The NAC Pilot Project: A Model for Nutrition Screening and Intervention for Developmentally Disabled Children with Behavior Disorders

Danielle M. Torisky, Ph.D., R.D.[1], Constance V. Torisky, M.Ed.[2], Sidney Kaplan, M.D., F.A.A.P.[3] and Cheryl Speicher, B.S.[4]

Abstract

Eighty-nine autistic and developmentally disabled children participated in a 3-phase pilot nutrition screening project. Dietary, anthropometric and biochemical measures of nutritional status were taken. Food sensitivity testing was included. Elimination diets and food challenge schedules were prepared; behavior was rated separately by parents and teachers during baseline, elimination, and challenge periods. Parents rated behavior as improved more frequently than did teachers. Low nutrient intakes included calcium, folacin, iron, and vitamin B_6; high intakes of sodium, fat and cholesterol were noted, and serum cholesterol levels were above normal for several children. Dietary improvement was observed for 10 of 19 children who participated in more than one phase. Autistic children had fewer average numbers of food choices than did other diagnostic groups. Foods which frequently tested positive for sensitivity included chocolate, cow's milk, peanut, soybean, egg, and corn. Results suggest that with further research, refinement of this protocol could prove useful in identifying dietary factors and nutrition problems to be addressed when planning treatment for behavior disorders.

Key Words

Nutrition assessment, autism, developmental disabilities, behavior disorders, food sensitivity, diet, food-behavior link.

Introduction

Parents, caregivers and educators of children with developmental disabilities and/or learning and behavioral disorders have begun to question the effectiveness and safety of drug treatment for children.[16] There is evidence of a link between certain psychotropic drugs and such side effects as Tardive Dyskinesia[3,7-14] and others,[3,15-17] Adverse interactions between certain psychotherapeutic drugs and nutrient metabolism are well established.[18-21] Prescription of such drugs as Ritalin and Mellaril for young children risks expensive and possibly lifelong addiction to chemical agents which may temporarily *mask* aberrant behavior, but ultimately does not *cure* them. While it is true that in many cases certain drugs and behavioral therapies have been successfully combined with appropriate educational program placement,[422] there are instances in which the prescription of a drug to control behavior is premature, inappropriate,[5] and even harmful.[23"24]

Dietary intervention in treating behavioral disorders has become both an attractive alternative and the subject of uncertainty and debate.[2529] Study of the relationship between nutrition and behavior has been conducted for the past two decades, with inconsistent results.[3031] Dietary factors linked to disorders in learning and behavior[25,29-30,32-34] have led many parents to seek nutritional advice for their children, to either (1) identify a dietary or allergic factor which could be influencing the behavior or learning problem, or (2) determine if their children's eating patterns are nutritionally adequate — or both. Many hope that by correcting the nutrition problem or food allergy, drug usage can be minimized or avoided altogether,[26] with the affected individual better able to control his/her own behavior through wise food choices, combined with counseling and educational techniques appropriate to the diagnosis.

The Nutrition Adjustment Center (NAC) pilot project was undertaken in order to:

(l)Provide a nutrition assessment and

1. Department of Health Sciences, James Madison University, Harrisonburg, VA 22807
2. Umbrella Services for Advancing Autistic Children, Inc., 500-G Garden City Drive, Garden City Plaza, Monroeville, PA 15146
3. 2645 Thorntree Dr., Pittsburgh, PA 15241
4. 1825 Oakwood Court, Lawrenceburg, IN 47025

screening service for families seeking to determine appropriate treatment for behavioral disorders diagnosed in their children,

(2)Create a *procedural model* for this service, focused on autistic and other develop-mentally disabled children and youth to rule out nutrient deficiencies and/or food sensitivities as contributory to aberrant behaviors before implementing drug intervention, and

(3)Document the dietary, biochemical and behavioral data collected during the project in order to guide future research in the field of diet, behavior and developmental disabilities.

A behavior rating and food challenge procedure was employed to address how dietary changes (or adjustments) might affect behavior of children at home and at school. Data were also collected regarding children's health and nutritional status, plus feedback from parents during the project.

Procedure

The NAC project took place in three phases over a four-year period, with some families participating in more than one phase. Eight basic elements of protocol were: (1) recruitment of participants, (2) collection of medical and developmental history, (3) entrance interview with family, (4) complete nutritional assessment, (5) food sensitivity testing, (6) preparation of elimination diet and challenge schedule, (7) behavior rating and challenge procedure, and (8) exit conference with family. See Table 1 for description of NAC staff and their roles. Table 2 presents a summary of project protocol.

Recruitment and Screening

Question and Answer brochures described the project, and outlined responsibilities and anticipated benefits. These were sent to fami-

Table 1. Nutrition Adjustment Center Staff and Their Responsibilities

Title	Description
1. Project director	Oversee, design, and implement project
2. Consulting pediatrician	Oversee medical components, participate in staffings, consult with parents
3. Clinical pediatric psychiatrist	Review and synopsize medical and diagnostic records
4. Clinical allergist/ otolaryngologist	Oversee and implement cytotoxic testing procedure, consult with NAC staff
5. Laboratory technician/ assistant to allergist	Conduct laboratory component of food sensitivity testing, report results
6. Nutritionists - 3	Conduct clinical nutrition assessments, prepare elimination diets, consult with parents, research food content/substitutions
7. Caseworker	Manage clerical component including records, phone contacts to families and schools; conduct follow-up interviews and write reports
8. Computer consultant	Program computer for dietary analysis
9. Nutrition research consultants (university-based)	Interpret biochemical values, make recommendations for biochemical testing
10. Clerical assistants	Type and file reports, forms, and diets, schedule appointments, make phone contacts

Staff deficiencies - needed but not funded

1. Statistician	3. School liaison
2. Behavioral psychologist	4. Family behavior specialist/consultant

lies known to have autistic or otherwise developmentally disabled children. Respon-dees were sent an intake form, to provide general information on the child's diagnosis, specific behavior(s) or other problem relevant to the project. Due to difficulty encountered with several families during Phase I, parents of prospective participants were interviewed by the project director to assess the likelihood of compliance with project protocol. This screening interview was given to all families by Phase III.

