Dietetics in Developmental and Psychiatric Disorders (DDPD®)
A dietetic practice group of the American Dietetic Association
Winter 2005
Volume 23, Number 3

In This Issue

Diet and Autism: A Historical Perspective of the Opioid Excess Theory
Cathy Zwick, MA, RD, CD

Autism Spectrum Disorder (ASD), a complex neurological disorder affecting social interaction and communication, has caught the attention of the medical community due to the alarming number of cases being diagnosed. There is no cure, no current FDA approved medications, and although there are treatments showing promising results, there is no one recommended course of intervention at this time. Unfortunately there is a discrepancy between the number of autistic children being diagnosed and the number of medical professionals to assist in the treatment of these children. As a result, parents are often forced to do their own research and are sometimes accused of turning to unconventional treatments. The gluten free casein free (GFCF) diet is just one example of a treatment often singled out due to what some may think is a lack of supportive research. What is often not known by the medical community, however, is that there is a history of supporting research for dietary intervention in Autism and other neurological disorders. It is also important to note that Celiac Disease can have associated neurological symptoms that can be alleviated with a strict adherence to a gluten free diet as reported in a 1966 study. This early research connecting neurological conditions with diet eventually led to the Opioid Excess Theory, the most widely accepted and plausible explanation as to why the GFCF diet has merit for individuals with ASD. This theory has, thus, been the basis for much of the research that has led to the recent popularity of this dietary intervention in Autism. The possible connection between neurological conditions and diet intensified when researchers began an in depth look at Schizophrenia and how diet may play a role in its treatment. In 1966, a subgroup of schizophrenic patients was found to be sensitive to a component in cereal grains. Later studies, continuing to look at Schizophrenia, a disorder that was once confused with ASD, supported these claims and proposed that the removal of two common dietary proteins found in grains and dairy products produced an improvement in problem behaviors. These early studies were crucial because ASD was not fully distinguished from Schizophrenia until 1971 and, although they are today two distinct diagnoses, there are some overlapping symptoms especially in the areas of social functioning. Finally, in 1971, a study of autistic children was published which showed a correlation between ASD and nutritional malabsorption, as well as to sensitivities to foods, specifically gluten. A connection...
Children of Children with Special Health Care Needs in collaboration with the Pediatric DPG was debuted at FNCE. This publication is designed to be a practical resource for practitioners that may see a small number of children with special health care needs in their practice setting, as well as a manual for those who work in these settings on a daily basis.

The ADA Quality Management Committee has approved for DDPD to develop Registered Dietitian Standards of Practice and Standards of Professional Performance in Behavioral Health Nutrition Care. Committee members are Terry Girard Anderson, Renee Hoffinger, Paula Kerr, Maria Soler, Susan Zabriskie and myself. Ellen Pritchett, ADA’s Director, Quality and Outcomes, is assisting us. The development of these Standards of Practice will define the basis of competent Behavioral Health Nutrition practice, reflect current, evidence-based practices, encourage consistency in Behavioral Health nutrition practices, and be the framework upon which future DDPD DPG education projects are based to challenge registered dietitians to move beyond experience-based practice to reach a higher level of evidence-based practice. If you have any questions or concerns about this project please do not hesitate to contact one of the members or myself.

Susan Zabriskie is working on a group home menu project. Rosalind Wilkins, Chair of Nominating Committee with her nominating committee has developed a position statement that falls here in New England. I know there is a lot of activity within DDPD underway and I encourage all members to be involved.

The Handbook is designed as a resource for any nutrition professional who works with children with special health care needs. I often refer to my original copy of the Handbook, and look forward to using the updated information. The handbook is $30 for ADA members and can be ordered from ADA’s Member Service Center at 800.877.1600 ext. 5000 or through ADA’s Web site at http://www.eatright.org/Public/ProductCatalog/104.cfm.
Adverse Food Reactions with Special Emphasis on Food Allergy, (audio) ADA 1994 Annual Meeting.


The Function of Dysfunction, (audio tape) Monika Woolsey, 1999 SCAN meeting session recording about Axis II disorders and counseling clients with these type of diagnosis.


DDPD Advertising Policy

The Dietetics in Developmental and Psychiatric Disorders Dietetic Practice Group accepts advertisements for our newsletter, Developmental Issues, under these guidelines:

- Advertisements will be limited to products and services that are of interest to our members, consistent with the goals for the dietetic practice group, and which promote sound nutrition of the patients we serve.
- We reserve the right to evaluate all statements in advertisements and to refuse to accept any copy that does not follow guidelines established through the American Dietetic Association.
- We require the following disclaimer in each issue of the newsletter: "The publication of an advertisement in Developmental Issues should not be construed as an endorsement of the advertiser or the product by the American Dietetic Association or this dietetic practice group.
- Rates: $2500 to sponsor an entire issue (which includes recognition at our Annual Meeting, a full page ad, a recognition notice, and on year complimentary subscription) $ 500 for a full page $ 350 for a quarter page $ 250 for a quarter page $ 125 for an eighth page (business card size).
- Published: Dietetic Practice Group members are entitled to a 20% discount.
- Advertisements may be submitted any time and advertisers will receive notification of acceptance within 30 days of submission, at which time scheduling for placement will be arranged.
- Advertisements must be received in camera-ready form by the designated deadline for publication along with payment in full made payable to The American Dietetic Association/DPDG 812 and sent to: Melisa Altman-Truth, Newsletter Editor, NutriSolutions@aol.com, 1556A Stoney Lane, Philadelphia, PA 19115. Phone: 215-969-0652.

DDPD A/V Library continued

pyramid choices appropriate for recovering substance abuse clients.

Fetal Alcohol Syndrome. (13 min video) National Health Video. Describes how alcohol affects unborn child; no known safe level of alcohol during pregnancy.

Psychiatric Resource

Skill Development: Assessing the Nutritional Status of the Elderly, (audio, 3 tapes) 1991 ADA Convention Panel: Includes as of lab data for screening; effect of pre-scription and non-prescription drugs; implications in malnutrition; application for dietitians in assessment of institutionalized and non-institutionalized elderly.


continued from page 1

tion between neurological disorders and diet was strength-ening as success was being reported with dietary interven-tions excluding gluten and casein.

