Developed by Susan Willis, MS, RD, CD, CSP, Spring 2009
Vermont Department of Health
Children with Special Health Needs Program

Purpose: Children and adolescents with Autism Spectrum Disorder (ASD) living in Vermont will be offered nutritional evaluation at least yearly to monitor growth, development and adequacy of calories, protein and macro and micronutrients. Nutritional evaluations can be requested by parents of children diagnosed on the spectrum, as well as community and school providers with parental consent. A referral to the Children with Special Health Needs nutritionist in each county can be made through Molly Holland, MPH, RD, State Nutritionist. After completing the required form, Referral for nutrition services, it can be mailed to CSHN, Vermont Department of Health, 108 Cherry Street, PO Box 70, Burlington, VT 05402 ATTN: Molly Holland. Once the referral for nutrition service is requested, the nutritionist in the appropriate county will be notified of the request for service and the nutritionist will make contact to set an appointment with the family. The nutritionist will make an appointment to visit the family in their home or location otherwise determined by the family.

Rationale: To ensure children with ASD are meeting nutritional requirements for growth and to maximize the child’s ability to participate in therapies. Literature suggests children on the spectrum are challenged with selective eating habits and food jags placing them at risk for suboptimal nutrient intake. In addition, parent experiences, made popular by several autism support networks and websites, as well as the Defeat Autism Now practitioners, suggest some children on the spectrum may benefit from dietary modification. Some parents describe noted improvements in speech/communication skills, focus, hyperactivity, night sleeping and the diarrhea/constipation cycle when their child maintained a gluten and casein free diet(1). Dietary modifications such as this, although beneficial in some children are not without risk.

A CSHN Nutritionist can:

• Assist the family in maintaining the appropriate diet while helping to find ways to meet all nutrient requirements. Ensuring children with ASD receive adequate calcium while avoiding casein is essential to long term growth and development.
• assist the family in monitoring food-drug interactions
• provide additional education regarding the use of high dose supplements often suggested in the autism community
• offer education and guidance for the risks versus benefits of high dose supplements; offer guidance for data keeping for monitoring the side effects or improvement of the intended symptom or behavior associated with the supplement
**Scope of Responsibility:** Nutrition evaluations will be conducted by CSHN nutritionists holding a Bachelor of Science degree in nutrition or higher and/or registered by the American Dietetic Association Credentialing for Dietetic registration. CSHN nutritionists are contracted by the State of Vermont to provide services within designated counties throughout the state.

**The following includes but does not limit what can be expected at an Initial Nutrition visit. 2 hours should be allotted for a thorough assessment.**

A comprehensive nutritional assessment includes:

1. Weight and height assessment; comparison of weight to height
2. Detailed diet history and food intake, including a 3 day food record to be completed and sent for analysis to the referring nutritionist prior to initial visit or as decided between family and consulting nutritionist, as well as food preference questionnaire. Diet history will include details of current and past use of vitamin and mineral supplements as well as complementary herbs or supplements.
3. Assessment of past and current meal patterns and behaviors as well as family identified strengths, challenges and concerns around feeding and eating.
4. A review of nutrition/feeding goals in place in IFSP/IEP.
5. A review of available laboratory tests.

Development of an individualized nutrition care plan which includes:

1. A review of the 3 day food record analysis. A computerized bar graph analysis will be provided with recommendations as needed/appropriate.
2. Recommendations concerning implementation of other dietary interventions.
3. Suggestions concerning mealtime patterns and behavior management.
4. Nutrition education and counseling, including suggestions for data collection to monitor interventions before and after implementation.
5. Suggestions for bowel management as needed.
6. Suggestions for appropriate vitamin and mineral supplementation, as well as omega 3 fatty acids. All recommendations will remain below established Tolerable Upper Limits as defined by the Dietary Reference Intakes, National Academy of Sciences. Amounts above said levels will need to be prescribed by the child’s medical doctor or managed by other family trusted provider. The CSHN Nutritionist will document amount taken daily, but will not prescribe/recommend high dose supplements. The CSHN Nutritionist will provide guidance for initiating and monitoring B6/Magnesium supplements if requested by family, however will not prescribe as treatment. All children receiving high dose B6/Magnesium will be recommended for referral to a pediatric neurologist to monitor side effects of B6/Magnesium at least yearly. Side effects of said supplements can be severe and irreversible (2). At the present time there is not a body of evidence to support recommending this as treatment. The AAP asserts "megavitamin therapy as a treatment for learning disorders and psychoses in children, including autism, is not justified on the basis of documented clinical results" (3).
7. Referral to other appropriate services.

A written report will be completed and distributed to the family and designated team members.

A plan for follow-up should be determined at the initial visit. The plan should include whether follow-up will occur in person or via phone and a date should be set one to three months from the initial visit as determined by degree of recommendations for change at the initial visit. Additional follow-up is at the discretion of the family. A child not enrolled in FITP or Medicaid, and who does not have or has not met the CSHN cost share deductible will be responsible for paying all costs associated with follow-up. All initial visits are covered by CSHN. CSHN Nutritionists do not bill insurance but will assist a family in receiving reimbursement as needed. The family should be made aware of this upon scheduling initial visit.

The following includes but does not limit what can be expected at a Follow-up Nutrition visit. This visit should typically take 1 hour.

Follow-up nutrition counseling includes:

1. Monitoring the child’s progress with a review of nutrition care plan suggestions/recommendations.
2. Answering parent questions, providing support and guidance.
3. Helping with identifying strengths and challenges of current intake and mealtime behaviors.
4. Obtaining a 24 hour recall to review for analysis which will be included in the written report provided to family after the visit.
5. Discussing other interventions, behavioral or dietary that were tried since initial visit.
6. Reviewing and revising the nutrition care plan.

A written report will be completed and distributed to the family and designated team members. Additional follow-up should be determined with family with consideration of at least yearly check-ins.

CSHN Nutritionists are available for the following additional services related to food and nutrition:

1. Consultation with child’s school for meal modifications and IEP Nutrition Goals/Objectives.
2. Consultation with school nurse to assist with monitoring growth and development or plan for nutritional supplementation as a medication.
3. Consultation with school OT and SLP’s for strategies for feeding challenges to help incorporate visual schedules, new food introductions and social stories.
4. Attendance at IFSP meetings, transition meetings, medical care conferences, and IEP meetings as requested by family. Children enrolled in FITP or CSHN and covered by Medicaid can have a CSHN Nutritionist in attendance at 2 meetings per year.
References:

