

BHN Newsletter

Behavioral Health Nutrition

a dietetic practice group of the
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Setting the Standard for Nutrition in Behavioral Healthcare

BHN Member Awards

2010 BHN Distinguished Member

During her forty years in behavioral health practice, Dr. Marion Taylor Baer has had the opportunity to participate in research, collaborate with multiple disciplines, develop and implement numerous programs, mentor and educate many students, and widely influence the promotion of nutrition programs directed to the specific needs of persons with Intellectual and Developmental Disabilities.

As one of the first dietitians working at what is now a University Center for Excellence in Developmental Disabilities (UCEDD), Marion had the opportunity to work with other pioneers in the field to shape the contribution of our profession to the interdisciplinary screening, assessment and treatment of children with disabilities and special health care needs. As an example, she was involved in the development and implementation of the first "Feeding Clinic" at the University of Southern California, University Affiliated Facility (USC/UAF) in 1972.

Starting in the 1980s, first in the Department of Health and Human Services (DHHS) Region IX (Arizona, California, Hawaii and Nevada) and later focusing on California, Marion was involved with interagency teams to look at the need for nutrition services. Collaboration continued through Maternal and Child Health Bureau (MCHB)-funded training grants, and demonstration grants which enabled her to work with others to improve nutrition services for children with disabilities and special needs.

When asked how she became interested in this career path, Dr. Baer states: "By chance. One of my fellow students at the University of California Los Angeles's (UCLA) School of Public Health was Phyllis Acosta, PhD, RD – one of the first pioneers in the field. She knew there was an open position at the UAF at University of Southern California Children's Hospital-Los Angeles (USC/CHLA) and convinced me that I was qualified. Once exposed, I became passionate about the population, prevention and treatment issues and the interdisciplinary approach to... everything!"

Of her numerous awards and honors, Dr. Baer was awarded the Lenna Frances Cooper Memorial Lectureship in September 2006 at the American Dietetic Association's Food & Nutrition Conference & Expo (FNCE) held in Honolulu, HI, presenting "Strengthening Nutrition Services for Children with Special Health Care Needs: the Leadership Challenge". In October 2008 she was presented the Mary C. Egan Award for Excellence in Maternal and Child Health Nutrition at the American Public Health Association's Annual Meeting in San Diego, CA. and in October 2009, Dr. Baer received the Distinguished Service Award from the Association of University Centers on Disability.

Dr. Baer continues her work as the Director of Leadership Education in Neurodevelopmental Disabilities (LEND) Program USC University Center for Excellence in Developmental Disabilities (UCEDD), Children's Hospital Los Angeles, and as Clinical Associate Professor, Pediatrics USC Keck School of Medicine. She credits her numerous accomplishments to the many outstanding professionals she has worked with throughout her career.

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Marion Taylor Baer, PhD, RD

FALL 2010

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Please join the

BHN Member Reception and Awards Presentation

5:30 pm November 7, 2010 at Westin Boston Waterfront, Carlton Room

to meet and congratulate this distinguished member.

BHN Newsletter is published quarterly (Winter, Summer, Summer, Fall) as a publication of Behavioral Health Nutrition, a dietetic practice group of the American Dietetic Association. The Summer and Fall issues are published electronically; members receive an email announcement and link for direct access. Newsletters are available on the BHN Website at www.bhndpg.org.

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Submissions: Articles about successful programs, research, interventions and treatments, meeting announcements and educational program information are welcome and should be forwarded to the editor by the next deadline.

Future Submission Deadlines

Winter 2011 **November 1, 2010**
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Individuals not eligible for ADA membership may apply to become a "Friend of BHN" for the subscriber cost of \$50.00. A check or money order should be made payable to ADA/DPG #12 and sent in care of the BHN Treasurer (see officer contacts in this newsletter).

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From the Chair

Kathy Russell, MS, RD

Hot! Hot! Hot! That is what my summer has been. BHN is also HOT! There is so much activity going on behind the scenes that I am amazed. There has been a wonderful response to our request for volunteers! For those that have indicated an interest, thank you! And thank you again! It is only through the dedication of wonderful volunteers that BHN is able to accomplish our goals. The work of many makes the load light.

Speaking of volunteers, I would like to highlight the work of some of our spectacular BHN Volunteers.

Our Publications Team, headed by newly appointed Julie Lovisa, RD, CD includes BHN Newsletter Editor, Diane Spear, MS, RD, LD and her team, Assistant Editor, Sharon Wojnaroski, MA, RD, and Student Editor, Stephanie Joppa, who work on putting together this newsletter for many months in advance. Diane has plans already in place for the spring 2011 newsletter, and I wouldn't be surprised if the plans extended beyond that! Look for wonderful articles in this newsletter and take advantage of the information in our archived newsletters at www.bhndpg.org. If you have any article ideas or topics that you would like to have included in the newsletter please contact Diane at newsletter@bhndpg.org. Another key member of the Publications Team is Tonya Price, RD, our website editor. Tonya works closely with our website host to make sure that the information you see is current and pertinent. In addition to the newsletter and website, Julie is responsible for BHN's publications, including processing orders, getting more printed, and facilitating updates.

Therese Shumaker, MS, RD, LD is BHN's Public Relations Chair. Therese's team includes our Sponsorship Chair (position **currently open**) who works to find sponsors for our many events, helping to keep costs to our members as low as possible. Our Webinar Coordinator, Beth Sobel, MS, RD is busy working to find cutting edge topics and speakers for upcoming webinars. BHN attempts to conduct a webinar on a topic for all four of our practice areas each year. Another member of our Public Relations Team is our Public Policy Liaison, Cinde Rutkowski, MA, RD, FADA. Cinde works diligently to keep abreast of the most current legislation affecting our practice areas.

It's all about you, our members! BHN's Membership Team takes that very seriously. Under the leadership of Milton Stokes, MPH, RD, CDN the needs of our members are addressed. Milton maintains our member listserv and responds to numerous inquiries by forwarding to the appropriate BHN volunteer for resolution. In addition, he facilitates information to and from our four Resource Professionals, Paula Cushing, RD – Intellectual and Developmental Disabilities; Linda Venning, MS, RD – Mental Illness; Renee Hoffinger, RD – Addictions; and (position currently open) – Eating Disorders. Milton also coordinates the activities of our student committee. The student committee members include Crystal Shores, student liaison; and Stephanie Joppa, student newsletter editor.

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Food & Nutrition Conference & Expo (FNCE) 2010 BHN Schedule of Events Boston Convention & Exhibition Center

Sunday, November 7, 2010

5:30pm – 7:30pm

Member Awards Reception

Westin Boston Waterfront, Carlton Room

Monday, November 8, 2010

10:30am – 1:00pm

DPG/MIG Showcase

Boston Convention & Exhibition Center
 Halls A, B1, B2 & C; Booth 11

Monday, November 8, 2010

3:30pm – 5:00pm

BHN Spotlight Session #335

Overcoming Obstacles in Eating Disorder Treatment

Debra Johnston, RD & Dena Cabrera, Psy. D

FNCE is the premiere event for food and nutrition professionals. Don't miss the latest nutrition science information, foodservice trends and access to the top experts. Register for FNCE at <http://www.eatright.org/fnce/>

BHN Member Awards

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**Paula Cushing,
RD, LDN**

Excellence in Practice: Intellectual and Developmental Disabilities

Paula's practice in the area of intellectual and developmental disabilities came as a result of various job opportunities that "just happened to be related to IDD." When living in Florida she worked as a consultant to intermediate care/adult congregate facilities and an intermediate care pediatric facility for developmental disabilities. Shortly after moving to Tennessee, Paula became a consultant to another intermediate care facility, and in 1999 accepted her current position as Regional Dietitian for Middle Tennessee in the Home and Community Based Services program serving adults with IDD living in the community.