Another component, which provided fuel for the Opioid Excess Theory, was the idea that unusual brain opioid activity might be causing problem behaviors typically seen in individuals with ASD. This idea strengthened when an animal study postulated that the injection of opiate drugs produced some of the same and most common behavioral problems seen in the disorder.1 This at first seemed to be an unusual correlation; however, if autistics were acting like opioid addicts, the study raised the question as to whether or not the opioid system was involved in the etiology of ASD. Around this same time, a case study, believed to be the first document attempt to determine the effect of food on autistic behavior, was also published showing that wheat and oats had long-term effects on the behavior of an autistic child.2.3 It seemed as though these fragmented, early studies had common relevance. They all revealed an interesting connection between neurological disorders, diet, and the opioid system of the brain responsible for certain problematic behaviors.

Although many of the earliest studies did not look at ASD specifically, they set the groundwork for future studies that later identified the neurochemical theory, known today as the Opioid Excess Theory, introduced by Jaak Panksepp in 1979.4 Because opiates are addictive, this could explain why so many children with ASD are self-limiters and eat only a handful of foods as if they are addicted.5.6 Another recent study reported behavioral and gastrointestinal improvements on a gluten free, casein free, and soy free diet in 56 of 61 participants with ASD.7.8

In addition to the behavioral consequences, the GFCF diet also addresses the gastrointestinal symptoms commonly reported. In addition to the behavioral consequences, the GFCF diet also addresses the gastrointestinal symptoms commonly reported.
a cure for ASD but rather have introduced an option for parents when considering treatments for their children. The anecdotal reports that have often been described as not being scientifically based, are, in fact, very important and must not be overlooked. Parents should not be dismissed, as they are vital members of the team of experts that is required in the care and treatment of any individual with ASD.

Unfortunately Autism is a highly stigmatized disorder, but parents and professionals are discovering daily that proper intervention can allow these individuals to reach their fullest potential. Autism deserves the attention of the medical community and nutritional professionals should play an important role in the treatment of these children as a GFPC diet, although challenging, can provide the essential nutrition that is often lacking in autistic children. While it is crucial to demand and evaluate science behind any diet, any parent will tell you that their child’s success on a GFPC diet, whether it is an improvement in behaviors, intestinal health, or nutritional status, is all the scientific proof they need.

REFERENCES:

DDP A/V Library continued

3. Feeding and Swallowing:
   Parents perspective on deci-sion to place a G-tube and life after placement of G-tube.

Mothers of Developmentally Delayed/Special Needs Children Talk About WIC, etc. (video, 1 hour) Texas Department of Health, 1994. Interview of moth-ers explaining situations and feel-ings associated with assistance program/oflevance.


Nutrition for Infants and Toddlers with Special Needs.
   (video, 24 min and viewers guide) University of Colorado School of Nursing, 1989. Basic nutrition, feeding plans, relationships.

Feeding Infants and Young Children with Special Needs.
   (video 26 min and viewers guide) University of Colorado School of Nursing, 1989. Techniques to alleviate feeding problems of specia-l needs clients.

 NIHANES III Anthropometric Procedures. (video, 30 min) CDC/NCHS. Outlines standard anthropometric procedures. Explanation and demonstration only.

The Missing Link. (video, 17 min and training guide) Frances Stern Nutrition Center, New England Medical Center Hospital, 1996. Designed to help Early Intervention professionals appreci-ate the importance of nutrition and feeding concerns in children with special health care needs.

Consuming Concerns—
   Nutrition Concerns in Early Intervention. (slide/20 min training guide) Frances Stern Nutrition Center and Eunice Kennedy Shriver Center UAP, 1996. Inversecive training on specif-ic nutrition issues and concerns of special needs children from birth to 3 years of age.

Marketing MNT to MCOS. (Written material, audio and slides) Workshop 3/17/96 ADA & Ross. Background/program and presentation resources.

Winning the Managed Care Game. (Written material, audio and slides)


Part 2. Food Processing Techniques, Thickeners, Recipes, Panning, Plating.


SUBSTANCE ABUSE RESOURCES

Assessment for Alcohol Exposure in Utero: Diagnostic Implications for Fetal Alcohol Effects & Fetal Alcohol Syndrome. (video, 30 min) The Shriver Center—Massachusetts Department of Mental Retardation. Very specific and thorough tech-niques and methods of identifica-tion; recommendations for contin-uum of assessment and care.

Substance Abuse & Nutrition. (20 min video & written materials) National Health Video. Explains how substance abuse may lead to malnourishment; vitamin & miner-al depletion; appetite loss, poly-drug use; immune system effects; role of nutrition in the recovery process tailored to food guide.
DDPD A/V Library continued

building routine by students with developmental disabilities.


Home Gastrostomy Care for Infants and Young Children. (video 27 minutes, manual test pkg.) University of Colorado School of Nursing. 1989. Principles, techniques, ADL’s.

Assessment of Growth and Development. (video) William Chumlea, PhD Cincinnati Production. Demonstration of anthropometric measurement and explanation of developmental physical expectations.

Dimensions of Feeding Techniques. (3 tape video series—30 minutes each) Rosalind Benner, RN ORDER SEPARATELY
1. Chewing & Swallowing— the basics
2. Feeding the patient
3. Progressing to independent feeding.


Nutrition Assessment of Children with Disabilities. (video 60 minutes) Boling Center for Developmental Disabilities, University of Tennessee at Memphis. Copyright 1988. Hosted by Elizabeth Emerick, MS, RD, Nutritionist. All aspects of nutrition assessments for children with developmental disabilities including behavioral, clinical, feeding skills, and biochemical aspects of assessment are reviewed on the VHS tape.

When Feeding is a Problem. (video, 15 min) The center for Human Nutrition, Omaha, Nebraska, 1990. The VHS tape presents a basic introduction to aspects of oral motor feeding problems such as tongue thrust and lip retraction.

Oral Structure, Swallowing and Digestion: Normal and Abnormal. (video, 16 min) Texas Department of Mental Health and Mental Retardation, Austin, Texas, 1991. The VHS tape presents an overview of the basics of swallowing; provides demonstrations of dysphasia in adults with developmental disabilities.

