**Wisconsin WIC CYSHCN Nourishing Special Needs Network Model of Identification and Intervention of Infants and Children with Special Health Care Needs**

**PURPOSE:** The purpose of the Wisconsin WIC CYSHCN Nourishing Special Needs Network is to improve access to nutrition services and support for infants and children with birth defects and other special health care needs in Wisconsin. Building on the existing capacity of the Women Infants and Children (WIC) Program, this Network is facilitating the recruitment and training of a Children and Youth with Special Health Care Needs (CYSHCN) WIC Nutrition Consultant(s) in each Division of Public Health Region.

**Historical Rationale:** The nutritional concerns of children with birth defects and other special health care needs include but are not limited to:
1. failure to grow at an appropriate rate,
2. formula or food intolerance/allergy interfering with the child’s growth and/or ability to consume “regular” formula or foods, and
3. dysfunctional feeding skills or behaviors.

CYSHCN should receive medical nutritional products and be provided with appropriate nutritional consultation in order to improve status, prevent complications and support the family in their efforts to nurture their child. This begins with early identification of nutrition-related concerns and is supported by appropriate referrals and care coordination. This process can be effectively implemented through WIC. WIC staff performs a basic nutrition assessment at every certification appointment (infants: one certification plus a follow-up individual appointment at about 6 months of age: children every 6 months). The WIC assessment includes growth, hemoglobin or hematocrit (starting at 1 year of age), medical and health problems, nutrition history and current eating practices, other health services received (well baby/child, immunizations, blood lead testing, if being seen by other specialist health care providers, etc.), and need for anticipatory guidance. WIC staff may be the first to detect if there is a need for a referral for assessment and diagnosis of a suspected health care need; if one has been diagnosed that warrants additional nutritional assessment and medical nutritional therapy; if a special formula is needed, should be changed based on the actual diagnosis, or perhaps is no longer needed; or if the quantity needed cannot be met by WIC alone. The goals of WIC are to assist in achieving positive changes in food habits and nutritional status and to prevent nutrition-related health problems. This is accomplished by:
1. providing supplemental food including several special and pediatric formulas
2. providing nutrition education,
3. promoting and supporting breast feeding and
4. being an adjunct to health care.

WIC projects are in every county of the state, servicing about 1 of every 2 infants and 1 of every 4 or 5 children under age five. Every local WIC project has a Nutritionist who is a Registered Dietitian and is committed to assuring that all high-risk families receive appropriate nutritional support. However, due to the continually increasing caseloads and the diversity of public health needs which they are addressing, local WIC project nutritionists have limited time to spend facilitating care coordination for CYSHCN. Nor is it the role of WIC to provide case management to this extent. Thus, when a WIC participant with special health care needs is at nutritional risk one of the following may result:
1. families may not get referrals to interventions that would benefit them,
2. there may be a lack of communication between WIC, Health care providers and Birth to 3 resulting in mixed messages, lack of follow-up, or prevention of more severe problems,
3. infants or children may be maintained on inappropriate formulas/supplements, or
4. the WIC nutritionist may be meeting the needs of CYSHCN at the expense of required services.
First Steps: In 2006, to meet the ever increasing demand for nutrition services in the CYSHCN population, the Nourishing Special Needs Nutrition Network was initiated. The original 1-2 WIC CYSHCN Nutritionists in each of the five public health regions developed a system that would address the following:

1. facilitation of referrals to other services including Badger Care, primary care, tertiary care, Birth-Three, economic assistance, Health Check, and registered dietitians providing medical nutritional therapy,
2. communication with families, health care providers or Birth-Three, about special needs or concerns,
3. facilitation of the provision of special infant and pediatric formulas through WIC,
4. collaboration with family, health care provider and pharmacists to ensure documentation for Medicaid reimbursement of nutritional products

Today: The Nourishing Special Needs Network members continue their work within the Wisconsin WIC program which now uses a sophisticated computer system named ROSIE (Real time, Online Statewide Information Environment) for certification and enrollment of participants and for program management. Specific questions to identify and track infants and children with special health care needs and feeding problems were added to the health and diet questionnaires within the ROSIE program. These questions alert WIC dietitians to the need for high risk follow up and modification of the WIC food package for special needs participants. These targeted questions also draw attention to the need for specific referrals to other health and social services available in the state of Wisconsin. Services currently available are Badger Care, Birth to 3 Program, Health Check, regional Children and Youth with Special Health Care Needs (CYSHCN) centers, economic assistance, primary care, tertiary care, and registered dietitians providing specialized pediatric Medical Nutrition Therapy (MNT). To maximize their training efforts, the Nourishing Special Needs WIC Nutritionists developed the WIC-CYSHCN Toolkit in June, 2008. The toolkit is currently under revision by the Network and will soon be available through WICshare with a link to the Waisman Center nutrition resource site. This cooperative and interactive online toolkit will be continuously updated and expanded. It currently includes roles for WIC nutritionists, an identification and intervention flow chart, guidance for ROSIE health and diet questionnaires, references for medical and nutritional conditions, referral forms, special formulas available from Wisconsin WIC, and a directory of agencies and providers specializing in CYSHCN for Wisconsin residents. A mentoring program for interested Wisconsin WIC dietitians is under development. Teleconferences and group trainings are offered to all Wisconsin WIC projects.

The collaboration of the network and the resulting training, data collection, targeted questionnaires, referral documents, and toolkit development helps WIC participants with special health care needs receive effective referrals and services faster. This network also provides WIC dietitians with a framework and support for navigating state and private healthcare provider systems. WIC Nutritionists who participate in the Nourishing Special Needs Network support WIC’s vital role as a partner of healthcare systems in identifying, serving and supporting families with children with birth defects and special needs.