DOCUMENT RESUME

ED 135 201 EC 093 177

AUTHOR	Rouin, Carole
TITLE	The Deaf-Blind Child and the Nutritionist, the Social Worker, and the Public Health Nurse. Proceedings.
INSTITUTION	California State Dept. of Education, Sacramento.; Southwestern Region Deaf-Blind Center, Sacramento, Calif.
SPONS AGENCY	Bureau of Education for the Handicapped (DHEW/OE), Washington, D.C. Centers and Services for Deaf-Blind Children.
PUB DATE	76
NOTE	16p.
EDRS PRICE	MF-$0.83 HC-$1.67 Plus Postage.
DESCRIPTORS	Conference Reports; *Deaf Blind; Elementary Secondary Education; Health Personnel; Multiply Handicapped; Nurses; *Nutrition; *Parent Role; Preschool Education; Severely Handicapped; Social Workers; *Teacher Role

ABSTRACT

Intended for parents and educators, the conference proceedings focus on the influence of the nutritionist, social worker, and public health nurse on the feeding of the deaf-blind child. Included are entries with the following titles: "Improving Nutrient Supply for Deaf-Blind Children" (J. Heffley), "Nutritional Care for the Handicapped" (M. Chetty), "Caring for the Deaf-Blind Child--Its Effects and Implications for Parents and Professionals" (M. Yu), and "The Deaf-Blind Child and the Special Nurse" (J. Horsley). (SBH)

Proceedings

The Deaf-Blind Child and the Nutritionist, the Social Worker, and the Public Health Nurse

Prepared by Carole Rouin, under the direction of

William A. Blea, Project Director, Southwestern Region Deaf-Blind Center, California State Department of Education; and

Robert Dantona, National Coordinator, Centers and Services for Deaf-Blind Children, Bureau of Education for the Handicapped, U.S. Office of Education

EC093177

This publication, which was funded under the provisions of Public Law 91-230, Title VI, Education of the Handicapped Act, Part C, Section 622, was published by the California State Department of Education, 721 Capitol Mall, Sacramento, California 95814. The activity which is the subject of this publication was supported in whole or in part by the U.S. Office of Education, Department of Health, Education, and Welfare. However, the opinions expressed herein do not necessarily reflect the position or policy of the U.S. Office of Education, and no official endorsement by the U.S. Office of Education should be inferred.

Printed by the Office of State Printing
and distributed under the provisions of the
Library Distribution Act
1976

Preface

Too often we emphasize feeding as a basic skill rather than food as an essential component of health; yet this is one of the areas that must be considered in the total education of the deaf-blind child. Because deaf-blind children are, more often than not, resistant to eating foods beneficial to growth and development, educators and parents must be cognizant of the need to provide them with an adequate diet, not only in quantity but also in quality. Nutritional research has shown that multihandicapped children have some unique dietary requirements which affect not only their personal health but also their learning and social behavior. We as parents and professionals must be aware of these influences.

Nutrition is just one area of information in which the social worker and the public health nurse must be prepared to give guidance to parents. These professionals must be cognizant of all factors impinging on the life of the deaf-blind individual, including their physical, mental, and social-emotional development.

The influence of the nutritionist, the social worker, and the public health nurse significantly overlaps into all areas of programming for the deaf-blind child. This conference was designed to make all of us working with the deaf-blind more aware of this interaction and to encourage parents and professionals to incorporate the knowledge presented here in developing total and effective life programming for the multihandicapped deaf-blind child.

WILLIAM A. BLEA
Project Director
Southwestern Region Deaf-Blind Center

Contents

Improving Nutrient Supply for Deaf-Blind Children

Presented by James Heffley
Head of Nutrition Counseling and Consulting Service, Austin, Texas

Although nutrition for children in residential schools is still not a hotly debated topic, more and more people, both layman and professional, are focusing attention on it. Interest and enthusiasm are growing with the realization that nutrition is subject to improvements, which sometime produce dramatic results.

