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**GUIDE for
NUTRITION
SERVICES
for MENTALLY
RETARDED
CHILDREN**

U. S.
DEPARTMENT
OF HEALTH,
EDUCATION,
AND WELFARE

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**GUIDE FOR NUTRITION SERVICES FOR
MENTALLY RETARDED CHILDREN**

Prepared by
Nutrition Section
Division of Health Services

U. S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
Social Security Administration
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GUIDE FOR NUTRITION SERVICES FOR MENTALLY RETARDED CHILDREN

Nutrition services are important in any health and welfare program which contributes to the prevention or amelioration, treatment, and rehabilitation of the mentally retarded. For normal growth and development, it is essential first to consider the usual nutritional needs of the child at his particular age, then to consider the modifications required because of the specific illness or handicapping condition which may alter normal food needs and feeding practices.

In some of the specific conditions resulting in mental retardation, such as phenylketonuria (PKU), disturbed metabolism may be a primary factor in causation. Dietary control may, therefore, be a major part of the treatment. In other conditions such as cerebral palsy, the physical disability itself poses certain nutritional and feeding problems; for example, the uncontrollable body motion of athetoids which necessitates a high calorie consumption for simple maintenance. Yet, for this same patient, chewing and swallowing quantities of food may be a laborious and frightening process. Adequate nutrition is also important in preventing some unfortunate sequelae of the primary handicap, such as anorexia and obesity. In addition, economic pressures resulting from the care and treatment of the handicapped child may mean that his family will need food budgeting guidance. These statements illustrate that nutrition services are as important for retarded children as for normal children. Of value in themselves for treating a specific condition, nutrition services often point the way to better overall treatment of the child and can benefit the entire family as well.

This pamphlet was prepared as a guide for use in working with the State maternal and child health and crippled children's agencies on the development of the nutrition component of services for mentally retarded children and their families. The contributions are considered from a broad point of view and not limited to the nutritionists' activities

in relation to special projects. The focus is on a wide scope of services for mentally retarded children in which nutrition has a place, e. g. , child health supervision, day-care centers and other group care facilities, sheltered workshops and crippled children's clinics.

PLACE OF NUTRITION IN SERVICES TO THE
MENTALLY RETARDED AND WAYS IN WHICH A
NUTRITIONIST MIGHT CONTRIBUTE

The services of a nutritionist are available to most health, education and welfare agencies which offer programs and services for the mentally retarded. The nutritionist's participation may depend upon such factors as: her training and experience, readiness of the project or program director and staff to include her as a consultant and/or team member, and the amount of time she can make available.

Since programs vary, the nutritionist may be used in different ways, depending upon the objectives and focus of the specific program. Program areas to which a nutritionist can contribute include:

- A. Program Planning
- B. Diagnosis and Evaluation of a Child's Problem
- C. Treatment and Followup
- D. Training of Professional Staff
- E. Research

Each of these program areas is considered below, and specific ways in which a nutritionist might contribute are suggested.

A. Program Planning -- The nutritionist can contribute to program planning by:

- 1. Surveying needs and resources to outline the job to be done, such as:
 - a. determining the nutritional services needed for the mentally retarded in the community and reviewing how well these needs are being met.
 - b. getting information on the nutrition and feeding problems associated with specific handicaps.

- c. obtaining information on the nutrition and food service component of standards of institutional and day-care services for mentally retarded children.
2. Recruiting and training personnel to provide nutrition services, e. g. ,
 - a. arrange with hospital dietary staff for nutrition consultation to be provided in the out-patient mental retardation clinics either on a referral basis or as a regular service.
 - b. recruit qualified nutritionists for part-time or full-time consultation in clinics, well child conferences, or other services for mentally retarded children.
 - c. assist in the orientation of personnel to the nutrition aspects of the program.
 - d. arrange for informal or formal types of training.
 3. Planning with administrators and program directors for ways to implement the nutrition component of services for the mentally retarded, e. g.,
 - a. discuss with the director of maternal and child health and the director of clinical program the need for nutrition consultation and possible role of the nutritionist in the mental retardation clinics.
 - b. confer with the director of public health nursing about ways to reach public health nurses throughout the State with current information on nutritional needs and feeding problems of the mentally retarded child.
 - c. work with the director of hospital facilities and institutions to plan for dietary consultation which might be needed in group care facilities for the mentally retarded.
 - d. meet with officials of voluntary agencies, such as National Association for Retarded Children and United Cerebral Palsy Association, to discuss ways

in which they could assist in the development of nutrition services in their programs.