A History of Mental Retardation. (video, 17 min) The Shriver Center—Massachusetts Department of Mental Retardation, 1989. Presented as “progression of time” through modes of thought treatment of MR. Excellent resource for staff, students, and professionals new to the field of MR.


New Direction in Dysphagia. (audio) Hartlage, Panther & Lewis. 1992 ADA Annual Meeting. Case studies and applications at a facility. Details diet, with some emphasis on fluids, compliance after discharge.

A New Home. (audio) Lewis, Garfield, Hunter, 1993 ADA Annual Meeting. The shift of services of patients with development delay and psychiatric disorders away from hospital or institutional setting to community-based facilities is reviewed.


and cannot serve new patients. For those individuals who are able to locate alternative health care, Medicaid expenses would probably increase for transportation.

Federal

Support Needed for the Newly Introduced Direct Support Professionals Fairness and Security Act

Many dietitians in the DDPD Practice Group train direct support staff who assist people with severe disabilities to prepare and to eat meals. Proper training makes direct support professionals key to initiating dietary changes and initiatives in their homes and communities. Support staff hourly wages are low while the job is often very demanding; consequently a high turnover rate is common. Many of the direct support professionals seek less demanding jobs in fast food and retail industries instead. This attrition causes a cycle of ret raining for the di etitian. Such turnover decreases in clients’ nutrition al gains, which could jeopardize the client’s health.

The Direct Support Professionals Fairness and Security Act, H.R. 5197, has been introduced in the House of Representatives by Reps. Lee Terry (R-NE) and Lois Capps (D-CA). It would provide funds to States to enable them to increase the wages paid to targeted direct support professionals in providing services to individuals with disabilities under the Medicaid program. The new Act will contribute to an improved national policy on the financing of long-term services and supports, which may include a salary increase for direct support staff. Take the initiative and contact your representative to urge him/her to co-sponsor the Direct Support Professionals Fairness and Security Act and/or when it is reintroduced in Congress. The Act will ensure that persons with disabilities will be better served by a direct support staff providing continuity of care. This is more likely to occur when wages are fair.

Statewide

New York – Health Services in Jeopardy for People with Developmental Disabilities

The NY State Department of Health is proposing rule changes that would effectively close part-time Article 28 clinics (including all part-time clinics serving children and adults with developmental disabilities). Full-time Article 28 clinics would then need to expand to cover the patient load; however, most expansion has been halted. Additionally, switching to Article 16 clinics wouldn’t provide the same range of medical services, not to mention that most already have waiting lists.
I arrived at our DDPD Executive Committee meeting on Saturday, October 2, only slightly late - getting from the East Coast to Anaheim in the morning proved to be a challenge for several of us! It was good to meet some of the newer Committee members in person. We had a chance to catch up on progress as a DPG, and begin to look forward towards next year.

While I always knew there was lots of networking going on at FNCE in addition to the many educational sessions, I never realized until this year just how much went on behind the scenes. As a past Newsletter Editor and Treasurer, I only knew there were training sessions to help people in those position get a better grip on needed skills, but that was just the tip of the iceberg!

As the Chair-Elect, I was also invited to participate in several meetings, and really enjoyed the opportunity to do so. I wanted to give at least a short report back to you, DDPD members, so let you, too, know some of the information behind the scenes. So let me tell you about a few meetings. (1) DPG Best Practices Forum, (2) DPG Foundation Lunch - to discuss endowments, and (3) DPG Chair, Chair-Elect/PD meeting

DPG Best Practices Forum

The Best Practices Forum met during a light lunch. It was a chance for the DPG Chairs and Chair-elect to get together to discuss best practices. There was a brief time for general networking as lunch was served beginning at 12:30, and the planned program agenda did not begin until 1:00.

The planned agenda was introduced by Lori Porter, Director of ADA's Practice Team. Speakers were officers from a variety of the DPGs. They offered examples that their practice groups had found beneficial in relation to several areas (noted below). We also had a chance for discussion (questions and answers) on each topic:

- DPG membership recruitment and retention
- Recruitment and retention are a concern for all the DPGs - which each exist to provide services to their members and to help keep the particular interests of the DPG’s members in mind for planning ADA’s strategic goals.
- Successful FNCE Program Planning
- Getting started early seemed to be the key point - especially for proposing a priority session and funding it! Also scheduling other meetings, which might include an Executive Committee meeting, breakfast or evening reception or other networking opportunities for the DPG members.
- Strategies for securing sponsorship and advertising funds
- Money is always needed: for meetings, for member resources, to bring in speakers, provide receptions and networking for DPG members, develop educational materials, expand newsletters, etc. Several of the DPGs have a specific person delegated to this task, such as a Fund-raising Chair or a Coordinator to develop partnerships with companies related to the practice of the DPG.
- One of the discussion topics was that some DPGs are more “allied” to some funding sources than others because of the nature of the group: The Diabetes Care & Education dietetic practice group came to mind - companies that provide medical supplies or food items aimed at diabetics are an easier connection and tie-in. Some of us, and I think our DPG is included, need to work a little harder to find these connections.
- Successful collaboration between DPGs
- Sharing resources was the key here - for example, several of the DPG’s join together to offer a big evening reception for members could pool their resources, and they spoke about their experiences, both good and bad - it requires a lot of coordination and preplanning! (Our DPG has done this in the past - both for FNCE program planning and for member receptions.)

DPG Foundation Lunch

The ADA Foundation invited us to a luncheon to explain what the ADA Foundation does as the philanthropic arm (501(c) 3) of ADA, to recognize the DPGs who currently offer scholarships or awards through the Foundation or who are 21st Century Club members, and to share their plans for the future and opportunities for partnership.

From the Foundation’s report: “What does the ADA Foundation Do?” their mission is to improve the nutritional health of the public by focusing on three things:

1. gving scholarships and awards to dietetics students and professionals.
2. funding dietetic research by dietetics professionals.
3. promoting healthy weight for kids public awareness program.”

New ADDITIONS

Kathryn Mosley’s presentation at the DDPD Breakfast Meeting October 4, 2004 entitled: “Phenylketonuria: New Approaches and Insight Treatment”. Also available is a 5 minute video that shows a woman with PKU who was untreated and severely affected and had been institutionalized for over 40 years with no treatment. The woman had significant behavioral issues, including head banging and out of control behavior. After her placement into a group home dietary intervention began. She was weaned off all of her medications and her behavior improved significantly. The video shows her behavior before treatment and four years later - coming in a trip to Disneyland. The video is in a CD form that plays on an IBM compatible computer.

Eating Disorders Resources


Gentle Eating, (audio 3 tapes) Marel Hanson, MS, RD. A new approach to disordered eating.

Eating Disorders: Interventions and Guidelines, (video, part 1 is 80 min, part 2 is 62 min) From ADA Seminar, LaRue Carter Hospital, August, 1993.

DEVELOPMENTAL DISABILITIES RESOURCES

The Fitness Program, (video 2 tape series & teaching guide) ORDER SEPARATELY. Fitness for all, exercising safely & effectively, fitness testing, fitness can be fun, fitness routines, teaching strategies, aerobic and muscle...

DEVELOPMENTAL ISSUES
Information about the Foundation is available at www.adaf.org

Suggestions for DPG involvement included: letting members know about the Foundation’s activities, contributions to an existing scholarship or award or to establish a new one, contributing a basket to the Silent Auction, making a donation to honor a colleague or the memory of someone, making a donation to the research endowment and healthy weight for kids initiative and encouraging participation of DPG members in FNCE events: buy tickets to the Gala, participate in the 5K run, yoga, or the Silent Auction.

DPG Chair, Chair-elect, and PID meeting

An afternoon meeting was also arranged for the DPG Chairs, Chairs-elect, and the Professional Issues Delegates (PID). We had assigned seating in a roundtable format, so DPG and PID could be seated together. We were provided an update on ADA services and new initiatives, including generational diversity and the strategic goals of ADA. Then, each table was given a large note-taking pad and the task to discuss one or two of the following topics (their choice) and provide feedback to the entire group. These topics/questions included:

1. DPG/PID Relationship
   a. Fall HOD Meeting Outcomes
   b. Current PID/DPG Structure/Process (evaluate how the process and structure of the PID/DPG system is working as it relates to professional issues being represented in the HOD)

2. DPG support of the Association’s diversity initiatives - brainstorm methods of how to support the Association’s diversity initiatives

3. Current projects to benefit the Association based on the ADA Strategic Plan

4. Professional Issues which will impact the Association

After a good time of talk and brainstorming at each table, the entire group then heard from a spokesperson from each table who summarized the results and discussion at each table. The time was extremely informative and also very hopeful about the use of diet in behavioral management with adults with PKU.

Counseling Tips for Nutrition Therapists

Molly Kellogg, RD, LCSW
Tip #9 - Dealing With Resistance

It is frustrating when our clients do not appear to accept responsibility for their behaviors or do just the opposite of what we know is good for them. It may be helpful to look at the issue from the perspective of resistance.

What does resistance sound and look like?

• “Yes, but…”

• “Well, I guess I could try.”

• The client returns for the next visit and has not done what you thought he had agreed to.

• The client does not return for a scheduled visit.

• Body language that looks like reluctance.

Resistance is what happens when we expect or push for change when the client is not ready for that change. Resistance is not something that exists in clients in a static sense. It arises as a normal, expected product of the interaction between the therapist and the client. One way we are asking. The reasons may not be clear to us or to the client, but they exist. Ignoring them gets us nowhere.

Ways to lessen the chances of eliciting resistance:

When we emphasize personal choice and control, resistance will be minimized.

Examples:

• When working with bulimics to brainstorm other ways to manage control, mirroring ambivalence, and working with experiments so the client can make some gains towards a larger goal.
cope with strong emotions, urging them to include binging and purging as one of the options demonstrates their degree of choice.

• When clients want to pursue a behavior you do not believe will work or disapprove of, before putting in your opinion, begin with: “That is one of your choices.”

• I often use this approach when clients are berating themselves. I don’t believe self-criticism helps at all, but arguing with them tends to bring up resistance. I begin with, “you can choose to call yourself those names and focus on what you dislike about yourself. Does it lead to the results you want? If not, would you be interested in other ways to talk to yourself?”

• When addressing lack of a change you expected, be willing to look at what happened without judgment: “Oh, that’s interesting! I wonder how that came about.”

Our clients’ behaviors are indeed much more in their control than in ours, so it makes sense to acknowledge this out loud and get back to what we can do to help them reach their goals. Unless they have contracted with you to be their food police and follow them around all day, leave them with the choice and control and stay in a consultant role.

Another important strategy is to track closely a client’s readiness and check in along the way. (See Tip #7 archived at www.mollykellogg.com) Carefully exploring how important the change is to her and her confidence in doing it can save time and aggravation later.

Approaching each possible behavior change as an experiment (see tip #3) can lessen the chance that resistance will emerge. When you take that approach, the only accountability clients have to you is to run the experiment. You are not asking them to commit to the change forever.

How to respond once resistance surfaces: The general approach that works here is to back off and come alongside your client. The sooner you catch it and come alongside your client, the sooner you can help them work through it. The general approach that works here is to back off and come alongside your client.

Some thoughts about eating disorders:

With eating disorders the ambivalence about change is often deeper, and more subconscious than with medical nutrition therapy clients. There may be significant medical consequences of the client’s choices and their families feel a strong temptation to push. Control issues often are a central theme in the psychological picture of an eating disorder. It’s clear why resistance can be powerful.

Work with this population demands that we pay careful attention to not provoking resistance. No matter what we do it will still come up. We will be most effective if we clearly acknowledge resistance as soon as it comes up and then work with it. Fighting an eating disorder head-on always leads to failure. Finding ways to come alongside eating disordered clients is one of the most challenging and gratifying aspects of the work.

When resistance doesn’t surface:

There may be a few clients out there for whom plain old accountability really works. These tend to be the clients who are clear about the importance of change, and have confidence. They just need input on how to accomplish it. All they need is someone to report to and help with making plans for the next step. After a while the changes become habit and they end with you. Boy, those clients are great and every now and then, we get lucky and one walks in.

Hope this is helpful.