In the past, it was assumed that nutrition requirements for an individual entailed only an adequate supply of calories and a calculated intake of nutrients to meet the Recommended Daily Allowance (RDA). However, nutritionists now realize that the diet must supply 40 or more essential nutrients in amounts suited to the needs of the individual.

Reasons for Nutrition Deficiencies

Proper nutrition seems to be particularly difficult to obtain for multihandicapped deaf-blind children. Some of the reasons for this difficulty, not all of which apply to every child, are as follows:

1. Deaf-blind children are less active than other children, and therefore consume fewer calories from which to obtain essential nutrients.
2. Deaf-blind children resist chewy or lumpy foods because of preexisting dental conditions.
3. Younger deaf-blind children may still rely on milk from a bottle as their primary calorie source, thereby decreasing opportunities for a varied diet.
4. General lethargy or lack of contact with the environment may fail to sufficiently motivate the deaf-blind child's eating behavior.
5. Teachers may use certain foods as rewards, which will require that these foods be withheld if the desired behavior is not manifested.
6. In residential schools, foods prepared in quantity may not be as appetizing as the home-cooked foods to which the deaf-blind child is accustomed.
7. The taste of some foods may be so disagreeable to deaf-blind children that no amount of coaxing or reward will induce the children to eat these foods.

Another aspect of nutrition which is particularly important for deaf-blind children is the possibility of an inherited high requirement for some nutrients. Although this complication is easy to ignore, its implications in the success of a nutrition program are enormous. When the Food and Nutrition Board some years ago decided to set recommendations in ranges rather than single numbers, it found, unfortunately, that information was not available. The board decided instead to incorporate a safety factor designed to cover the nutrient requirements of the majority of healthy people. Most deaf-blind children would not be considered among the majority of people that enjoy good health, and therefore their nutritional intake safety factor should receive closer attention.

Nutrition Improvement Program

A successful nutrition program for deaf-blind children must ensure that each child receives, either from the daily diet or from a suitable supplement, generous amounts of all known nutrients. Other factors in each child's environment that must be considered in planning the diet include the child's medication, degree of stress, and activity level.

Program Objectives

To accomplish the overall goal of fully adequate nutrition for each child, the following objectives were set:

1. To improve each child's diet by reducing the consumption of refined starchy foods and by increasing the consumption of fresh, wholesome, unrefined foods
2. To devise a suitable supplement program for each child for nutrition insurance

3. To provide inservice training for teachers, aides, houseparents, and cooks in basic nutrition and its practical application

Diet Improvement

To meet the first objective, each child's caloric intake had to be relatively constant, and the following changes were made in the school menu when feasible:

1. White sugar was replaced with molasses, honey, or brown sugar, and the intake of sweets was reduced overall.
2. White bread and white flour products were replaced with unrefined whole-grain products.
3. Canned fruits and vegetables were replaced with fresh fruits and vegetables.
4. Candy rewards were replaced with wholesome foods such as raisins or fruit juices.

A juicer was purchased to increase the intake of fruits and vegetables of children who were formerly bottle-fed and not accustomed to chewing their food. If all food choices were determined to be wholesome foods, the children were allowed, within reasonable limits, to meet their caloric requirements with foods of their own choosing. This practice precluded the serious risk of the children becoming deficient in some of the essential nutrients.

Supplement Program

To meet the second objective, it was necessary to know which nutrients were likely to be deficient in a particular child's diet. A computer-assisted diet evaluation was conducted to measure the average daily intake of all essential nutrients for each child. On the basis of this evaluation, a program was designed to ensure a fully adequate intake of all nutrients, either from dietary sources or from supplements.

A nutrient deficiency in the child's diet does not necessarily mean that the child will have a deficiency for that particular nutrient. The diet history evaluates only supply, while sophisticated blood and urine tests are required to estimate the child's demand.. The child is obviously not deficient until demand exceeds supply. The RDAs are simply estimates of average demand and are not applicable to individuals. However, these recommendations are useful because it is time consuming and costly to determine the demand for a particular nutrient by a particular individual. But, the limitations of the RDAs should be borne in mind when they are used.

