assistance

SKILL NEEDS

1. Use of equipment and supplies
2. Completion of health procedures
3. Routine checks and troubleshooting ventilation problems
4. Recognition of signs and symptoms of an emergency
5. Use of emergency backup equipment
6. Implementation of emergency procedures
7. Administration of medications

COMMON EDUCATIONAL IMPLICATIONS

1. Impaired motor function
2. Impaired vocalization
3. Preferential seating
4. Use of augmented systems of communication
5. Access to social opportunities
6. Adequate funding for necessary resources
7. Adult trained to provide health care
8. Essential supplies and back-up emergency equipment
9. Procedural safeguards including risk management plan
10. Educationally relevant placement in the least restrictive environment

PHYSICAL EDUCATION ACTIVITY CONSIDERATIONS

Participation in physical education and extracurricular activities should be encouraged. Many children will have associated physical disabilities and will require adapted physical education services. Temperature tolerance range and increased need for humidification outdoors may be factors in participation.

VENTILATION: EMERGENCY PROCEDURES

AUDIBLE OR VISUAL ALARMS ON VENTILATOR

- High Pressure Alarm: Air is meeting resistance and is not reaching the lungs, i.e., a mucus plug in the tracheostomy.
Low Pressure Alarm: There is a leak in the system and the child is not getting enough volume, i.e., the tubing is disconnected.
Treatment: Check the child first! Treatment guidelines, pages 40-46.

WARNING SIGNS AND SYMPTOMS OF RESPIRATORY DISTRESS

COMMON SYMPTOMS

1. Changed depth or pattern of breathing
2. Extreme level of anxiety or fatigue
3. Stridor or wheezing
4. Paleness or blueness of skin
5. Sweating
6. *Nasal flaring
7. **Retractions
8. Increase in heart rate

*Visible movement of the nostrils during attempts to breathe
**Inward sucking of the chest wall visible between the ribs or at the breastbone

CHILD'S NORMAL SYMPTOMS

SIGNS OF SEVERE RESPIRATORY DISTRESS

COMMON SYMPTOMS

1. Generalized blue or black appearance of the skin
2. Lack of response
3. Lack of air movement
4. A decrease or absence of heart rate

CHILD'S NORMAL SYMPTOMS

COMMON PROBLEMS

1. Dislodged tracheostomy Treatment: Refer to page 125 CPG, 1989
2. Plugged tracheostomy Treatment: Refer to page 129 CPG, 1989
3. Aspiration Treatment: Refer to page 127 CPG, 1989
4. Ventilator malfunction Treatment: Refer to pages 40-45 CPG, 1991

EMERGENCY INFORMATION

AMBULANCE SERVICE	NAME	NUMBER
EMERGENCY ROOM	NAME	NUMBER
PHYSICIAN	NAME	NUMBER
PARENT OR GUARDIAN	NAME	NUMBER

home number work number

I am aware that if my child has an emergency in school and I am not available, the school principal or alternate will have my child transported to the emergency room. I will be responsible for all expenses incurred due to this emergency.

Signature Parent/Guardian Date

Original: School Nursing Copy: Principal, Teacher

Parts of this document were revised from *Getting It Started and Keeping It Going*, Children's Hospital, New Orleans, pages 118 and 119

F A C T S

SPINA BIFIDA

WHAT IS IT?

Spina bifida, open spine, and neural tube defect are general terms used to describe a midline defect of the skin, spinal column and spinal cord which occurs during fetal development. There are several different types of spina bifida which are identified by the location and type of defect. Terms that may be used to differentiate among the types include: spina bifida occulta, meningocele, myelomeningocele, spina bifida cystica, spina bifida aperta and myelodysplasia.

Effects of spina bifida on various body systems can be mild to severe. Nerve involvement can affect sensation, motor abilities, and/or bowel and bladder control. Some children will walk independently, while others will need assistive devices. Hydrocephalus (water on the brain) can prevent spinal fluid from leaving the brain and being reabsorbed into the blood stream. If untreated, hydrocephalus can cause pressure to build in the brain, eventually causing brain damage.

CAUSE

The definite cause of spina bifida is not known. There is no clear genetic pattern to the predisposition. Currently, it is believed that there is more than one factor involved. Genetic counseling and prenatal diagnosis are available, although there is no treatment to prevent this condition.