4. Determining priorities -- Nutritionists can help the staff decide upon the services in which there is most immediate need for calling attention to the nutrition component, such as deciding whether to first:
 - a. work with parent groups, or
 - b. provide dietary consultation to group care facilities for the mentally retarded.
5. Evaluating the nutrition component -- Activities related to evaluation of special projects and other programs or services for mentally retarded children could include:
 - a. appraising needs for nutrition services in program.
 - b. setting up of short- and long-term objectives for the program.
 - c. thinking through what can be done within limitations of time, staff and other demands for nutrition services.
 - d. recording pertinent information and movement toward goals.
 - e. analyzing with the staff -- needs, gaps, accomplishments, etc.

B. Diagnosis and Evaluation of a Child's Problem -- The nutritionist can contribute to diagnostic and evaluative services and tools in some of the following ways:

1. Case history and records, by:
 - a. assisting in the development of the nutrition component of records and reports.

- b. advising and/or assisting the staff on methods for securing and recording dietary data. As a demonstration for the staff, a nutritionist might take a diet history, obtain information about family food practices, economic resources and the parent's problems in feeding the child, which should be considered in planning a dietary regimen for the child.
 - c. reviewing and summarizing pertinent nutrition information in records. Work with the staff members on the interpretation and use of such data.
2. Other diagnostic and evaluative tools, such as:
- a. acquainting the staff with and helping them to utilize the opportunities which the feeding situation affords for observation of problems and related useful information.
 - b. arranging for the parent to feed the child in a clinic observation room where it might be possible for the team to observe. In other instances, this might be done in the home.
3. Evaluation conferences -- The nutritionist can:
- a. evaluate diet and food habit history, interpret findings to staff, and suggest how the family could be helped with planning a diet to insure nutritional adequacy for the retarded child, e. g., kinds and textures of food, method of preparing, techniques of feeding, and equipment for feeding, and food budgeting.
 - b. interpret the role of a nutritionist in relation to continuing work with the family. Usually, she would advise with the staff members responsible for followup services; but, upon request, where need is indicated, she might give direct consultation or service to the patient either at the clinic or in his own home.
 - c. suggest a local resource person who could assist with the followup on the dietary aspects of the case.

4. Interpretation of findings to parents:
 - a. The nutritionist might, if it seems indicated, participate in this area of service. Usually, the staff member or members responsible for discussing findings with the parents will include the nutritionist's recommendations. If the need is indicated, they would tell the parents of the availability of the nutritionist's services and acquaint them with the kinds of assistance she could offer.

C. Treatment and Followup -- The nutritionist can participate by:

1. helping staff members plan practical ways of assisting the patient and family in carrying out the dietary aspects of the medical recommendations and of home training in the activities of daily living, such as preparation of food and teaching the child to feed himself.
2. providing guidance and consultation to the staff members of the agency or special project on food and nutrition problems related to special medical conditions such as phenylketonuria, galactosemia, cerebral palsy, etc.
3. interpreting need to consider cost of therapeutic dietary regimens and the possible need for financial support.
4. working with administrators and staff members of agencies and institutions concerned with group care to improve nutrition and food service standards and practices. This might involve such group care facilities as: day-care centers, nursery schools, special education classes, sheltered workshops, camps, hospitals, and other types of public and private institutions.
5. meeting with parent clubs and other community organizations to interpret the nutritional needs of mentally retarded children and ways of handling their feeding problems.

- D. Training of Professional Staff -- The nutritionist can contribute in many ways to a variety of training programs, including:

Basic Training -- Nutritionist can work with persons responsible for the basic professional preparation of the various disciplines such as: physicians, dentists, nurses, social workers, dietitians, nutritionists and teachers. There may be a real need to help them recognize and appreciate the development of services to the mentally retarded child, including the nutrition component of such services.