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• I see; you really do hate gyms. Since you would like to be more active, would you like to brainstorm other ideas together? (Acknowledging the resistance and coming alongside)

• I sense you aren’t ready to work on this right now. That’s fine with me. This is your session. (emphasizing personal choice and control)

• Thanks for reminding me that we need to do this in ways that will work for you.

• When addressing lack of a change you expected, be willing to look at what happened without judgment: “Oh, that’s interesting! I wonder how that came about.”

• Our clients’ behaviors are indeed much more in their control than in ours, so it makes sense to acknowledge this out loud and get back to what we can do to help them reach their goals. Unless they have contracted with you to be their food police and follow them around all day, leave them with the choice and control and stay in a consultant role.

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How to respond once resistance surfaces: The general approach that works here is to back off and come alongside your client. The sooner you catch it and respond by backing off, the sooner you two can get back to work. As long as you push when resistance is present the work will get nowhere.

This may sound like:

• I can tell I’ve gotten us off track here. Can you help me review what is important to you right now? (Going back to checking on importance and meaning)

• I agree, there’s no point in trying something that’s not going to work. (mirroring client’s low confidence to change)
cope with strong emotions, urging them to include bing and purging as one of the options demonstrates their degree of choice.

• When clients want to pursue a behavior you do not believe will work or disapprove of, before putting in your opinion, begin with: “That is one of your choices.”

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This may sound like:

• I can tell I’ve got us off track here. Can you help me review what is important to you right now? (Going back to checking on importance and meaning)

• I agree, there’s no point in trying something that’s not going to work. (mirroring client’s low confidence to change)

• I see; you really do hate gyms. Since you would like to be more active, would you like to brainstorm other ideas together? (Acknowledging the resistance and coming alongside)

• I sense you aren’t ready to work on this right now. That’s fine with me. This is your session. (emphasizing personal choice and control)

• Thanks for reminding me that we need to do this in ways that will work for you.

Some thoughts about eating disorders:

When eating disorders the ambivalence about change is often deeper, and more subconscious than with medical nutrition therapy clients. There may be significant medical consequences of the client’s choice, and their families feel a strong temptation to push. Control issues often are a central theme in the psychological picture of an eating disorder. It’s clear why resistance can be powerful.

Work with this population demands that we pay careful attention to not provoking resistance. No matter what we do it will still come up. We will be most effective if we clearly acknowledge resistance as soon as it comes up and then work with it. Fighting an eating disorder head-on always leads to failure. Finding ways to come alongside eating disordered clients is one of the most challenging and gratifying aspects of the work.

When resistance doesn’t surface:

There may be a few clients out there for whom plain old accountability really works. These tend to be the clients who are clear about the importance of change, and have confidence. They just need input on how to accomplish it. They need someone to report to and help with making plans for the next step. After a while the changes become habit and they end with you. Boy, those clients are great and every now and then, we get lucky and one walks in.

Hope this is helpful.

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Information about the Foundation is available at www.adaf.org

Suggestions for DPG involvement included: letting members know about the Foundation’s activities, contributions to an existing scholarship or award or to establish a new one, contributing a basket to the Silent Auction, making a donation to honor a colleague or the memory of someone, making a donation to the research endowment and healthy weight for kids initiative and encouraging participation of DPG members in FNCE events: buy tickets to the Gala, participate in the 5K run, yoga, or the Silent Auction.

An afternoon meeting was also arranged for the DPG Chairs, Chairs-elect, and the Professional Issues Delegates (PID). We had assigned seating in a roundtable format, so DPG and PID could be seated together. We were provided an update on ADA services and new initiatives, including generational diversity and the strategic goals of ADA. Then, each table was given a large note-taking pad and the task to discuss one or two of the following topics (their choice) and provide feedback to the entire group. These topics/questions included:

1. DPG/PID Relationship
   a. Fall HOD Meeting Outcomes
   b. Current PID/DPG Structure/Process (evaluate how the process and structure of the PID/DPG system is working as it relates to professional issues being represented in the HOD)

2. DPG support of the Association’s diversity initiatives - brainstorm methods of how to support the Association’s diversity initiatives

3. Current projects to benefit the Association based on the ADA Strategic Plan

4. Professional Issues which will impact the Association

After a good time of talk and brainstorming at each table, the entire group then heard from a spokesperson from each table who summarized the results and discussion at each table. Everyone had written on, and kept additional notes, so we hope that information from this session can - and will! - be used by ADA.

If you have any particular questions about any of the above, please ask me - email works well, but you can leave a message on my phone, too.

I appreciated the opportunity to represent DDPD at these meetings, and really learned a lot about how DPG’s work, and how we can all work together to increase our visibility and worth as dietetics professionals.

Counseling Tips for Nutrition Therapists

Molly Kellogg, RD, LCSW

Tip #9 - Dealing With Resistance

It is frustrating when our clients do not appear to accept responsibility for their behaviors or do just the opposite of what we know is good for them. It may be helpful to look at the issue from the perspective of resistance.

What does resistance sound and look like?

• “Yes, but...”
• “Well, I guess I could try.”
• The client returns for the next visit and has not done what you thought he had agreed to.
• The client does not return for a scheduled visit.
• Body language that looks like reluctance.

Resistance is what happens when we expect or push for change when the client is not ready for that change. Resistance is not something that exists in clients in a static sense. It arises as a normal, expected product of the way we are asking. The reasons may not be clear to us or to the client, but they exist. Ignoring them gets us nowhere.

Ways to lessen the chances of eliciting resistance:

When we emphasize personal choice and control, resistance will be minimized.

Examples:
• When working with bulimics to brainstorm other ways to control, mirroring ambivalence, and working with experiments so the client can make some gains towards a larger goal.

DDPD also sponsored a member breakfast with Kathryn Moseley, MS, RD from the Children’s Hospital of Los Angeles speaking to us about the phenylketonuria (PKU) diet in the adult client. She presented the history and specific metabolic pathways that are blocked in PKU and its manifestations. Ms. Moseley told the audience about the differences between the phenylalanine (Phe) restricted diet and the new therapy using large neutral amino acids (LNAA). The PreKunil tablets contain LNAA which cross the blood brain barrier and has been shown to decrease brain Phe and allow for utilization of the other LNAA needed for protein and neurotransmitter synthesis. The treatment requires taking approximately ten tablets three times each day with meals and minimal protein restriction.