TREATMENT

Health care needs are extensive, but advances have improved the management of ongoing health and medical problems. Management requires the collaboration of many specialists. Initially, surgery is performed to close the open spine defect. Shunts are placed to prevent complications from hydrocephalus. Braces, casting procedures, and/or wheelchairs enable the child to have mobility. Intermittent catheterization can relieve urinary incontinence. Bowel training and diet modifications can help bowel control. Skin care, pressure relief, ambulation, and weight control can relieve problems with pressure sores. Surgery to manage scoliosis (abnormal curvature of the spine) and

other orthopedic problems can be performed. Occupational and physical therapy encourage motor and cognitive development and function. Nutritional management is an ongoing need to prevent obesity. Not all of these interventions will be required for each child and will depend on the child's level of involvement and needs.

PROGNOSIS

Children with spina bifida present complex medical problems that can be managed. The child can become an active, functioning member of society.

PROBLEMS FOR CHILDREN

Most children with spina bifida have no difficulties with intellectual functioning. However, adjustments to school can be difficult because of health care management issues (such as catheterization) and physical differences in participation during the school day. As adolescence approaches, weight management can be an issue. The child must also deal with the peer group, as well as feelings about self as they relate to being different.

PROBLEMS FOR FAMILIES

Unique problems for families include the child's dependence on the parent for bowel and bladder care and hygiene. This dependence can cause problems related to separation and sexuality. Frequently, children will be mobile with wheelchairs but will be dependent on the parents for transportation because of the need for a lift. Spina bifida children are at risk for obesity due to a combination of factors, including limited physical activity and the use of food for recreational activities.

Institute for Public Policy Studies
Vanderbilt University, Nashville, Tennessee
Rev. Chronic Illness Program at Children's Hospital
New Orleans, Louisiana

SPINA BIFIDA

INFORMATION NEEDS

1. History of Illness
2. Predisposing Factors to Urinary Tract Infection
3. Signs and Symptoms of Shunt Malfunction
4. Proper Positioning and Body Mechanics
5. Sensation
6. Complications of Immobility
7. Equipment Needs
8. Medications and Side Effects
9. Temperature Requirements
10. Fluid Needs
11. Diet/Fluid Requirements
12. Warning Signs and Symptoms and Emergency Procedures (Forms attached)

SKILL NEEDS

1. Detection and Interventions to Prevent Urinary Tract Infection, Shunt Malfunction, Skin Breakdown, and Constipation
2. Evaluate and Reduce Environmental Hazards Because of Decreased Sensation (e.g., no scooting on rough floor, wear socks in pool)
3. Pressure Relief Techniques
4. Proper use of Splints, Braces, Wheelchair or Other Devices
5. Administration of Medication
6. Detection of an Emergency and Implementation of Emergency Procedures

COMMON EDUCATIONAL IMPLICATIONS

1. Time and Privacy for Catheterization
2. Increased Fluid and Fiber Needs
3. Assistance with Perceptual and Special Coordination Skills
4. Mobility and Accessibility of Environment
5. Temperature Precautions

PHYSICAL EDUCATION ACTIVITY CONSIDERATIONS

Children with spina bifida can participate in physical activities. Adaptive Physical Education may be necessary for the child. Children with spina bifida are able to go on field trips. If the child wears braces, areas need to be checked frequently for pink marks indicating pressure on the skin. Prolonged temperature extremes may need to be avoided. Skin contact with rough surfaces below point of paralysis should be avoided. Children who are in wheelchairs can be involved in most activities.

PINA BIFIDA: EMERGENCY PROCEDURES

WARNING SIGNS & SYMPTOMS

COMMON SYMPTOMS—Urinary Infection:

- Decreased Urine Volume
- Foul Smelling Urine
- Cloudy Urine
- Unusual Blood in Urine
- Increase in Temperature
- Chills

CHILD'S NORMAL SYMPTOMS

TREATMENT

- Allow to Rest
- Encourage Fluids
- Contact the Parent

COMMON SYMPTOMS—Shunt Malfunction:

- Change in Vision
- Headaches
- Vomiting
- Significant Change in Behavior
- "Sleepy" or "Tired"
- Seizure

CHILD'S NORMAL SYMPTOMS

TREATMENT

- Allow to Rest
- Contact Parent
- Contact Physician
- Implement Seizure Precautions

COMMON SYMPTOMS—Skin Problems:

- Prolonged Redness of an Area (greater than 10 minutes)
- Blistering
- Abrasions/Cuts
- Swelling

CHILD'S NORMAL SYMPTOMS

TREATMENT

- Change Child's Position
- Massage Reddened Area
- Contact Parent

Plan was individualized by: _____

Parent's Signature _____

Provider's Signature _____

Date _____

EMERGENCY INFORMATION

AMBULANCE SERVICE _____

NAME

NUMBER

EMERGENCY ROOM _____

NAME

NUMBER

PHYSICIAN _____

NAME

NUMBER

PARENT OR GUARDIAN _____

NAME

home number _____

work number _____

ALTERNATE CONTACT _____

NAME

home number _____

work number _____

I am aware that if my child has an emergency in school and I am not available, the school principal or alternate will have my child transported to the emergency room.

Signature Parent/Guardian _____

Date _____



Nursing Copy School Principal, Teacher

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Chronic Illness Program at Children's Hospital
New Orleans, Louisiana

2/80

Female Catheterization
A Training Guide
Skills Checklist

Child's Name: _____

Date of Birth: _____

Person Trained: _____

Position: _____

	Demo		Return Demonstration			
	Date	Date	Date	Date	Date	Date
I. Information (Verbal Recall)						
A. Defines - Procedure to empty bladder of urine						
B. Completes at _____ o'clock (In emergency complete earlier rather than later)						
C. Completes where _____ (Consider privacy and access to bathroom)						
D. Position for catheterization:						
E. Identifies Equipment:						
1. Type of Catheter						
2. Lubricant						
3. Urine receiving pan						
4. Cleaning material						
F. Identifies body parts:						
1. Labia Majora						
2. Labia Minora						
3. Meatus						
4. Position of Urethra						
II. Procedure:						
1. Washes hands						
2. Gathers equipment						
3. Positions child for catheterization						
4. Arranges equipment for procedure						
5. Puts on clean gloves						
6. Lubricates catheter and places on clean surface						

Child's Name: _____

Female Catheterization
A Training Guide
Skills Checklist

II. Procedure: (cont.)	Demo	Return Demonstration					
	Date	Date	Date	Date	Date	Date	Date
7. Cleans:							
a. Prepares cleaning materials							
b. Opens labia minora & majora							
c. Cleans from front of folds to back of meatus							
d. Uses swab only once							
e. Wipes a minimum of 3 times							
8. Grasps catheter about 3 inches from tip							
9. Inserts into urethra until urine begins to flow							
10. Advances 1/2 inch more							
11. Allows urine to flow by gravity into shallow pan or toilet							
12. <u>Child Specific:</u> Gently press on bladder to help empty (This information needs to be prescribed for each child)							
13. Removes catheter slowly when urine stops flowing							
14. Stops and waits until all urine has drained if urine begins to flow again during removal							
15. Dries and dresses							
16. Washes equipment and puts used catheter in home container							
17. Reports any problems to parents							

Checklist approved by:

 Parent/Guardian

 Date

Gastrostomy Button Feeding
A Training Guide
Skills Checklist

Child's Name: _____

Date of Birth: _____

Person Trained: _____

Position: _____

	Demo	Return Demonstration					
	Date	Date	Date	Date	Date	Date	Date
I. Information (Verbal Recall)							
A. Defines - Procedure to feed directly to stomach							
B. Completes at _____ : _____ (time)							
C. _____ cc's (Amount) _____ Formula/feeding (Type of feeding)							
D. Feeding to be completed in _____ minutes							
E. Position for feeding _____							
F. Identifies Equipment:							
1. 60 cc catheter tip feeding syringe							
2. Adapter with tubing and clamp							
3. Prescribed diet at room temperature							
4. Tap water							
II. Procedure:							
1. Washes hands thoroughly							
2. Gathers equipment							
3. Positions child							
4. Attaches the adapter to feeding syringe							
5. Opens safety plug and attaches the adapter with feeding syringe to the button							
6. Pours feeding into syringe until about one-half full							
7. Elevates the feeding above the level of the stomach. Opens clamp. Allows feeding to go in slowly 20-30 minutes. The higher the syringe is held, the faster the feeding will flow. Lowers syringe if the feeding is going too fast.							