The diet evaluations indicated that virtually every deaf-blind child's diet was lacking in vitamin E, pantothenic acid, linoleic acid, zinc, and copper. Additional dietary deficiencies—up to 13 clear-cut deficiencies in one child's diet—were found for most children. Most of the dietary deficiencies were attributed to an inadequate caloric intake, or about two-thirds of the recommended amount, which probably reflects the low activity level of multihandicapped children. Even when the child's caloric intake was lower than normal, the RDAs were met for the following nutrients: protein and all individual amino acids, vitamin B-12, phosphorous, iodine, and cobalt.

The dietary intake of several other nutrients was low, but synthesis by intestinal bacteria apparently provided all of the vitamin K and much of the biotin required by the child. Sunshine can be substituted for vitamin D in the diet, especially in a sunny climate. Also, drinking water in certain areas of the country may provide trace elements. Therefore, when dietary intake does not provide the RDAs of nutrients, other sources may be used to provide vitamin D, vitamin K, biotin, and some trace elements.

The lack of nutrients constitutes a health hazard to deaf-blind children. Among children in the program, the degree of dietary deficiencies varied from an estimated 15 percent niacin deficiency in one child to an estimated 80 percent vitamin E deficiency in all the children. When the children had consumed the RDAs of calories, most of the essential nutrients were furnished at the recommended levels. However, the most frequent cases of dietary deficiency occurred among children who consumed the recommended number of calories but did not receive adequate amounts of nutrients. In these cases the children usually had lower than average activity levels, and the amount of food required to supply adequate nutrients often led to obesity. Therefore, the children's diet had to be supplemented to provide the deficient nutrients.

The supplement program encouraged more frequent snacks, which were tailored to each child's dietary deficiencies. Also, a vitamin supplement was given to the children to ensure that they received abundant amounts of those nutrients likely to be deficient in the general diet. Further, the following changes in the menu were recommended as the result of this evaluation:

1. About one-half of the butter served to the children was replaced with vegetable oil margarine. Vegetable oil supplies more vitamin E

and essential fatty acids than butter, but should not be used exclusively because of a poor ratio of vitamin E to essential fatty acids.

2. More organ meats were included in the menu. A problem of palatability may be encountered with these stronger-flavored meats, but combining them with other foods in casseroles, for example, may be helpful. Most organ meats are good sources of B-vitamins, including pantothenic acid.
3. More nuts and nut-butters were used. Nuts contain many trace minerals in quantity. Although peanuts are inexpensive and typical of other nuts in nutrient content, the exclusive use of peanuts is not advised because variety tends to improve a diet.
4. A larger variety of fresh, in-season produce was used. While iceberg lettuce contains many nutrients in relation to its caloric content, it can be varied with other greens such as spinach, leaf lettuce, and cresses. Folic acid in these vegetables is particularly important for improving the children's diets.
5. More whole-grain products were used. The process used to mill grain tends to deplete many nutrients and trace minerals.

In addition to nutrients, the diets of all children were low in bulk. While bulk is nonnutrient, it is essential for normal bowel function. An increased use of vegetables and whole-grain products will increase bulk.

Inservice Training

Since the teachers, aides, houseparents, and cooks have considerable impact on the diets of students in residential schools, inservice training sessions were considered necessary. Most staff members lack specific knowledge of the principles of nutrition and the application of new nutritional knowledge to the residential school situation. The implementation of a nutrition improvement program requires the cooperation of the entire staff, and cooperation is much easier to obtain when the situation is well understood by all involved. The material covered in inservice training sessions emphasized everyday applicability of the following principles of nutrition:

1. Every person has nutrient requirements which are unique; requirements for one or more nutrients may be far above average for a specific individual.
2. Fresh, wholesome, unrefined food is the best source of all 40 or more essential nutrients; processed foods have lost varying amounts of many essential nutrients.
3. Every person's diet is subject to improvement, either by food choice or by supplementation. Diets commonly consumed in America are usually subject to considerable improvement.