In her current position, Paula oversees the provision of nutrition services to individuals with IDD by providing technical assistance to community nutrition/therapy providers and residential/day providers. Other responsibilities include providing nutrition education, training and consultation to individuals and their staff and families.

Paula has provided numerous presentations and written numerous articles on nutrition and IDD. She coordinated and co-authored the development and 2008 publication of BHN's *The Adult with Intellectual and Developmental Disabilities: A Resource Tool for Nutrition Professionals*. She has served as the BHN IDD Resource Professional since 2007. Paula states that "This position and involvement with the practice group have opened all kinds of doors for me, offering many networking opportunities and experiences that have helped to increase my knowledge in the IDD field and strengthen my clinical skills. I am very grateful to BHN and attribute my increased involvement at the national level to their encouragement and support!"



**Jessica Anne
Setnick, MS, RD,
CSSD**

Excellence in Practice: Eating Disorders

BHN is pleased to name Jessica Setnick as the 2010 recipient of its Excellence in Practice: Eating Disorders Award. Jessica began graduate school with the goal of receiving a master's degree in sports nutrition and becoming the nutritionist for the Dallas Cowboys football team. She has a bachelor's degree in anthropology and has loved the behavioral aspect of nutrition – why humans make the choices they make. As Jessica progressed in school, she says she fell in love with eating disorders – when the behavioral aspects of nutrition go astray. Jessica's philosophy: "Due to the high rate of eating disorders and our special role as food and nutrition experts, all dietitians need to be trained in basic eating disorders care regardless of their practice area."

Jessica's many contributions to the profession include the creation of Universal Precautions for Dietitians to help assess for eating disorders in any patient population. She has presented to many professional, medical and community groups about the identification and treatment of eating disorders. Jessica has co-authored or reviewed the Eating Disorder section of ADA

Nutrition Care Manual; Texas Dietetic Association Nutrition Care Manual; ADA Position Statement on Anorexia, Bulimia and other Eating Disorders; and *The Eating Disorders Book of Hope and Healing*, in addition to many articles for professional and community publications.

As founder of Eating Disorders Boot Camp and Advanced Eating Disorders Boot Camp training workshops, Jessica has provided training to over a thousand RDs. She believes that although behaviors and psychology are important in all aspects of nutrition, the mental health arena is the place where the RD's counseling skills and humanity are really allowed to shine.

Jessica is a past Chair of BHN and a past Eating Disorders Resource Professional for BHN. In 2011, *The Eating Disorders Clinical Pocket Guide*, authored by Jessica, will be published by ADA as the ADA Pocket Guide to Eating Disorders.



**Ruth Leyse-
Wallace, PhD, RD**

Excellence in Practice: Mental Illness

Recipient of the award for Excellence in Practice: Mental Illness, Ruth Leyse-Wallace, following graduation from the internship and Master's degree program at Kansas University Medical Center, began her career at Oswatomie State Hospital in Kansas.

Ruth's first dietetics position at this state operated psychiatric hospital was a fascinating eye-opener. It was her introduction to treatment of substance abuse and the gamut of acute and chronic psychiatric problems. A few years later Ruth took a position as the first full-time dietitian at The Menninger Foundation in Topeka, Kansas. She was on a team that organized one of the country's first long-term residential treatment programs for eating disorders. These two positions coincided with her personal interest in psychology.

It was during this time that the first literature was published by Richard Wurtman, PhD, MD demonstrating that nutrients and diet could influence the brain. Since then Ruth has practiced clinical dietetics in psychiatric hospitals, treatment programs, outpatient clinics, and in private practice for more than twenty-five years in Arizona, Nevada and Southern California. She has authored two books, numerous articles, and given many presentations on the subject of nutrition as it relates to various aspects of brain function and mental health.