Parents completed a comprehensive, 111-item Developmental and Social History Form adapted from that designed by Rimland[35] this provided specific data regarding diagnosis, nature of behavioral disorder, parent recall of child's behavioral development, as well as information concerning the participant's physical health and medical history. Informed consent for participation was also obtained, along with releases for school and medical records to document diagnoses. A summary and analysis of medical and developmental history was prepared for each child's family by project medical staff.

Entrance Interview

Each family was interviewed at the Center, where they completed a Family Survey Form

Table 2. Basic Components of NAC Protocol[1]

Component	Description[2]
(1) Recruitment - Screening	* NAC Q and A brochure * Explanation of project purpose and responsibilities * Personal Screening Interview * Medical developmental history summary & analysis
(2) Entrance Interview	* Family Survey Form Completed including demographic data * Program procedures, tests and scales explained
(3) Nutrition Assessment	* Dietary * Biochemical * Anthropometric/Clinical * Summary and care plan
(4) Food Sensitivity Testing	* Cytotoxic procedure (to be checked by food challenge * 74 foods, 9 colors/additives, 7 herbs/spices, coffee, tea, tobacco
(5) Elimination Diet and Challenge Schedule	* Nutritionally balanced, individualized diet prepared with 7-day menu and snack sheet * Food Challenge Schedule planned
(6) Behavior Rating and Challenge Procedure	* Food challenged on Wednesdays and reactions noted * Behavior rated Fridays by parents and teachers separately (Conner's Scales)
(7) Exit Conference	* Pre-conference summary prepared for physician * Optional for family * Results and information shared, feedback obtained, recommendations made

1. Note: This represents the general sequence of events, in actual practice there was often overlapping occurrence of protocol steps.
2. Developed by Phase III of project.

to provide demographic data. Program procedures, tests and scales were explained during this visit; anthropometric and clinical measures of nutritional status (described below) were also taken at this time.

Nutritional Assessment

Nutrition History. A Food and Nutrition Questionnaire was administered to parents, which included items addressing children's food consumption patterns, mealtime behaviors, presence of nutrition-related disorders (e.g., diabetes, phenylketonuria), and history of known food and nonfood allergies. Portions of the 22-item questionnaire were adapted from an instrument developed at the Pennsylvania State University and described by Raiten and Massaro.[36] Additional information was obtained through a telephone interview regarding food preferences, supplements and medications, cooking facilities, school lunch participation and general lifestyle of the fam-ily.

Dietary assessment. Parents were instructed in keeping seven-day food records for children; these were computer-analyzed for 29 nutrients, and compared to the 1980 Recommended Dietary Allowances (RDA's).[37] Overall dietary adequacy was assessed through calculation of the Nutrient Adequacy Ratio (NAR) developed by Guthrie and Scheer,[38] and was calculated as follows:

$$\text{NAR} = \frac{\text{24-hour intake of nutrient}}{\text{RDA for that nutrient}} \times 100$$

A NAR less than 67% or two-thirds of the RDA was considered as inadequate or low.

Biochemical tests. During Phase I, a university laboratory analyzed blood samples of participants for serum zinc, magnesium and copper, and whole blood lead. Thiamin (vitamin B_1) was evaluated by degree of saturation of the erythrocyte transketolase enzyme, which requires thiamine pyrophosphate (TPP) as a co-factor. Pyridoxine (vitamin B_6) status as assessed using both erythrocyte alanine amino transferase (ALAT) and plasma pyridoxal phosphate (PLP) assay procedures.

During phases II and III, a second laboratory tested for 24 blood parameters; this included serum zinc, magnesium and copper, zinc protoporphyrin as a more sensitive measure for lead,[39] hemoglobin, hematocrit and other iron status indicators, cholesterol, triglyceride, glucose liver enzymes, thyroid hormones, electrolytes (e.g., sodium, potassium), blood proteins (albumin, globulin), blood urea nitrogen (BUN), creatinine, uric acid, calcium, phosphorus, and alkaline phosphatase. TPP and ALAT assays were not employed in Phases II and III, but plasma PLP was retained as a preferred measure of Vitamin B_6 status.

During Phase III, water companies of participants were contacted to obtain current water analysis reports; this was done to identify and consider any substances thought to have possible impact (negative or positive) on nutritional status (e.g., lead, iron).

Obtaining a biochemical profile was done not only as part of a complete nutritional assessment, but also to investigate any metabolic or medical disorders which might be related to behavior, and to help ascertain patterns that might suggest relationships between biochemical indicators and specific diagnostic categories (i.e., autism, ADD) of participants. Of particular interest were iron, vitamin B_6, lead, copper and zinc.

Iron deficiency anemia is one of the most common nutritional disorders among children in the U.S. today.[4041] Low hemoglobin levels and other iron status values have been associated with diminished attention span and poor school performance.[40,42]

Dietary thiamin and B_6 levels were reported to be adequate in a group of autistic children,[43] and while normal blood levels of B_6 were found in one study of schizophrenic, autistic and psychotic children,[44] another found a small group of autistic and learning disabled children deficient in either thiamin or vitamin B_6.[45] Others have found evidence of behavior improvement using B_6 supplements with autistic[46] and B_6 plus niacin with hyperactive[47] children. One investigator demonstrated that vitamin B_6 supplements increased blood serotonin to normal levels in hyperactive children.[48] Thus the controversial question of vitamin B_6 abnormalities and/or above-average requirement (or "dependency") in special populations was considered in the NAC project.