The nutrition improvement program was not an experiment to determine whether improved nutrition would benefit the children; therefore, there is not a formal evaluation of the program. Besides the impressions of the staff that the children were benefited, an increased growth rate of 4.6 percent versus 2.3 percent gain under the supplementation program constitutes the primary indication of benefits attributable to nutritional improvement.

A nutrition improvement program need not be prohibitively expensive. A change in the menu to provide more nutritious foods can probably be accomplished at an additional cost of less than $25 per child per year, and a well-rounded vitamin supplement can be provided for less than $15 per child per year. Both aspects of improving nutrition are necessary to ensure a fully adequate intake of all essential nutrients. The benefits from improved nutrition in terms of reduced medical expenses and improved educational performance are very likely to repay entirely the cost of the program.

Nutritional Care of the Handicapped

Presented by Malini Chetty
Nutritionist, Childrens Hospital of Los Angeles

Adequate nutrition is an important factor in the growth and development of both normal children and handicapped children. For some handicapped children, proper nutrition may be one of the most important factors for survival and for development into useful and productive members of society.

In theory, one of the primary causes of functional retardation is poor nutrition, both in the prenatal and early infancy period. Numerous research studies have emphasized the relationship between nutrition and child development. Evidence is mounting that the nutritional limitation in the mother leaves an indelible imprint on the newborn, resulting in low-birth weight. The low-birth weight infants are more subject to handicaps and, frequently, low IQs.

Effects of Malnutrition

Numerous studies have emphasized the effects of malnutrition on growth and development. Malnutrition causes growth retardation, reduction in brain size and cell number, poor intersensory development, and delays in adaptive and language skills. These effects are more prominent in the younger child. In the older child, malnutrition affects learning power and school performance. Researchers are now able to assess the subtle changes in growth, learning, and behavior that are caused by poor diets.

Types of Malnutrition

Two types of malnutrition are common. One type is primary malnutrition or inappropriate food intake, which may be caused by the following:

1. Lack of knowledge of nutritional principles
2. Inadequate knowledge of the quality and quantity of food
3. Mechanical difficulties with sucking, swallowing, and chewing
4. Behavior problems
5. Low economic status

Secondary malnutrition coexists with some other reason. The food intake may be adequate, but the nutrients do not reach the cells. The reasons for this type of malnutrition are as follows:

1. Genetic defects, where children cannot tolerate some nutrients or need them in abnormal amounts
2. Long-term medication, such as anticonvulsants, which may interfere with nutrient metabolism
3. Malabsorption
4. Physiological stress caused by illness or emotional problems

Feeding Difficulties

In the deaf-blind child the visual and auditory handicaps add yet another dimension—fear of the unknown. Although the nutritional needs of this group of children are not different from those of normal children, they may present feeding difficulties, which in turn reduce nutritional intake. Often, these children are afraid of new foods that are presented to them. They may not accept the transition from pureed foods to a coarser, textured food simply because they are not prepared for these new foods. Extreme patience is needed in feeding these children. The first step might be to have them dip their fingers into the food and then have them lick the food off their fingers with their tongue. Also, the children might find it helpful to smell the food before it is presented to them. The senses of touch and smell should be used in teaching the deaf-blind child whenever possible.

Nutritional Requirements

Blindness or deafness or both are not a disease entity. Varying degrees of these two handicaps occur with many diseases or conditions—the well-known disease being rubella. There is no special therapeutic diet for a deaf-blind child, unless the accompanying disorder warrants such a diet. For all purposes the deaf-blind, like the normal child, needs a nutritious and well-balanced diet that will promote growth and maintain good health.

Nutritional assessment and management are a vital part of the care and rehabilitation of the handicapped. This part of diagnostic work not only helps us to assess the functions at the cellular level, but it could also be used as a basis for planning an intervention. The present tools are not adequate, but in time they will become more and more sophisticated. The nutritionist relies instead on the correlation of several indirect measures, such as nutritional history, including dietary, medical, developmental, socioeconomic data, clinical evaluation, laboratory evaluation, and feeding assessment.

At the present level of knowledge, it can be assumed that developmentally disabled people have the same nutritional needs as normal people. New discoveries of genetic disorders manifested by metabolic disturbances occur regularly. In some metabolic disturbances, diet intervention can prevent mental retardation and/or death. This group represents less than five percent of the developmentally disabled.

Knowledge regarding the special nutritional needs of other identifiable groups is sorely lacking. Researchers have yet to conduct definitive studies that establish different guidelines for use in assessing the nutritional status of these children.

In summary, nutrition not only plays a vital part in the comprehensive care of handicapped children, but it also is an important factor in both the primary and secondary prevention of such conditions.

Caring for the Deaf-Blind Child: Its Effects and Implications for Parents and Professionals

Presented by Muriel Mei-ton Yu
Children's Convalescent Center Inc., Bethany, Oklahoma

Case History of Lori

Lori is a nine-year-old rubella deaf-blind girl. She was born with cataracts in both eyes, profound neurosensory hearing loss, and a heart defect. She is the second and youngest child born to a migratory family in Oklahoma. Her father and mother were 21 and 20 years old, respectively, at the time of her birth. Caring for Lori in the past nine years has produced stressful experiences both for her parents and for the professionals who have attempted to assist Lori and her family along the way.

Even though Lori was a full-term baby, her birth weight was below normal (one of many congenital rubella characteristics), and she had to be kept in an incubator for two weeks. Congenital sensory loss prevented Lori from normal child development, including crawling, sitting up, and walking. Up until a year ago, she had been diagnosed as hyperactive and was unable to control her temper tantrums without medication.

While resources were limited in many ways, Lori's parents persisted in providing her with the best of care. Since her mother is from Oklahoma and her father is from California, the family moves between the two states regularly, and Lori has been in medical centers and special education programs in both states. However, because of her father's inability to maintain long-term employment in one location; most of Lori's training was rather fragmented and superficial. At the age of nine, Lori had virtually no communication skill, uncontrollable temper tantrums, and the social skills of a three-year old.

Deaf-Blind Program

The family moved back to Oklahoma last summer. They enrolled Lori in our deaf-blind program at Children's Convalescent Center as an inpatient because they lived sixty miles away. Of all the deaf-blind children I have seen, Lori comes the closest to reminding me of Helen Keller in the "Miracle Worker." She has long, unruly blonde hair which always hangs in her face. She had no communication skills, so she punched and pulled to get attention, and she threw a fit whenever she did not get her way. In protest at being separated from her family, she refused food completely. This refusal of food caused much fright and concern to everyone. It is important to note at this point that Lori had been placed in another residential school two years earlier and had been sent home after two weeks because of this same behavior.

Educational Training

It was under these very adverse conditions that educational training began. Needless to say, it was trying for our teachers, nurses, and aides, but it was even more trying for Lori's mother. She called long distance every day only to be told that Lori had still not eaten anything. The staff tried to be calm and reassuring, but inwardly they were just as frantic as Lori's mother; perhaps more so. Lori was legally and morally under their care. However, Lori's hunger strike was halted in a few days time, and we now have the opposite problem with her. She will not stop eating, and she is getting fat.

I shall never forget those first agonizing days for Lori's mother. With good rationalization and strong determination, she continued to pick up Lori on Saturdays and bring her back on Sundays, painful as it must have been for her. Given a little encouragement, she acknowledged freely how her days at home had been so unbearable and full of miseries that she sought outside employment to occupy her mind by something other than worry about her daughter. As Lori slowly adapted to her new environment and made good progress, her mother began to relax and relinquish many of her real and/or imaginary concerns about Lori. It is still difficult for her to be separated from Lori during the week, but she no longer stops at the nursing station each weekend to mention one of Lori's ailments and ask for special medical attention.