She discussed the challenges of diet adherence with children after the age of six to eight years old, due to high cost, need to prepare most foods at home, and restrictiveness of diet. She discussed the use of biochemical tests such as the phenylalanine/tyrosine ratio and use of Phe test kits for monitoring blood levels. She discussed the potential for finding patients initially diagnosed with PKU and now non-compliant with the diet. She showed a video (which is available at http://www.pikutext.com) that shows a woman with PKU who was untreated and severely affected and had been institutionalized for over 40 years with no treatment. The woman had significant behavioral issues, including head banging and out of control behavior. After her placement into a group home dietary intervention began. She was weaned off of all her medications and her behavior improved significantly. Kathryn discussed the pending studies with B4H therapy in the US to help individuals with PKU be able to metabolize Phe. This presentation was extremely informative and also very hopeful about the use of diet in behavioral management with adults with PKU.
Report From the Chair-Elect on FNCE Activities
Lee Shelly Wallace, MS, RD, LDN, FADA

I arrived at our DDPD Executive Committee meeting on Saturday, October 2, only slightly late - getting from the East Coast to Anaheim in the morning proved to be a challenge for several of us! It was good to meet some of the newer Committee members in person. We had a chance to catch up on progress as a DPG, and begin to look forward towards next year.

While I always knew there was lots of networking going on at FNCE in addition to the many educational sessions, I never realized until this year just how much went on behind the scenes. As a past Newsletter Editor and Treasurer, I only knew there were training sessions to help people in those position get a better grip on needed skills, but that was just the tip of the iceberg!

As the Chair-Elect, I was also invited to participate in several meetings, and really enjoyed the opportunity to do so. I wanted to give at least a short report back to you, DDPD members, to let you, too, know some of the information behind the scenes. So let me tell you about 3 particular meetings: (1) DPG Best Practices Forum, (2) DPG Foundation Lunch - to discuss endowments, and (3) DPG Chair, Chair-Elect/PID meeting.

DPG Best Practices Forum

The Best Practices Forum met during a light lunch. It was a chance for the DPG Chairs and Chairs-elect to get together to discuss best practices. There was a brief time for general networking as lunch was served beginning at 12:30, and the planned program agenda did not begin until 1:00.

The planned agenda was introduced by Lori Porter, Director of ADA’s Practice Team. Speakers were officers from a variety of the DPGs. They offered examples that their practice groups had found beneficial in relation to several areas (noted below). We also had a chance for discussion (questions and answers) on each topic:

• DPG membership recruitment and retention

Recruitment and retention are a concern for all the DPGs - which each exist to provide services to their members and to help keep the particular interests of the DPG’s members in mind for planning ADA’s strategic goals.

• Successful FNCE Program Planning

Getting started early seemed to be the key point - especially for proposing a priority session and funding it! Also scheduling other meetings, which might include an Executive Committee meeting, breakfast or evening reception or other networking opportunities for the DPG members.

One of the discussion topics was that some DPGs are more “allied” to some funding sources than others because of the nature of the group: The DiabetesCare & Education dietetic practice group came to mind - companies that provide medical supplies or food items aimed at diabetics are an easier connection and tie-in. Some of us, and I think our DPG is included, need to work a little harder to find the connections.

• Successful collaboration between DPGs

Sharing resources was the key here - for example, several of the DPG’s joint meeting to offer a big evening reception for members could pool their resources, and they spoke about their experiences, both good and bad - it requires a lot of coordination and preplanning! (Our DPG has done this in the past - both for FNCE program planning and for member receptions.)

DPG Foundation Lunch

The ADA Foundation invited us to a luncheon to explain what the ADA Foundation does as the philanthropic arm (501(c) 3) of ADA, to recognize the DPGs who currently offer scholarships or awards through the Foundation or who are 21st Century Club members, and to share their plans for the future and opportunities for partnership.

From the Foundation’s report: “What does the ADA Foundation Do?” their mission is to improve the nutritional health of the public by focusing on three things:

1. giving scholarships and awards to dietetics students and professionals
2. funding dietetics research by dietetics professionals
3. promoting healthy weight for kids public awareness program.”

DDPD Audio-Visual Library

DDPD members can receive one tape per order. A deposit of $15 for one tape ($20 for two-tape series) should be sent. Make check payable to ADA-DDPD 12. The deposit will be returned if tapes are received within one month of the date mailed. Include your name, address, and daytime phone number along with the name of the tape ordered. Send request and deposit to the AV Librarian:

Joyce Lowe MS, RD
507 Chestnut St
Clinton, SC 29325-3017
JoyceLowe@Charter.net

If the ordered tape is out on loan, your name will be placed on a waiting list and mailed when the tape is returned. ADA-DDPD is not responsible for damages to tape player that may occur. Please carefully inspect tapes to make sure they are not damaged.

Please contact the AV Librarian for updated listings or more detailed information about any of the tapes listed.

ADA FNCE Meeting tapes are generally one hour per tape.

NEW ADDITIONS

Kathryn Moseley’s presentation at the DDPD Breakfast Meeting October 4, 2004 entitled: “Phenylketonuria: New Approaches and Insight Treatment”. Also available is a 5 minute video that shows a woman with PKU who was untreated and severely affected and had been institutionalized for over 40 years with no treatment. The woman had significant behavioral issues, including head banging and out of control behavior. After her placement into a group home dietary intervention began. She was weaned off of all her medications and her behavior improved significantly. The video shows her behavior before treatment and four years later during a trip to Disneyland. The video is in a CD format that plays on an IBM compatible computer.

EATING DISORDER RESOURCES


Counseling the Dysfunctional and Noncompliant Patient, (audio 2 tapes) Lisa Beckley-Plaisted, 1999 SCAN meeting session 

Secrets of Success, (audio tape) Claudia Plaisted, 1999 SCAN meeting session 

Introduction of New Population Programs, (video 2 tapes & teacher guide) ORDER SEPARATELY. Fitness for all, exercising safely & effectively, fitness testing, fitness can be fun, fitness routines, teaching strategies, aerobic and muscle-
building routine by students with developmental disabilities.