Elevated blood levels of lead have been associated with groups of learning disabled,[49] hyperactive[31,50] and autistic[51] children. Cohen[51] recommended that "all autistic and atypical children should have a blood lead determination

as part of their general medical evaluation." High serum copper levels have been reported in hyperactive[52] and institutionalized mentally retarded individuals who practiced pica (eating of nonfood items).[53] The latter were also reported to have low plasma zinc levels. Massaro et al.[54] found slightly lower plasma zinc levels in learning disabled children when compared to autistic and control group children.

A review of studies employing hair mineral analysis[55] point to a possible association between high levels of lead and cadmium, and deficiencies of other minerals, with accompanying undesirable behavior in certain populations.

Anthropometric and clinical assessment. Anthropometric measurements of participants included height, weight, arm circumference and triceps skinfold. These were interpreted for parents using the National Center for Health Statistics (NCHS) growth charts. Children were examined for overt clinical signs of malnutrition and/or food allergy (e.g., rashes, puffiness under eyes, etc.).

During Phase III the Minor Physical Anomalies inventory developed by VonHilsheimer and Kurko[56] identified facial, head and hand features which have been shown to be associated with autism,[56,60] hyperactivity or "behaviorally disordered",[24,56,58,61,62] and attention deficit disorder (ADD, or formerly "learning disability").[24,56-58]

Nutrition assessment summary and care plan. A summary of nutritional/medical findings and a care plan addressing dietary needs was prepared for each participant, and written in the Subjective - Objective - Assessment -Plan (S.O.A.P.) format.

Food Sensitivity Testing

The cytotoxic method of Bryan and Bryan[6364] was employed in testing participants for food sensitivity; tests were conducted by the staff clinical allergist and a trained laboratory technician. Blood samples were taken from each participant and exposed to 78 antigens (64 foods/food ingredients, nine food colors/additives, three herbs/spices, coffee and black tea). By phase III the battery had expanded to include an additional 10 foods, four herbs/ spices, and tobacco. Blood samples were observed for cell lysis in magnification on a video screen connected to a microscope; sensitivity reactions were classified as marked, moderate, slight, or nonsensitive.

While skin prick and oral provocation are more commonly utilized for testing classic food allergic and pseudo-allergic food additive intolerance, respectively;[65,66] however, NAC staff were concerned that such tests would be too invasive, extensive and possibly traumatic for children participating in the project. The cytotoxic method was selected since it required only a single blood sample to identify a relatively large number of possible reaction-causing food substances.

Preparation of Elimination Diet and Challenge Schedule

The *elimination diet* was a nutritionally adequate, individualized dietary pattern and seven-day menu in which those foods which yielded a positive cytotoxic reaction *in vitro* were omitted. Foods *reported* to cause an allergic reaction were also eliminated, even if they yielded negative results on the cytotoxic test.

Since many of the foods eliminated for six weeks were common sources of key nutrients (e.g., wheat, soy), nutritionists provided appropriate substitutes in order to ensure nutrient adequacy and allow for the children's growth and caloric needs during the elimination period. The food exchange system[67] was used to plan flexible meal patterns which fit the recommended guidelines of 50-60% of total calories from carbohydrate, 12-15% from protein, and 30% or less from fat. Along with the seven-day menu, nutritionists provided recipes and lists of food to be included or eliminated on the diet. A "Special Snack Sheet," modified for each participant according to food restrictions, provided a list of ideas for tasty and nutritious snacks. Each family was given an individualized "how-to" reference and diet manual. This three-ring notebook contained the nutrition summary and care plan, seven-day menu, recipes, snack sheets, and reference handouts on allergy food substitutions and shopping tips. Every effort was made to provide the information and support that the family might need to implement a new and possibly difficult diet for their child.

The six-week elimination diet was followed by reintroduction (or *challenge)* of cytotoxic test-positive foods: A challenge schedule was

prepared for each participant; foods were re-introduced weekly, one at a time, until all had been challenged.

Behavior Rating and Challenge Procedure

On the first day of the challenge period, the first food was given at breakfast, or one half-hour before, in a serving size usually taken by the child. Parents indicated portion size and form of the food (e.g., cooked, raw, mashed). They then noted whether or not an immediate physical (i.e., rash, hives, headache, itching, etc.) or behavioral (see below) reaction occurred after giving the food. If there were no immediate reaction(s) after breakfast, the food was given one hour later, then again with the evening meal, and any reactions noted. This procedure was repeated for up to three days or until a reaction occurred. Whether a reaction occurred or not, the food was discontinued after the third day, and the elimination diet resumed for the remainder of the week. This allowed at least four days of elimination before challenging with the next food.

The Conners Behavior Rating Scales[68,69] were used to assess the behavior of participants during the elimination and challenge procedure - and during a baseline period preceding elimination - by both parents and teachers separately. At home, parents completed the parent Conners Scale, consisting of 93 items grouped in 25 categories (e.g., Problems of Eating, Problems of Sleep, Temper). For each item, the child was rated on a four-point scale (e.g., Item: Throws and breaks things. 0 = not at all, 1 = just a little, 2 = pretty much, 3 = very much). Thus a *low* score on Conners scales was considered desirable.