In the meantime, Lori has progressed cognitively from a two-year-old level to a five-year-old level: has obtained some receptive and expressive language through manual communication; has significantly reduced her temper tantrums; and is engaging in many kindergarten-level school activities. Her parents and the staff can hardly believe she is the same small, unruly girl that she was six months ago.

Challenges and Difficulties

I wish I could end the case here because then we could say all ends well. But the truth is, challenges and difficulties are still ahead. As deaf-blind children grow older, parents will continue to face different phases of the difficult task of caring for a deaf-blind child. Just when things seem to be under control, other types of developments and concerns come into play. With Lori, the concern is puberty. Studies have shown that rubella children enter puberty earlier than normal children, and many have entered puberty at ages eight or nine. Lately, Lori's breasts have started to develop, and she has begun to stimulate herself sexually.

How do you prepare a deaf-blind girl for physical and sexual changes, especially when she has limited language skills? Lori's mother has been worried for some time and has hoped that Lori would have language by the time she entered puberty. That wish did not come true.

Parental Hardships

Is Lori an unusual case, you might ask? No, actually Lori represents hundreds of deaf-blind children, and her parents are representative of a great number who have gone through many hardships in attempting to care for their deaf-blind child.

Let's stop for a moment and try to get a clear picture of all that has been happening to these particular parents. At a very young age, this mother gave birth to a multihandicapped child with serious visual, hearing, and heart defects. Emotional trauma was experienced the moment the child was born. The birth of a child is a momentous occasion to any family, and long before birth the parents who have a handicapped child have their dreams and hopes tossed out abruptly. At the same time, because of their defects, the deaf-blind child requires considerable medical attention, including numerous evaluations and corrective surgery. Clinic and office visits of these children are so numerous that no accurate record can be kept. So Lori's parents, along with many others, are subject to continuous emotional stress because of their child's poor physical condition in addition to the initial emotional trauma of having a handicapped child.

The medical costs as well as prothesis costs for these children are another concern. They are prohibitive for most families with average incomes who might not qualify for welfare or medical assistance. Parents continually have to find additional funds for surgery, for eye glasses, or for a hearing aid. In addition, there is the ever increasing cost for education and remedial programs, such as speech and language or physical and occupational therapy. While the cost of public clinics is nominal, private clinics have higher fees, and parents of deaf-blind children are only too familiar with running here and there to different clinics and agencies to obtain necessary remedial therapy for their children. So, in addition to emotional strain, parents are constantly loaded with financial commitments and burdens.

Assuming that the parents are exceptional in their ability to cope with emotional upsets and are able to meet the overwhelming financial burdens, their quest for care for their deaf-blind child is not yet over.

Since the deaf-blind program is rather new, continuity of programs as well as a total program concept are still in the modifying and revising stage. This causes parents with older deaf-blind children to feel apprehensive and hopeless. Vocational possibilities and marriage are two haunting ghosts from which parents cannot find escape. They also worry about who will take care of their child after they are gone; this is particularly true if the parents are reaching middle age and beyond. With a normal child, the obligation of the parents usually has a termination point, but with a deaf-blind child there is no ending.

Professional's Role

After learning what parents have to go through to provide care for their deaf-blind child, I would like to direct your attention to us, the professionals, who are in the helping role and who by choice or otherwise are involved with these children and their families. What is it like for us to work with these children and families?

I will tell you what it is like for me. First of all, not being the parent of a deaf-blind child myself, I treatment. Since all deaf-blind children require an individually prescribed program, it is essential that parents be included to set mutual goals as well as be informed of any educational plans. One mother, after her child had been in our program for two years, finally said that she felt persecuted the first day she came to the clinic. She sat in the waiting room listening to her five-year-old son screaming and hollering upstairs with the teacher. She was not told what kind of activities her son was engaging in, and, in her rich imagination, she was sure he was being physically abused. Think how much additional stress we, the professionals, were causing this mother when we thought we were being so helpful!

When possible, tangible and concrete support such as financial resources and medical appointments should be provided for these overwhelmed parents. However, there are times when emotional and intangible support is needed and may be of more value. A year ago, for example, a three-year old deaf-blind child was struck suddenly with viral meningitis. The young parents already had had more than their share of misfortunes; this boy had many anomalies from birth, and the father had recurring cancer and was undergoing surgery and treatment. Why meningitis on top of all that? What could I possibly do or say to these parents? I wanted to avoid them, because I felt so helpless and depressed. Instead I went to the hospital and paced the hospital hallways with them, feeling just as saddened as they did, looking at that lifeless little boy struggling so hard for life. When he finally pulled out of it, it was a joyous victory for all of us. Later, that mother said to me, "You really care."

No matter how difficult the circumstances, however wide the distance, and how often I lose my own perspective looking at these families of deaf-blind children, seeing what they have gone through day in and day out, I can truly say, if given similar circumstances, I am sure I would not have done as well as some of these parents have done!

In my sincere wish to be of assistance to these parents, I am constantly reminded of a parent who said, "Nobility is not what parents of handicapped children seek. They seek proper awareness of all people, including professionals, of their capacity to be parents, and of their children even under highly unusual circumstances. They ask that those professionals seeking to help handicapped children take a closer look at how these parents, with less training and more unfavorable hours, manage to live their own lives and enrich the lives of all their children."

The Deaf-Blind Child and the Special Nurse

Presented by June Horsley

ssor, Social Services, Loma Linda Medical Center, Loma Linda, California

Early Nursing Regulations

If one thinks that nurses have a hard job today, then listen to the following job description for nurses put out by the Cleveland Lutheran Hospital in 1887. Regulations required that nurses, in addition to caring for 50 patients, sweep and mop daily the floors in their ward and dust the patients' furniture and window sills. They had to maintain an even temperature in the ward by bringing in a scuttle of coal each day. Because it was important to have sufficient light to observe the patient's condition, they were required to fill the kerosene lanterns, clean the chimneys, and trim the wicks each day and to wash the windows at least once a week.

Nurses reported to work at 7 a.m. and left at 8 p.m. daily, except on Sunday when they were dismissed at 12 noon. Graduate nurses were given an evening off each week for courting purposes or two evenings a week if they went to church regularly. Any nurses who smoked, used liquor, made use of a beauty parlor, or frequented dance halls gave the director of nurses good reason to suspect their worth, intentions, and integrity. Nurses were instructed to set aside a goodly sum of their earnings each payday so that they would not become a burden on society. Nurses who faithfully performed their labors, serving their patients without fault for a period of five years, were given a pay increase of five cents a day, provided there were no hospital debts outstanding.

Modern Nursing Philosophy

But nursing has come a long way from what it was in 1887, particularly in relation to those gray areas that fall between medical practice and nursing skills. In 1955, the American Nurses Association declared that the practice of the professional nurse would include performance for compensation of any act in the observation, care, or counsel of the ill, the injured, or the infirmed; the maintenance of health or the prevention of illness; the supervision and teaching of other personnel, or in the administration of medication and treatment prescribed by a licensed physician. The Association also went on to say that nurses would be trained in the principles of biological, physical, and social sciences, and be well acquainted with the art of diagnosing and prescribing. But some careful delineation needs to be made on what nurses can and cannot do in these areas. On certain occasions, the nurse will be expected, in a professional capacity, to do assessment, diagnosis, and treatment. This is a complex situation, and the legal ramifications can be rather frightening. However, it directly and frequently affects the public health nurse and maternal and child care nurses. Nurses are asked by the community to take almost total care of the population, which means they need medical knowledge as well as social, behavioral, and psychological knowledge.