Dr. Leyse-Wallace's current professional activities include writing and producing educational materials as well as lectures and workshops for professional and public audiences. As Ruth has stated, research regarding the influence of various nutrients on biochemistry, mental status and behavior has grown tremendously. Just as rewarding is the growth of public interest in nutrition and psychology. This combination of biological science and the psychological aspect of the human condition has enabled Ruth to create an interesting and satisfying career path.

Join us, won't you?

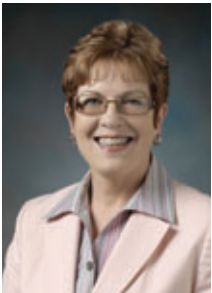
Sign up and gain FREE access to hundreds of members and their expertise through the member-only BHN listserv! We have a wonderful exchange of information, ideas, and resources. Find practice supports and prompt responses to challenging questions.

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BHN Spotlight Session at the Food & Nutrition Conference & Expo (FNCE) 2010

Breaking Down Walls: Overcoming Barriers and Obstacles in Eating Disorder Treatment



Debra Johnston, RD



Dena Cabrera, PsyD

Remuda Ranch Programs for Eating and Anxiety Disorders

Difficulty engaging in treatment for patients with eating disorders is often common and often times expected. Resistance is part of the nature of the disorder and relates to the complexity of the illness. Eating disorders are serious mental illnesses and impact the biological, psychological, social and spiritual well-being of the individual. Genetic studies have shown the tremendous impact on the etiology of eating disorders influenced by alterations of brain functions, impaired cognitive processing, biochemistry, and judgment. Further, emotional functioning and quality of life are restricted in these individuals. They often exhibit comorbid psychiatric conditions, including anxiety, depression, and substance use disorders.

Individuals with eating disorders often struggle in their social relationship because often times the pursuit of thinness contributes to all consuming practices of an eating disorder thus excluding relationships. They are often unable to engage in work or school which begins to impact self worth, esteem, and purpose in the individual's life. Food, weight and shape begin to be the only focus in these individuals life and therefore greatly impact their true meaning and value. Congruently, we are living in a hostile recovery environment in that our culture praises and affirms individuals who are thin and beautiful. Therefore, someone who is biologically

onesource...
endless opportunities

ADA Food & Nutrition Conference & Expo

November 6-9, 2010 Boston, MA



vulnerable to an eating disorder may be triggered to develop an eating disorder based on a multitude of environmental factors, including family issues, trauma identity, and cultural issues. The analogy often used is that genetics load the gun, something in the environment pulls the trigger.

These ideal beauty messages our culture presents makes it difficult for someone struggling with an eating disorder to recover. According to our culture, they are doing exactly what they need to be doing to fit in, be beautiful, feel admired and ultimately feel loved. They are dieting just as our culture preaches. They are doing exactly what they are taught to do in this culture to succeed. Therefore, this environment makes it extremely difficult to recover.

However, despite these environmental negative factors, there is tremendous hope in eating disorder recovery. The *breaking down walls* presentation focuses on obstacles and challenges involved in treating seriously ill clients with eating disorders, especially those unready for recovery. From a bio, psycho social, spiritual framework, the session will highlight effective strategies to motivate patients who are having difficulties engaging in eating disorder treatment.

Eating disorder specialists, Dr. Dena Cabrera, a clinical psychologist and Debra Johnston, RD, will join together demonstrating treatment approaches from both psychological and nutritional perspectives. A treatment tool box including motivating strategies, nutritional protocols and behavior analysis will be shared to help professionals working with those individuals who are fearful of making changes. They will also address how tensions between professional disciplines as well as those

between providers and families, can challenge the work with these clients. Effective treatment guidelines will help join treatment team members by providing strategies for building unity across patients' diverse needs. Given that we all are impacted by the cultural messages, it will also be important that treatment team members address eating or body image biases. These biases could potentially affect the client's treatment. Dr. Cabrera and Debra Johnston look forward to providing excellent training based on their collective experience of 30 years of working with eating disorders.