Teacher Conners Scales were completed by classroom teachers in school or training program settings. This scale consisted of four sections: (a) nature of the child's problem, (b) academic achievement, (c) standardized test results, and (d) any special academic placement. In addition, teachers rated participants on 39 items regarding classroom behavior, group participation and attitude toward authority, using the same four-point scale. (Note: During Phase III, addenda were prepared for both parent and teacher Conners Scales which addressed behaviors unique to autistic and otherwise non-verbal individuals, e.g., fails to establish eye contact, does not attempt to speak, etc. Copies of this scale and its accompanying results may be obtained from the second author.)

All trials began with a baseline period of three weeks, during which participants consumed their original diet, then the six-week elimination diet, followed by weekly food challenge, the total challenge period lasting for as many weeks as there were suspected sensitive foods for the participant.

Average values for both parent and teacher Conners Scale scores were computed for each participant for baseline and elimination periods. *Lower* scores represented more desirable behavior; thus a 25% *decrease* in score values from the baseline average was considered as improvement. Scores were also computed for each food challenge period. A 25% increase from the last three weeks' elimination score average was considered regressive behavior, and suggested an observed reaction to the challenged food. It was intended that parent and teacher observations and comments recorded at the end of each scale would assist in indicating if, and to what extent, any reactions occurred.

Exit Conference

An optional final interview or exit conference was made available for each participating family after all food trials were completed, and results for each case compiled. Both project director and staff physician were present at this interview, during which (a) family feedback was obtained, (b) medical and nutrition information was reviewed and clarified, (c) dietary recommendations were made, and (d) a written summary report was provided, consisting of results compiled and prepared by all NAC staff involved in the case. Upon parent request, copies of this report were sent to physicians, schools, or other educational and health care professionals who were working with their child.

Findings

Sample

A total of 89 individuals initially took part in the NAC project over three phases. Table 3 indicates that for all three phases, roughly three-quarters were male, and most participants were children between 9 and 11 years old. The diagnostic composition of the group varied from one phase to the next, but most

were autistic or had attention deficit disorder (ADD). "Others" included those with Down Syndrome, mental retardation and other developmental disabilities. All participants had a documented behavioral problem. Twenty-two children participated in more than one phase.

The following is a summary of behavioral and nutrition-related findings which merit further investigation. (NOTE: Slight variations in sample sizes for phase and diagnostic group in this section are due to the fact that some participants did not provide data for each component of the NAC procedure.)

Behavior

Improvement in behavior was observed from baseline to elimination periods during

Table 3. Description of of NAC Participants Initial Sample

	Phase		
	I	**II**	**III**
Sample size	57	32	23
Age			
Average age	9.7	10.4	10.9
Age range	2.5-28	3-25	4-26
Gender			
# (%) male	45 (79)	23 (72)	17 (74)
#(%) female	12 (21)	9(28)	6(26)
Diagnosis			
#(%) Autistic	13(23)	15 (47)	5(22)
# (%) ADD	28 (49)	10(31)	12 (52)
#(%) Other	16(28)	7(22)	6(26)

Table 4. Children Showing Improvement[1] on Conners Scales from Baseline to Elimination Period

	Number of scales completed	**Number (percent) children with improved scores**
PHASE I		
Parent scale[2]	48	27 (56%)
Teacher scale[2]	25	8 (32%)
Parent-teacher scale agreement[3]	25	5(20%)
PHASE II		
Parent scale	31	17 (55%)
Teacher scale	26	7 (27%)
Parent-teacher scale agreement	26	5 (19%)
PHASE III		
Parent scale	24	14 (58%)
Teacher scale	21	7 (33%)
Parent-teacher scale agreement	21	3 (14%)

1. Improvement defined as decrease of 25% or more in average Conners scale score, using 3-week Baseline average and average of last 3 weeks of Elimination period
2. Behavior rated separately by parent and teacher in home and school settings, respectively
3. This represents those children for whom improvement was observed by both parent and teacher separately

all three phases. As seen in Table 4, this was more pronounced from the view of parents than from teachers. More than half of the parent scales completed in each phase indicated a 25% or more decrease in behavior rating score. In contrast, roughly one third or less of teacher scales completed from Phase I to III indicated improved scores. A considerable number of teacher scales were missing, since teachers were not always able to complete scales as requested; this suggests that the low percentages obtained for parent-teacher agreement (Table 4) in each phase reflects incomplete data available rather than actual differences in behavior as observed by each group.

In general, average score changes were not significant from elimination to challenge periods, i.e., when suspected foods were reintroduced weekly to participants' diets. This was true for all three phases, but does *not* mean that reactions to specific foods did not occur; written comments from Phase III (reported below) suggest that certain reactions were observed.

Parent and Teacher Observations

Open-ended questions at the end of each Conners Scale enabled many parents and teachers to provide detailed responses during Phase III. Data from this phase were chosen for analysis since procedures by this time were more refined, with comments similar to those received in previous phases. Parent responses fell into the areas of: (1) problems not addressed in the scale, (2) physical and behavioral changes noted during baseline, elimination, and challenge periods, (3) general concerns. Teacher comments addressed: (1) social and academic changes in behavior, and (2) family and other environmental influences which they believed were of importance, and (3) physical changes.

For 23 participants who provided written responses, nine parents noted physical changes during elimination, and 10 noticed physical reactions after food challenges. Changes during elimination included increased or decreased appetite, constipation or flatulence, smoother complexion, and one child with "irregular" breathing (also noted by his teacher) which began during the first week of elimination but disappeared four weeks later. Some physical reactions thought by parents to be the result of food challenges included gastrointestinal symptoms, skin reactions including eruptions and redness/itchiness, dark circles under the eyes, sneezing, headaches, and coldlike symptoms. One child was reported to sleepwalk after a corn challenge, and another developed pica (to his own clothing) following challenge with swiss cheese.