Changing Role of the Nurse

A number of years ago nurses were told never to diagnose. They were supposed to refer all cases requiring diagnostic work to a doctor. But the day of the nurse-practitioner has changed this somewhat. Nurses are able to do diagnostic and assessment work within their area of specialty, where they have increased training and increased skills as demonstrated by both practice and examination.

The role of the nurse that works with youngsters with multiple handicaps is changing even more. The nurse may be dressed in jeans and riding on horseback to do rural casefinding, or may be traveling in a mobile unit to do screening in county facilities, or may be busy showing a parent some techniques in infant stimulation. The nurse also may be involved in using the Denver Developmental Screening Test out in the community, screening children for hearing, for vision, and for coordination and ambulation. The nurse in this role must have a general idea of the child's developmental state to determine whether the youngster is functioning physiologically, psychologically, and socially. A nurse functioning in this role needs to know child development, both physical and psychological, in addition to the basic nursing skills. Furthermore, the nurse should know of any rubella-related complications so that diagnostic work can be expedited when the child is seen at home or in a clinic.

Frequently, nurses are the first people to see these youngsters, so it is important to do a thorough examination. The nurse must check for abnormalities, risk factors, skin color, muscle tone and posture responses, ambulation, coordination, and dental hygiene. Also, medication must be checked on a regular basis. This covers a lot of material; therefore, the nurse needs to know what to look for when children are seen for the first time.

Where does the nurse start looking at a deaf-blind youngster? The nurse usually starts at the top of the child's head and then works down to the bottom of the child's feet. These youngsters can have complications anywhere along the body. They can have scalp infections, ear infections, sinus infections, and multiple mouth problems. They can also have sensory dysfunctions that involve sensory input and motor output. The nurse should check the reflexes, the symmetry of the face, the symmetry of the different halves of the body, and the development of long and short bones. These youngsters have different developmental stages so that the growing edges of the bones are not as advanced as other youngsters of the same age. Two or three observable abnormalities in this area indicate that the nurse should look for major abnormalities elsewhere, even if they are not readily observable.

The liver and spleen should be checked. Many rubella youngsters have oversized livers and spleens, and this condition should be reported to the doctor.

The nurse should have some knowledge about physical therapy and what kinds of things to do in the range of motion. If the deaf-blind child has tightened heel cords from toe walking, the nurse needs to know how to relax the heel cord. The nurse can at least start exercises until the child can be referred to a physical therapist for regular treatment.

Another area in which public health [illegible] [illegible]t involved with deaf-blind children [illegible] personal hygiene. It is a difficult task for these children, but they can learn with time and with careful instruction to go through these behaviors on a routine basis. The public health nurse also needs to be able to assist parents concerned about explaining menstruation and sex to their adolescent deaf-blind children. Parents need help understanding their child's sexual development. They want to know what to do when their son or daughter begins to masturbate; whether or not they should use the pill for contraceptive purposes; and how to explain inappropriate interpersonal relationships.

Total nursing care includes promoting and maintaining optimal health and well-being for the individual and assisting the family to cope with situations which arise and threaten it as a functioning unit. Facilitation of survival, recovery and growth, and reducing human wastage is all part of improving the quality of total nursing care. I hope this leaves you all thinking of areas where a special nurse can be involved more intensely with deaf-blind children and their families.

Bibliography

Barsch, Ray H. *The Parents of the Handicapped Child: The Study of Child-Rearing Practices* (American Lecture Series). Springfield, Ill.: Charles C. Thomas, 1968.

Chess, Stella, and others. *Psychiatric Disorders of Children with Congenital Rubella.* New York: Brunner/Mazel, Inc., 1972.

Dembo, Tamara. "Sensitivity of One Person to Another," *Rehabilitation Literature,* Vol. 25, No. 8 (August, 1964), 231–235.

Ehlers, Walter. *Mothers of Retarded Children.* Springfield, Ill.: Charles C. Thomas, 1966.

Love, Harold D. *Parental Attitudes Toward Exceptional Children.* Springfield, Ill.: Charles C. Thomas, 1972.

75-214 03—0969 300 6-76 2M