Plan to attend
BHN's spotlight session
on **November 8, 2010,**
3:30pm – 5:00pm and
expand your ability to . . .

1. Incorporate strategies to manage patients and their families who are unready to take action for recovery.
2. Identify ways to confront and discuss obstacles that arise between team members.
3. Utilize skills to deal with team members' eating or body image biases that could potentially affect the client's treatment.
4. Apply intervention strategies to build unity among the treatment disciplines, families, and clients.

Primer on the RD's Role in Substance Abuse

Renée Hoffinger, MHSE, RD, LD

When it comes to dietetic triage, substance abusers are generally classified as “nutritionally at risk”. Note that physiologically, “substance abuse” doesn’t just refer only to those patients we see in a substance abuse treatment setting, per se, but rather all those we see for any reason whom also happen to abuse alcohol and drugs, legal or illegal. (SAMHSA data for 2008 reveal that 19 million Americans age 12 and up – that’s 7.6% of us – needed treatment for an alcohol use problem; 7.6 million (3%) for illicit drug use.) (1). Those reasons often include diagnoses such as HIV infection, mental illness, liver disease, hypertension, etc which can be further complicated by substance abuse. Hence, having a basic grounding in the effects of substance abuse on nutritional status and best practice counseling strategies may improve the efficacy of our practice. HIV is specifically addressed as the similar adverse effects of HIV and substance abuse exacerbates HIV disease and can complicate successful treatment of both conditions.

Nutritional Implications of Substance Abuse

To examine these dynamics in more detail, you are invited on a “head to toe” “fantastic voyage” through the body. Starting up top, we know that substance abuse impairs judgment. This often leads to poor food choices, unsafe sex, as well as fights and accidents that might otherwise have been avoided. The appetite center in the hypothalamus is “switched off” by many drugs, notably cocaine. Coupled with the anorexia of HIV, drastic weight loss may result. Heavy alcohol intake leaves little room for calories from actual food containing needed nutrients. Marijuana may be known to cause the “munchies” but the target foods are far from nutrient dense. Erratic, poor quality food intake can play havoc with neurotransmitters and blood glucose, leading to generally foul moods, which in an unconscious effort to “change the channel” can serve as cues (or “triggers”) to continued drug use.

Travelling on down to the mouth, those aforementioned brawls and accidents may leave our client with missing, loose, and rotten teeth (brushing, flossing, and regular dental care are not on the binger’s “to-do” list), which makes

chewing, and hence digestion, challenging. Poor dentition, dry mouth, bruxism and tooth decay from amphetamines (aka “meth mouth”), as well as mouth sores due to marginal malnutrition and the oral manifestations of HIV, all serve as aversive behavioral cues for eating hard and acidic foods, further restricting variety and quantity of intake. Taste buds scorched by cigarette smoke aren’t as excited by food (if it doesn’t taste good, why eat it?) and encourage salt usage. Crack cocaine users often feel a constriction of the throat (supraglottitis) and may fear being unable to swallow.

Further along the GI tract we see esophageal varices (varicose veins) associated with portal hypertension due to alcoholic cirrhosis. The diseased liver enlarges and hardens, causing a backup of blood, distending the esophageal tributaries which may rupture, resulting in life-threatening hemorrhage (2, 3). Alcohol use increases gastric secretions and signals the pyloric sphincter to relax, often resulting in reflux (aka GERD), as well as alcoholic gastritis and pancreatitis. The exact mechanism for alcoholic pancreatitis is still being debated (4) but in any case it may lead to Insulin Dependent Diabetes Mellitus and impaired absorption of essential fatty acids, fat-soluble vitamins and calcium.

But it is in the liver, the originally “multi-tasker”, that dietitians really sit up and take notice. Detoxifying is “trumps” for the liver. What this means is that drugs, and especially alcohol, demand the liver’s attention, disrupting business as usual. The rate of alcohol metabolism is dependent on ADH (alcohol dehydrogenase), found mostly in the liver. ADH can oxidize ~ ½ ounce of ethanol, the amount in one drink, per hour to acetaldehyde, a substance even more toxic than alcohol, which in turn is oxidized to acetyl CoA. Both steps require NAD (nicotinamide adenine dinucleotide), which is then unavailable for a variety of other metabolic processes, including glycolysis and the TCA cycle. While waiting to be oxidized, alcohol and acetaldehyde continue to circulate, wreaking damage throughout the body. Remember: alcohol lyses cell membranes – this is how it works as a disinfectant. Excess acetyl CoA is rerouted to fatty acid synthesis, fatty acid clogs the liver rendering it less efficient as a nutrition

powerhouse. The body’s acid-base balance shifts to acid, vitamin D is not activated, folate is not retained, bile not released, and liver cells die eventually resulting in irreversible fibrosis.

Amino acid and protein synthesis slow down, as does the metabolism of any other drugs, prescription and otherwise (5).

Arriving in the small intestine we notice that diarrhea, caused by alcohol and most abused drugs, results in mal-digestion, untimely fluid losses, and lactose intolerance. Opiates have quite the opposite effect: constipation that persists despite increasing fiber and fluid intake.

Due to space limitations, this is a non-inclusive review of the nutritional implications of drug abuse. (Consult references below for the full story) The bottom line is that excessive alcohol and drug use can interfere with normal nutrient intake and metabolism leading to muscle wasting, anemia, multiple nutrient deficiencies, and fatigue, as well as increasing one’s risk for a variety of cancers, heart disease, diabetes, neurological disorders, kidney failure, pancreatitis and, of course, liver disease.

For RDs who work with HIV+ patients this may sound quite familiar: anorexia, loss of lean body tissue, lipodystrophy, damaged liver due to polypharmacy, and a complicated medical profile (hypertension, gastritis, diabetes). Add to all this compromised food access due to lack of finances, infirmity, difficulty cooking, and possibly mental illness, and one can easily see how drinking, drugging and HIV together can create a powerful, downward spiral of malnutrition.

Counseling Strategies

So, what’s a dietitian to do? This depends on many variables including: whether your patient is sober or still using, type of setting, and most importantly, the patient’s degree of motivation. The prime imperative is to get the patient off drugs and alcohol and initiate substance abuse treatment. The RD (assuming you are seeing the patient in the medical setting and they are not yet engaged in substance abuse treatment),



Renée Hoffinger

Primer on RD's Role

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as a relatively non-intimidating member of the health care team, can often be instrumental in this regard. Alcohol on the breath, diet recalls with massive intake of alcohol and long sleeves in warm weather (to cover IV drug sites) are tip offs to trigger referral to substance abuse treatment. Active users are poor candidates for nutritional counseling, but once in recovery the following goals can help in mapping out a strategy:

1. Replenish nutrients - Reverse deficiencies and improve nutrition, and hence mental status so patient can optimize benefit from cognitive therapies. We do this by steering the client towards nutrient-dense foods and suggesting an iron-free multivitamin.
2. Keep mood and emotions on an even keel – Stress that what one eats can either support or sabotage one's program of recovery. By eating a balanced diet with three squares plus healthy between-meal snacks and avoiding concentrated sweets and caffeine, your client can avoid the liftoffs and letdowns of erratic blood glucose levels, which in turn can lead to foul mental/ emotional states which serve as cues to using drugs of choice.
3. Diet as part of a healthy lifestyle - As my illustrious OT colleague has said: "It is hard to eat wheat germ for breakfast and snort cocaine for dinner". In other words, people in recovery are often turning over the entire leaf: getting clean and building healthy relationships, healthy exercising habits, and new ways of thinking. Some even go so far as to quit smoking! Healthy diet fits right in and provides an avenue for practicing self-control and nourishing oneself, as well as managing health conditions such as hypertension and diabetes.