Behavioral changes were reported by parents, and several of these coincided with teacher comments during the same week. Some of these included temper outbursts and occasionally violent behavior. Less extreme changes were problems with restlessness, distractibility, hyperactivity, difficulty concentrating on school tasks, and mood changes (e.g., from silliness and giggling to crying and whining). For some children, undesirable behaviors were pre-existing, i.e., reported by the parent or teacher during the baseline period; these either improved, remained unchanged, or appeared to worsen during elimination and challenge.

Teacher comments did not indicate that they were aware of the nature of the elimination diet nor timing of food challenges. Some expressed doubt or objection regarding the project. Parents indicated varying degrees of difficulty implementing elimination and challenge procedures at home. Some expressed hope that diet intervention would solve longstanding behavior problems; they often associated changes in behavior (and sometimes physical reactions) to particular food challenges. (Note: It was not possible in this study to keep parents blind to diet changes.)

Overall, observations and comments reflected a wide range of views, from considerable doubt to great hope and belief in the efficacy of dietary change in the treatment of behavior disorders. While this necessitated caution in the interpretation of behavior rating scale results, the written data were extremely valuable in providing information and suggesting variables to be included in the refinement of future methods of rating behavior in school and home settings.

Diet and Nutrition

For many of the children who participated in more than one phase of the project, dietary improvement was noted, i.e., the total number of low nutrients found in seven-day diet records decreased from one phase to the next.

Data for 19 of 22 repeat participants (see Table 5) indicate that 10 of the 19 (53%) showed decreases in one or more low nutrients, three showed increases in more than one low nutrient (or a decrease in diet quality), and six showed no change. For the latter group it should be noted that one of these (Participant N) was consuming adequate amounts of all nutrients assessed in both Phases I and II, and two others (E and Q) each had only one low nutrient in both of the phases in which they participated (i.e., possibly "less room for improvement").

The total number of inadequate NARs (Nutrient Adequacy Ratios), and low intakes of other nutrients (e.g., phosphorus, potassium, sodium) with no RDA at the time of the project but each with an Estimated Safe and Adequate Daily Dietary Intake, were tallied for each phase; percentages of children with low nutrient intakes are shown in Table 6. *Over one quarter of the participants in each phase were initially consuming inadequate levels of four or more nutrients in the diet.* The percentage of participants deficient in no more than one nutrient increased progressively from 37% to 52% from Phase I to Phase III. Despite differing sample sizes among phases, this trend may be significant in light of the improvement observed in 19 repeat-phase children, as described earlier.

When the NAC population was considered as a whole, the most prevalent low dietary intakes were found in 7-day food records were for calcium, folacin, iron, vitamin B_6, total kilocalories, fiber, and percentage of total kilocalories from carbohydrates. RDAs for most other vitamins were met by a majority of the population, and protein intake was found to adequate in all but one child. Nutrients

Table 5. Total Number of Low Nutrients in 7-Day Diet Assessment for NAC Repeat-Phase Participants

NAC Participant	Phase I	Phase II	Phase III	(Differences in parentheses) Dietary Improvement[1]	No Change[2]	Decreased Quality[3]
A	4	4			✓ (0)	
B	8	2		✓ (-4)		
C	1	0		✓ (-1)		
D	2	1		✓ (-1)		
E	1	1			✓ (0)	
F	7	2		✓ (-5)		
G	5	14				✓ (+9)
H	2	5				✓ (+3)
I	2	0	2		✓ (0)[4]	
J	1	0		✓ (-1)		
K	13	4		✓ (-11)		
L	2	1		✓ (-1)		
M	10	8	5	✓ (-2)		
N	0	0			✓ (0)	
O		4	4		✓ (0)	
P		3	7			✓ (+4)
Q		1	1		✓ (0)	
R		6	0	✓ (-6)		
S		11	5	✓ (-6)		

1. **Dietary improvement** defined as a decrease in number of low nutrients (i.e., nutrients with NAR of less than 66% or 2/3 RDA for that nutrient) found from one phase to the next
2. **No change** defined as equal numbers of low nutrients found from one phase to the next
3. **Decreased quality** defined as an increase in number of low nutrients found from one phase to the next
4. Average over time was "no change" for this participant

consumed in *greater* than recommended amounts included sodium, cholesterol, and total kilocalories from fat.

Variety of foods in the diet was estimated by tallying the total number of different food items consumed in a seven-day period by each participant. Table 7 shows that for each phase, average numbers of food choices were somewhat less for the autistic group than for ADD or other diagnostic groups.

The most common food craving in the N AC population as a whole was for "sugar and sweets," reported for 34 children over all phases. *Nonfood* cravings were also found (e.g., metal, dirt, clothing, wood, paper, tobacco) for 10 out of 83 participants for whom nutrition history questionnaires were completed. These 10 represented 5 out of 17 (29%) autistic, 4 out of 50 (8%) ADD, and only one of the "Other" participants. It is interesting that while total numbers were small, relatively more of the autistic participants reported nonfood cravings (pica).