Home Gastrostomy Care for Infants and Young Children. (video 27 minutes, manual test pkg.) University of Colorado School of Nursing. 1989. Principles, techniques, ADL’s.

Assessment of Growth and Development. (video) William Chumlea, PhD. Cincinnati Production. Demonstration of anthropometric measurement and explanation of developmental physical expectations.

Dimensions of Feeding Techniques. (3 tape video series—30 minutes each) Rosalind Benner, RD ORDER SEPARATELY
1. Chewing & Swallowing— the basics
2. Feeding the patient
3. Progressing to independent feeding.


Nutrition Assessment of Children with Disabilities. (video 60 minutes) Boling Center for Developmental Disabilities, University of Tennessee at Memphis. Copyright 1988. Hosted by Elizabeth Emerick, MS, RD. Nutritionist. All aspects of nutrition assessments for children with developmental disabilities including behavioural, clinical, feeding skills, and biochemical aspects of assessment are reviewed on the VHS tape.

When Feeding is a Problem. (video, 15 min) The center for Human Nutrition, Omaha, Nebraska. 1990. The VHS tape presentation provides a basic introduction to aspects of oral motor feeding problems such as tongue thrust and lip retraction.

Oral Structure, Swallowing and Digestion: Normal and Abnormal. (video, 16 min) Texas Department of Mental Health and Mental Retardation, Austin, Texas. 1991. The VHS tape presents an overview of the basics of swallowing, provides demonstrations of dysphagia in adults with developmental disabilities.

A History of Mental Retardation. (video, 17 min) The Shriver Center—Massachusetts Department of Mental Retardation, 1989. Presented as “progression of time” through modes of thought treat-ment of MR. Excellent resource for staff, students, and profession-als new to the field of MR.


A New Home. (audio) Lewis, Garfield, Hunter, 1993 ADA Annual Meeting. The shift of services of patients with development-al delay and psychiatric disorders away from hospital or institutional setting to community-based facili-ties is reviewed.


Federal
Support Needed for the Newly Introduced Direct Support Professionals Fairness and Security Act
Many dietitians in the DDPD Practice Group train direct support staff who assist people with severe disabilities to pre pare and to eat meals. Proper training makes direct support professionals key to initiating dietary changes and initiatives in their homes and communities. Support staff hourly wages are low while the job is often very demanding; consequently a high turnover rate is common. Many of the direct support professionals seek less demanding jobs in fast food and retail industries instead. This attrition causes a cycle of retraining for the dietitian. Such turnover decreases in clients’ nutrition-al gains, which could jeopardize the client’s health.

The Direct Support Professionals Fairness and Security Act, H.R. 5197, has been introduced in the House of Representatives by Reps. Lee Terry (R-NE) and Lois Capps (D-CA). It would provide funds to States to enable them to increase the wages paid to targeted direct support profession-als in providing services to individuals with disabilities under the Medicaid program. The new Act will contribute to an improved national policy on the financing of long-term services and supports, which may include a salary increase for direct support staff. Take the initiative and contact your representative to urge him/her to co-sponsor the Direct Support Professionals Fairness and Security Act and/or when it is reintroduced in Congress. The Act will ensure that persons with disabilities will be better served by a direct support staff providing continuity of care. This is more likely to occur when wages are fair.

Statewide
New York – Health Services in Jeopardy for People with Developmental Disabilities
The NY State Department of Health is proposing rule changes that would effectively close part-time Article 28 clin-ics (including all part-time clinics serving children and adults with developmental disabilities). Full-time Article 28 clinics would then need to expand to cover the patient load; however, most expansion has been halted. Additionally, switching to Article 16 clinics wouldn’t provide the same range of medical services, not to mention that most already have waiting lists and cannot serve new patients. For those individuals who are able to locate alternative health care, Medicaid expenses would probably increase for transportation.
a cure for ASD but rather have introduced an option for parents when considering treatments for their children. The anecdotal reports that have often been made not as being scientifically based, are, in fact, very important and must not be overlooked. Parents should not be dismissed, as they are vital members of the team of experts that is required in the care and treatment of any individual with autism.

Unfortunately Autism is a highly stigmatized disorder, but parents and professionals are discovering daily that proper intervention can allow these individuals to reach their fullest potential. Autism deserves the attention of the medical community and nutritional professionals should play an important role in the treatment of these children as a GFPC diet, although challenging, can provide the essential nutrition that is often lacking in autistic children. While it is crucial to demand and evaluate science behind any diet, any parent will tell you that their child’s success on a GFDC diet, whether it is an improvement in behaviors, intestinal health, or nutritional status, is all the scientific proof they need.

REFERENCES:

DPPD A/V Library continued

3. Feeding and Swallowing: Parents perspective on decision to place a G-tube and life after placement of G-tube

Mothers of Developmentally Delayed/ Special Needs Children Talk About WIC, etc. (video, 1 hour) Texas Department of Health, 1994. Interview of mothers explaining situations and feelings associated with assistance programs/medical care.


Nutrition and Feeding Initiatives for Autistic Children.

Feeding and Infants Children with Special Needs. (video 26 min) University of Colorado School of Nursing, 1988. Basic nutrition, feeding plans, relationships.


NHANES III Anthropometric Procedures, (video, 30 min) CDC/NCHS. Outlines standardized anthropometric procedures. Explanation and demonstration only.

SUBSTANCE ABUSE RESOURCES


Assessment for Alcohol Exposure in Utero: Diagnostic Implications for Fetal Alcohol Effects & Fetal Alcohol Syndrome. (video, 90 min) The Shriver Center—Massachusetts Department of Mental Retardation. Very specific and thorough techniques and methods of identification; recommendations for continum of assessment and care.

Substance Abuse & Nutrition. (20 min video & written materials) National Health Video. Explains how substance abuse may lead to malnutrition; vitamin & mineral deprivation; appetite loss, polydrug use; immune system effects; role of nutrition in the recovery process tailored to food guide.