Child's Name: _____

Gastrostomy Button Feeding
A Training Guide
Skills Checklist

II. Procedure (cont.)	Demo	Return Demonstration					
	Date	Date	Date	Date	Date	Date	
8. Refills the syringe before it empties to prevent air from entering stomach							
9. Flushes the button with _____ cc's of water when feeding is complete							
10. After flushing, lowers the syringe below the stomach level to facilitate burping							
11. Removes the adapter with feeding syringe and snaps safety plug in place							
12. Keeps the child in a feeding position for at least 30 minutes after completing feeding							
13. Washes syringe and tubing with soap and warm water and puts in home container							
14. Reports any problems to parents							

Checklist approved by:

Parent/Guardian

Date

Chronic Illness Program/VACP
at Children's Hospital, New Orleans, Louisiana
1986 (Rvd. 6/89)

Suctioning
Clean Technique
Skills Checklist

For: _____

Person Trained: _____

Position: _____

	Demo	Return Demonstration					
	Date	Date	Date	Date	Date	Date	Date
A. States name and purpose of procedure.							
B. <u>Identifies Supplies:</u>							
1. Suction machine with tubing.							
2. Non-disposable suction catheter with adapter.							
3. Saline.							
4. Cup of tap water.							
5. Resuscitator bag.							
C. <u>Steps:</u>							
1. Assembles supplies.							
2. Washes hands.							
3. Turns on suction machine and checks function.							
4. Removes catheter from storage bag being careful not to touch the last 5 inches of catheter.							
5. Attaches catheter to suction tubing.							
6. Uses resuscitator bag to give 3-5 breaths.							
7. Inserts catheter into trach tube without suction.							
8. Advances catheter to end of trach tube or until child coughs.							
9. Applies suction by putting thumb on adapter.							
10. Twirls catheter between fingers as it is pulled out of trach tube, staying in no more than 10 sec.							
11. Gives 3-5 breaths with resuscitator bag after catheter has been removed from trach tube.							
12. Repeats suctioning in above order (7-11) until secretions are removed.							

Suctioning
Clean Technique
Skills Checklist

	Demo	Return Demonstration					
	Date	Date	Date	Date	Date	Date	Date
13. Uses drops of saline or prescribed solution in trach tube (if secretions are thick), follows with extra breaths, then suction.							
14. Uses different catheter and suction nose and mouth in the same way.							
15. Suctions large amounts of tap water through catheter(s) and suction tubing when suctioning is complete.							
16. Suctions air through catheter(s) to dry it./							
17. Disconnects suction catheter from tubing and stores in a bag or container with a lid.							
18. Cleans and sterilizes catheters as recommended.							

Checklist content approved by:

_____ Parent/Guardian Signature

_____ Date

Summary of Skills Training and Recommendations

_____ Date _____ Instructor _____ Person Trained

Strengths of Trainee: _____

Weaknesses of Trainee: _____

Recommendations for follow-up and further training: _____

Recheck Recommended: _____

Ventilator Assisted Care Program/CIP
Children's Hospital, New Orleans, LA 70118
1987

Tracheostomy Care
Skills Checklist

For: _____

Person Trained: _____

Position: _____

	Demo	Return Demonstration					
	Date	Date	Date	Date	Date	Date	Date
A. States name and purpose of procedure.							
B. <u>Identifies Supplies:</u>							
1. Trach ties or trach tube holder.							
2. Hydrogen Peroxide.							
3. Cotton tipped applicators.							
4. Tracheal gauze or sponges.							
5. 3 clean containers.							
C. <u>Steps:</u>							
1. Assembles supplies.							
2. Washes hands thoroughly.							
3. Positions child.							
4. Removes old trach gauze or sponges from the trach.							
5. Cleans stoma with hydrogen peroxide and cotton swabs.							
6. If trach with inner cannula, removes inner cannula. Inserts sterile inner cannula and locks in place.							
7. Replaces old trach ties or holder with a new one.							
a. Holds flange, cuts old ties and removes or removes holder.							
b. Replaces ties or holder with clean.							
c. Ties ends securely with double knot or secures holder.							
8. Cleans removed inner cannula:							
a. Soaks inner cannula in peroxide and cleans with a small brush, pipe cleaners or cotton swabs.							
b. Rinses with tap water, soaks in 70% denatured, clear alcohol for 20 minutes.							
c. Rinses with sterile water, shakes dry and stores.							

Checklist content approved by:

Parent/Guardian Signature

Date