Anthropometric data was collected for 94 individuals over all phases (this includes the 89 for whom behavior rating scales were completed). When diagnostic groups were compared in terms of weight-for-height, 73% of ADD children (n = 52) fell above the 50th percentile, while 61% of autistic (n = 23), 72% Down Syndrome (n = 7), and 42% of "Other" children were in this range. Falling between the 5th and 50th percentiles were 27% of ADD, 30% of autistic, one Down Syndrome child, and half of the "Other" group. Falling below the 5th percentile for weight-

Table 6. Percent of Children with Low or Inadequate NARs[1] and Low Intakes of Nutrients without RDAs[2] in Each Project Phase

	Numbers of Low Nutrients/NARs			
	0-1	**2-3**	**4-6**	**7 & above**
Phase I (%) (n = 57)	37	35	17	11
Phase II (%) (n = 32)	43	18	21	18
Phase III (%) (n = 23)	52	18	22	8

1. Less than 2/3 1980 RDA
2. Less than 1980 Estimated Safe and Adequate Daily Dietary Intakes; also includes fiber if less than 5 gram intake, and percent of total kilocalories from carbohydrate if less than 50 percent

Table 7. Average Numbers of Food Choices on Seven-Day Records in NAC Population[1] by Phase and Diagnostic Category

	ADD (n = 55)	**Autistic (n = 28)**	**Other (n = 17)**
Phase I	52.5	47.3	52.6
Phase II	55.6	54.3	58.8
Phase II	58.8	47.6	64.9

1. Sample sizes for each diagnostic category differ from figures in Table 3, since food choice data were taken from all who completed food records, even if behavior rating scales were not completed

for-height were no ADD children, 9% of autistic, one Down Syndrome child, and 8% of "Other" children. While sample sizes for each group are unequal, the data suggest that ADD and possibly Down Syndrome participants were relatively heavier for their heights than the others. Such would be expected for Down Syndrome children, who often have difficulty with overweight and obesity.[70]

Biochemical

The university laboratory employed in Phase I (see Procedure) completed tests on 32 participants. (Four others were unavailable for testing at this lab, and another lab was employed for them; few values were found outside of normal ranges.) Of the 32, nine children (28%) had serum zinc levels above, and eight (25%) had zinc levels below the normal range of 90-120 mcg/dl. The average value was 106.3 mcg/dl. The average serum copper value was 134.2 mcg/dl - at the high end of the normal range of 70-140 mcg/dl - and 11 children (34%) had copper levels above this range. Three had whole blood lead levels above 30 mcg/dl; however, two of these were retested and levels found to be normal. Three children had transketolase (indicating thiamin status) levels in the low range, and seven had plasma pyridoxal phosphate (PLP or vitamin B_6 status indicator) below the normal range.

Differences in average values were examined for diagnostic groups in Phase I; while sample sizes were small and uneven among groups, it was interesting to note that Autistic participants appeared to have higher average serum zinc levels (122.7 ±42.7; n= 10) than did ADD (100.9 ± 14.8; n = 16), Down Syndrome (95.9 ±20.7; n= 3), and "Others" (91.3 ±10.7; n = 3). Serum copper levels were relatively higher for Down Syndrome (146.2 ±31.2) and ADD (139.7 ± 26.6) compared to Autistic (125.1 ±21.7) and "Others" (123.5 ± 33.0). A higher average PLP value was found for the Autistic group (57.0 ± 26.0) compared to the other groups (51.1 ±23.0 "Other," 38.1 ± 17.7 ADD, and 26.8 ± 6.9 Down Syndrome); the higher average for Autistic children may have been influenced by one individual who was taking a vitamin B_6 supplement, and whose PLP value was 120.5 pmol/ ml. There did not appear to be appreciable differences between the diagnostic groups in Phase I for serum magnesium, whole blood lead, and alanine amino transferase.

In phases II and III, a private laboratory was employed; blood samples were analyzed for 37 participants (23 in Phase II, 14 in Phase III) using Chem Screen 24 (see Procedure). Few individuals fell outside of normal ranges for vitamin or trace minerals, including iron status indicators, in either phase. In contrast to the findings of Phase I, no children had serum zinc or copper values outside of normal ranges. However, despite small sample sizes, several above-normal blood lipid components were noteworthy; 19 out of 23 children in Phase II (83%) had serum cholesterol levels above 170 mg/dl; of these, 14 (61%) were over 200 mg/ dl. Similarly in Phase III, 12 out of 14 (86%) had cholesterol above 170, with half of these over 200 mg/dl. Four individuals in Phase II and six (43%) in Phase III had serum triglyceride levels greater than 88 mg/dl. Cholesterol levels of 120-170 mg/dl were recommended for children ages 2-19 years of age by the National Institutes of Health.[71] The American Academy of Pediatrics recommends dietary intervention for children up to 19 years of age with serum cholesterol greater than 176 mg/dl.[72]

When blood cholesterol levels were compared with dietary cholesterol, total fat intake, and percent of kilocalories consumed from fat (Table 8), a pattern was observed which suggested greater amounts of dietary fat and cholesterol were associated with higher cholesterol levels.

All individuals with blood cholesterol values above 170 mg/dl were advised to have further cholesterol testing, including a lipid profile, at a university lipids laboratory after they completed participation in the project. They were also given dietary counseling which focused on "heart healthy" food choices.

Water analysis reports were reviewed for (a) minerals which could contribute nutrients to the diet (e.g., calcium, iron), and (b) elements which might interfere with absorption of nutrients or be toxic (e.g., lead). Levels of minerals and metals reported to be in the water were in very minute amounts; while it was concluded that mineral content of area water did not contribute significantly to diets of participants, future studies of this kind might nevertheless investigate water supplies to rule out toxicity and/or significant nutrient contribution.