Pre-service and In-service Training -- The nutritionist can contribute to these types of training in some of the following ways:

1. Related to special project, by:
 - a. participating in evaluation conferences.
 - b. giving guidance to project staff on the need for meeting normal nutritional needs of children as well as needs due to special condition.
 - c. demonstrating ways of dealing with specific problems, such as methods of feeding and equipment which might be useful; meal planning and food preparation for the phenylketonuric child.
 - d. interpreting nutrition component of project to groups or individuals in communities (parent groups, professional staff of other agencies).
 - e. preparing teaching materials related to nutrition, such as pamphlets, posters, charts.
2. Related to overall in-service training program within agency, by:
 - a. participating in workshops and institutes, such as those on growth and development, child nutrition, services to the mentally retarded child.

- b. planning and participating in training programs for food service personnel in schools, and other group care facilities.
 - c. keeping agency and project staff aware of current literature and developments in other projects as related to nutrition.
3. Related to training programs of other groups and agencies such as welfare and education departments concerned with services to mentally retarded children, by:
- a. contributing to professional education of teachers preparing for mental retardation services.
 - b. contributing to in-service training programs for caseworkers on nutritional aspects of services to mentally retarded children for which they have some responsibility.
- E. Research -- The nutritionist might function in planning, collecting and analyzing data:
- 1. as an actual member of research staff.
 - 2. in an advisory capacity to a study group.

WHO CAN PROVIDE NUTRITION SERVICES

In any community, the nutrition services for mentally retarded children and their families can be provided as a part of health services in varying degrees by a variety of professional personnel -- the physician, nurse, social worker, physical therapist, speech therapist, occupational therapist, etc. The major responsibility for planning, developing and implementing the nutrition component of services to mentally retarded children, however, usually rests with a "nutrition-trained person." The term "nutritionist" is used broadly in this discussion to refer to a person who might be the nutritionist in an official or nonofficial health agency; the dietitian on the staff of a hospital or other group care facility; or an individual with professional training in nutrition or therapeutic dietetics who is temporarily inactive professionally, but available on a part-time basis.

If a nutritionist is to make a worthwhile contribution to services for the mentally retarded, she will need to understand and appreciate these aspects:

1. the organization and objectives of the specific program to which she gives consultation and how such a program is related to the general philosophy and objectives of services for mentally retarded children,
2. the nutritional problems, the methods and techniques of feeding the handicapped child, and
3. the ways to plan and implement the nutrition component of services.

Many well-qualified dietitians and nutritionists have had little or no experience with mentally retarded children. The specific management of the mentally retarded has generally not been a part of their training. Therefore, a primary need is to provide adequate preparation for nutritionists and dietitians for participation in services for the mentally retarded.

PREPARATION OF NUTRITIONISTS FOR PARTICIPATION IN SERVICES FOR THE MENTALLY RETARDED

Orientation to mental retardation programs and services as well as to the problems, methods and techniques of feeding the handicapped child can be obtained through:

1. talking to nutritionists and other professional workers who have had actual experience in caring for and handling handicapped children.
2. visits to institutions caring for retarded children and observation of the planning, preparation and service of food to these children.
3. visits to day care and other group programs for observation of food service and mealtime activities as one way to learn more about the abilities and special needs of mentally retarded children.
4. home visits with the public health nurse, social worker or other professional members of the team to observe and learn about nutrition and feeding problems encountered by parents and to learn what techniques they have found successful in handling them.
5. attending meetings of parent groups to learn their viewpoint of programs and problems, some of which relate to feeding.
6. attending, as an observer, conferences or other meetings of an agency or project staff when they make plans to implement their services.
7. observing the "work-up" of selected patients in diagnostic and treatment centers including attendance at evaluation case conferences.
8. attending short-term training courses such as those offered at the Mental Retardation Training Center in Tulsa, Oklahoma.

9. attending and participating in State and regional workshops and institutes on mental retardation which are of a multi-discipline nature.
10. reviewing literature to become familiar with philosophy, programs, services, research, etc., in the field of mental retardation.