When the two structurally-similar peptides, Pro-Glycine alpha and Pro-Glycine beta, were identified as potential neurotransmitters in the brain, it opened the door to further research. However, initial studies were met with skepticism and resistance. It was not until the 1990s that growing recognition of anecdotal reports, along with emerging biomedical interventions, began to change the landscape.

The Opioid Excess Theory, first proposed by Jaak Panksepp in 1979, gained traction in the 1990s. This theory suggests that excessive amounts of opioid-like substances, such as endorphins, can disrupt normal brain function and contribute to behavioral and cognitive symptoms. Researchers further identified these urinary peptides in the urine and cerebrospinal fluid of autistic individuals.

Another recent study reported behavioral and gastrointestinal improvements on a gluten-free, casein-free, and soy-free diet in 56 of 61 participants with ASD. This shows that dietary intervention can be effective in managing the symptoms associated with ASD. However, it is important to note that the effectiveness of dietary intervention varies across individuals and requires careful monitoring by healthcare professionals.
Children with Special Health Care Needs

Nutrition Care Handbook

Lynn Grieger, MS, RD

Children with Special Health Care Needs Nutrition Care Handbook is an ADA publication from authors in the Pediatric Nutrition DPG and DDPD. The original Pocket Guide was published in 1997, and is now updated and expanded in this new version. The handbook is designed to meet the needs of nutrition professionals who serve children with special health care needs such as developmental disabilities, mental retardation, birth defects, low birth weight, metabolic disorders, and other disorders. More of these children are now seen in all areas of community health services, with over 50% having health problems that place them at nutritional risk. WIC and Head Start nutritionists, dietitians in community hospitals, and community health dietitians will find essential and practical information in this Handbook.

The Handbook is organized by common functional nutrition problems instead of diagnosis, because typically the presenting nutrition concern - poor growth, inadequate diet, feeding difficulty - is the nutrition professional’s primary concern. Chapters on growth, diet, feeding, and fluid and bowel management include information on both healthy infants and children and children with special health care needs. Case examples discuss both assessment and intervention techniques. The chapter on community services and programs outlines the variety of resources available in most communities. Topics are cross-referenced between chapters, and a glossary includes most terms used throughout the book. A very helpful resource list includes books, manuals, Internet sites, newsletters and magazines for additional information.

The Handbook is designed as a resource for any nutrition professional who works with children with special health needs. I often refer to my original copy of the Handbook, and look forward to using the updated information. The handbook is $30 for ADA members and can be ordered from ADA’s Member Service Center at 800-877-1600, ext. 5000 or through ADA’s Web site at http://www.eatright.org/Public/ProductsCatalog/104.cfm.

The publication of Children with Special Health Care Needs in collaboration with the Pediatric DPG was debuted at FNCE. This publication is designed to be a practical resource for practitioners that may see a small number of children with special health care needs in their practice setting, as well as a manual for those of us who work in these settings on a daily basis.

The ADA Quality Management Committee has approved for DDPD to develop Registered Dietitian Standards of Practice and Standards of Professional Performance in Behavioral Health Nutrition Care. Committee members are Terry Girard Anderson, Rosalind Wilkins, Andrea Shotton, Maria Soler, Susan Zabriskie and myself. Ellen Fritchett, ADA’s Director, Quality and Outcomes, is assisting us. The development of these Standards of Practice will define the basis of competent Behavioral Health Nutrition practice, reflect current, evidence-based practices, encourage consistency in Behavioral Health Nutrition practices, and be the framework upon which future DDPD education projects are based to challenge registered dietitians to move beyond experience-based practice to reach a higher level of evidence-based practice. If you have any questions or concerns about this project please do not hesitate to contact one of the members or myself.

Susan Zabriskie is working on a group home menu project. Rosalind Wilkins, Chair of Nominating Committee with her nominating committee has developed a menu guide to help menu planners work with children with special health care needs. I often refer to my original copy of the Handbook, and look forward to using the updated information. The handbook is $30 for ADA members and can be ordered from ADA’s Member Service Center at 800-877-1600, ext. 5000 or through ADA’s Web site at http://www.eatright.org/Public/ProductsCatalog/104.cfm.
Dietetics in Developmental and Psychiatric Disorders (DDPD®)
A dietetic practice group of the American Dietetic Association

Winter 2005
Volume 23, Number 3
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In This Issue

Diet and Autism: A Historical Perspective of the Opioid Excess Theory
Cathy Zwick, MA, RD, CD

Autism Spectrum Disorder (ASD), a complex neurological disorder affecting social interaction and communication, has caught the attention of the medical community due the alarming number of cases being diagnosed. There is no cure, no current FDA approved medications, and although there are treatments showing promising results, there is no one recommended course of intervention at this time. Unfortunately there is a discrepancy between the number of autistic children being diagnosed and the number of medical professionals to assist in the treatment of these children. As a result, parents are often forced to do their own research and are sometimes accused of turning to unconventional treatments. The gluten free casein free (GFCF) diet is just one example of a treatment often singled out due to what some may think is a lack of supportive research. What is often not known by the medical community, however, is that there is a history of supporting research for dietary intervention in Autism and other neurological disorders. It is also important to note that Celiac Disease can have associated neurological symptoms that can be alleviated with a strict adherence to a gluten free diet as reported in a 1966 study. This early research connecting neurological conditions with diet eventually led to the Opioid Excess Theory, the most widely accepted and plausible explanation as to why the GFCF diet has merit for individuals with ASD. This theory has, thus, been the basis for much of the research that has led to the recent popularity of this dietary intervention in Autism.

The possible connection between neurological conditions and diet intensified when researchers began an in depth look at Schizophrenia and how diet may play a role in its treatment. In 1966, a subgroup of schizophrenic patients was found to be sensitive to a component in cereal grains. Later studies, continuing to look at Schizophrenia, a disorder that was once confused with ASD, supported these claims and proposed that the removal of two common dietary proteins found in grains and dairy products produced an improvement in problem behaviors. These early studies were crucial because ASD was not fully distinguished from Schizophrenia until 1971 and, although they are today two distinct diagnoses, there are some overlapping symptoms especially in the areas of social functioning. Finally, in 1971, a study of autistic children was published which showed a correlation between ASD and nutritional malabsorption, as well as to sensitivities to foods, specifically gluten. A connection

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