Food Sensitivity

During Phase I, 66 individuals were given cytotoxic food sensitivity tests; during phase II, 29; and during Phase III, 25. (For all phases, a total of 120 tests were conducted, which include 23 individuals being tested more than one time.) Most common food substances yielding positive results in Phase I were Red Dye #4 (20% of the group), chocolate, cow's milk, and Red Dye #3 (each 19%). For Phase II, between 21% and 48% of the group tested positive for these same foods, along with peanut, soybean, Yellow Dye #5 and #6, whole egg, and corn. For Phase III, between 20% and 40% of the group tested positive for (in order of decreasing frequency) Red Dye #40, soybean, chocolate, corn, Yellow Dye #5, egg white, cow's milk, peanut, Red Dye #3, and goat's milk.

Discussion

Behavior

At first glance, it would appear that parents noted greater improvement in behavior than did teachers when children began elimination diets, i.e., when suspect foods were removed. It is difficult, however, to compare parent and teacher ratings of behavior for several reasons. First and of statistical concern is the considerable proportion of missing Teacher Conners Scales compared to that of parents. Teachers, while agreeing to rate behavior for the project, may have encountered difficulties completing scales due to other classroom responsibilities and attention to other students. Since parents had enrolled their children in the project, it is possible that some were more eager to complete the scales — and were more *able* to do this, since the child was the focus of their attention.

Secondly, teachers saw participants in a different environment than did parents; the standards for academic/social behavior certainly differ to some degree from the expected and hoped-for behavior at home. Further, the Conners instrument evaluated social interaction behaviors to a greater degree than learning behaviors. Also, children may have conducted themselves differently in the home than they did in the school environment, with its additional social stimuli. Some children may have had access to eliminated foods from vending machines, or traded foods from home-packed lunches, and thereby possibly affecting their own behavior, as well as teacher ratings. Since challenge foods were given in the mornings, it is possible that any effect if present may have dissipated by the end of the school day, when children were to be rated by parents.

Third, behavior improvement for a child with an *initially* favorable Conners Scale score was not likely to be as significant as a more dramatic score improvement for a child with an initially *poor* behavior rating.

Table 8. Serum Cholesterol Levels Versus Dietary Cholesterol and Fat Intake for Phases II and III Participants

Serum cholesterol level (mg/dl)	Number of children	Average dietary cholesterol (mg)	Average fat consumption (grams)	Percent of total kilocalories consumed from fat
Less than 170	3[1]	208±47.3[2] (158 -252)[3]	66.8 ±21.1 (42.5 - 79.0)	36.3 ±6.4 (29-41)
170 - 200	14	316.5 ± 139.7 (95 - 533)	81.0 ± 18.2 (45 - 101)	35.8 ±5.8 (27 - 49)
Greater than 200	20	321.2 ± 167.1 (118-744)	87.8 ±31.4 (31 - 149)	40.8 ±9.1 (31-66)

1. One child excluded due to medication change affecting dietary intake between completion of 7-day food record and blood testing
2. Mean plus or minus standard deviation
3. Range

Fourth, the structure and discipline imposed by an elimination diet may have transferred to other areas of family discipline, with resulting improvements in behavior. This idea is reflected in a work by Satter,[73] who suggested that behavior improvement can occur either due to actual food elimination, or because the child is "impressed by [the parents'] firmness in refusing to give into [his/ her] demands."

Finally, comments and observations of parents and teachers did suggest some pre-existing positive and negative bias toward diet and behavior; in such cases, validity of behavior rating may have been adversely affected. Such bias should be carefully considered and even measured as a variable in future studies of this kind.

Even considering their subjective nature, it is clear from parent/teacher observations that in several cases, dramatic or physical changes did occur during the course of elimination and challenge procedures. In the case of food challenges, which were necessarily conducted one at a time, it is possible that significant score increases (suggesting positive reactions) could

have become statistically "lost" in the average challenge score. Further, a single food challenge - even if it were positive - might have less overall impact than would several suspect foods consumed together, and therefore produce a less detectable reaction. It should also be considered that the Conners Scales themselves may not be well-suited for measuring behavioral *reactions* of nonverbal and/or autistic children.

Diet and Nutrition

While a majority of children who participated in the pilot study were well-nourished in terms of recommended amounts of protein and most vitamins, one-fourth of each phase population was initially deficient in four or more key nutrients - including calcium and iron. The latter have been found to be deficient in other pediatric populations, including teenagers.[7476] Results here suggest that these nutrients — along with folic acid, vitamin B_6, percentage of total kilocalories from carbohydrate, and fiber — are also worthy of attention for nutrition educators serving similar developmentally disabled populations.

Over half of the children who participated in more than one phase of the project showed an improvement in dietary intake - this could be attributed to several factors. First, a nutritionally adequate elimination diet plan was provided by staff nutritionists, especially in cases when multiple foods were to be avoided. Nutrition counseling focused on U.S. Dietary Goals. Further, parents' recording skills on seven-day food records may have improved from Phase I to later phases. Finally, increasing attention to food and nutrition through the NAC pilot project experience may have resulted in better nutrition for the whole family. Such an effect might be investigated in a future study.

Dietary improvements observed also raise an interesting question: when behavior improvements *did* occur for dietary reasons, how many were due to the elimination of suspected foods rather than to overall improvement of an initially deficient diet? Ruling out the latter factor would be helpful in future investigations.

Findings indicate that autistic children chose relatively fewer food items in their diets than did other diagnostic groups. In a study by Massaro et al.,[54] parents' perceptions of autistic children's food choices were described as "preferring the same foods at mealtimes," a pattern not observed in the control group. Raiten and Massaro[36] later reported more ritualistic behavior at mealtime for autistic children when compared to controls. More surveys are needed to determine if and to what extent such an eating style can result in a rigid and/or limited diet for autistic individuals.

A relatively higher number of autistic children in the former study[54] exhibited evidence of *nonfood* cravings (pica) than other children. While numbers were small, it is interesting that a 33% incidence of pica was reported in the autistic group, compared to 3% in the control group. Further research is needed to determine if a relationship exists between pica and any biochemical and/or behavioral disturbances unique to autistic individuals.

Autistic children in the NAC population tended to be lighter in weight and shorter in height compared to NCHS growth charts, and relative to ADD children. This observation agrees with that of Massaro et al.,[54] who found learning disabled children to be taller, and autistic children shorter, than age-matched

controls. Further investigation into the growth of autistic and other developmentally-disa-bled children may be warranted to determine if these findings are the result of nutritional inadequacies, biochemical dysfunctions unique to the diagnosis, or even medications which could be interfering with growth.

Of special concern was the high intake of dietary fat, cholesterol, and sodium in the project population—this in combination with less than recommended intakes of fiber and carbohydrate (including the complex type) suggested a diet less than optimal in promoting cardiovascular health. Further, the children in phases II and III who had moderate to high serum cholesterol levels also had higher average dietary fat and cholesterol intakes (Table 8); since a relatively large proportion of these children *did* have high cholesterol levels, similar populations might benefit from the attention of nutrition and cardiovascular health educators. They might advise families in practicing dietary and lifestyle habits which promote cardiovascular wellness, and assist special school food services and institutions in planning heart-healthy menus for students and staff.

The higher average serum zinc levels found for autistic children in Phase I were in agreement with the findings of Massaro et al.;[54] however, while they reported higher average serum copper for autistic children in their sample, the average values for copper were higher for ADD children in the NAC population.

Food Sensitivity

While there are limitations associated with the cytotoxic food sensitivity methodology, several of the foods — particularly chocolate, cow's milk, peanut, corn, soybean, and egg — have been cited by others[77-80] as having produced sensitivity reactions in individuals. It is also interesting to note that in many cases food *colors* elicited positive test results, in light of the theory of Feingold.[81]

During and since completion of the NAC pilot project, it has been recognized that truly accurate diagnosis of food allergies, sensitivities, and intolerances remains somewhat elusive; this is due in part to the complex pathophysiology of food-induced reactions, which include both allergic and pseudo-allergic mechanisms.[82] Results from some immunological studies suggest that the phenomenon of white blood cell autocytoxicity may be linked to the action of Immunoglobulin E (IgE),[83] as well as other non-IgE mechanisms,[84,,86] in the presence of specific food antigens. In these studies, cell autolysis was assessed quantitatively by uptake of trypan blue (TB) dye, which suggests a more objective clinical measure of food-induced cytotoxicity (especially if confirmed by food elimination and challenge procedure). Perhaps greater potential exists for the future use of cytotoxic testing of food sensitivity than has been previously considered.

Implications for Future Research

Refinements in design and methodology we recommend for future studies include the following:

1. Limit scope of the study to two or three distinct diagnostic groups, e.g., autistic and ADD (now termed ADHD) without a mixed "other" group.

2. Include an age-matched control group of children without behavioral disorders for comparison of dietary, biochemical, and anthropometric parameters.

3. Conduct the study in a school district wherein support can be enlisted from the school dietitian and foodservice manager, in order that special diets can be subject to greater control in the school setting. A social worker on staff could serve as a liaison between parents, teachers, dietitian/foodservice staff, and investigators. (Some parent and teacher comments indicated misunderstanding of basic nutrition concepts; the school dietitian could play an important role in communicating the principles of good nutrition, the nature of elimination diets, and the challenge procedure — all without divulging the experimental timing of any particular case.)

4. Seek more standard and sophisticated analysis of blood components which are of interest and concern (e.g., cholesterol, vitamin B_6); if the study is longitudinal, select a single university laboratory for all analyses if funding permits.

5. Employ *two* food sensitivity measures — one to cross-check the other — and continue to follow with elimination and challenge procedure. A double-blind procedure would be made possible through the use of standard food antigen capsules during the challenge phase (here particular attention should be paid to issues of investigator

liability, informed consent, etc.).

6. If pica emerges in a particular group, investigation of any relationships between such behavior and unusual biochemical parameters might be warranted.

7. Revise and expand the behavior rating instrument to include (1) specific behaviors unique to the diagnostic group(s) being examined, and (2) physical as well as behavioral changes or reactions.

8. Pre-existing views concerning food and nutrition, and family factors of interest (e.g., support, conflict) might be assessed separately using appropriate measures during the recruitment and screening period, and included as study variables. It is recognized that certain family factors can impact on the dietary practices of family members,[87,95] and at the same time, that families of autistic and develop-mentally disabled children face unusual stresses and challenges.[96] For instance, to what degree might parental authority be compromised owing to a child's particular handicap?

Recent national emphasis on nutrition services for children with special health care needs has focused on programs which are "coordinated, interdisciplinary, family-centered, and community-based";[100-101] future studies could more closely examine the effectiveness of nutrition education efforts and interventions which target special populations, within the context of such unique family environments.

NAC sought both to provide a comprehensive service not available locally, and to develop a model for nutrition screening and intervention for developmentally disabled children; assessment and intervention methods changed and evolved as the pilot study progressed. Results strongly suggest potential benefit of such a service to participating individuals and their families, in terms of improved food choices, nutritional status, and possibly behavior change. This warrants further investigation and refinement of the model, so that in cases wherein nutritional deficiency and/or food sensitivity is suspected, (a) appropriate nutrition intervention might be incorporated as an adjunct to existing behavior management programs, and (b) drugs might be more appropriately prescribed *after* ruling out nutrient deficiencies and/or dietary factors.

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