Empowering your clients for dietary change can be challenging in the best of situations. In the case of long-term substance abusers you may need to trade in your usual perspective for a new view. Consider that your client's emotional development was largely arrested at the age at which substance abuse first began. This means that a lot of the "emotional potty training" that usually comes with chronological maturity may be missing. Barriers to achieving optimum medical and nutrition outcomes in addicts may include difficulty tolerating intense emotions, externalization (blaming

others for their woes), poor frustration tolerance, denial, and manipulation. Additionally, clients may have substance-induced mental illnesses indistinguishable from "real" mental illness until it clears up after a period of sobriety. All these may keep them from dealing constructively and proactively with the issue at hand and make it difficult for you to establish a therapeutic rapport. For example, to evade the sadness and anxiety of an HIV diagnosis, they may avoid testing and subsequently present at later stages of HIV disease. Receiving an HIV diagnosis may cause a relapse or increase substance abuse to numb emotional pain. In addition, they may lack a sober support system having alienated friends and family through their manipulative, demanding behaviors and illegal activities. The concept of sobriety may be threatening since drinking buddies may be their sole source of companionship.

Ironically, HIV status may actually serve as an asset, that "cosmic kick in the butt" (6) to finally engage in treatment and make long needed lifestyle changes. When this time arrives, the most helpful counseling strategies are "patient-centered": Understanding the patient as a unique human being, building a therapeutic alliance, and unconditional positive regard. This might include non-judgmental active listening, encouraging expression of feelings, providing reliable support while not over-helping and resisting manipulation. The "ownership" evoked by inviting their participation in goal setting and strategies for attaining those goals increases the likelihood of success. Build on past successes. If the client has quit smoking cigarettes or using drugs, remind them of their ability to make such difficult behavioral changes to strengthen their confidence and self-efficacy for dietary change. To gain new perspective and avoid burnout clinical supervision is highly recommended. This simply means discussing difficult cases as a treatment team or with a more experienced colleague.

The techniques of Motivational Interviewing (MI), initially developed to facilitate behavioral change in chemical dependencies (7) can be applied to a wide range of adherence issues, including diet. It is basically client-centered counseling using reflective listening statements to help clients explore and resolve ambivalence and believe in their ability to change. Akin to the soft martial arts (tai chi, aikido), you channel rather than confront.

As RDs we can often choose the depth of our interaction with our patients. It can run the gamut from a polite offering of diet handouts to being deeply present with people at transformative times of their lives. I consider the latter to be a privilege and an opportunity. Working with alcoholics and addicts in recovery can be fun (yes, fun!) and rewarding, allowing us, as RDs, to challenge, stretch and hone our counseling skills.

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6. Callen M. *Surviving AIDS*. New York: Harper Collins Publishers, 1990.
7. Miller WR and Rollnick S. *Motivational Interviewing – Preparing People to Change Addictive Behavior*. The Guilford Press. 1991.

Ref #4 made its debut at ADA's Food & Nutrition Conference & Expo (FNCE) 2008 and can be ordered via www.bhndpg.org. Very thorough coverage of topic including a vast reference list, by an RD with many years of experience in the field.

Other Useful Tools:

Nutrition & Recovery – A Professional Resource for Healthy Eating During Recovery from Substance Abuse by Trish Dekker, M.Ed., R.D. Centre for Addiction and Mental Health, 2000. Includes not only background info but curricula and handouts. Order via http://www.camh.net/Publications/CAMH_Publications/nutrition_recovery.html

The Sober Kitchen - Recipes and Advice for a Lifetime of Sobriety by Liz Scott. The Harvard Common Press, 2003. Written by an alcoholic chef. Excellent!

About the Author: Renée Hoffinger, MHSE, RD, LD is BHN's resource professional for the addictions practice area and recipient of the BHN 2008 Excellence in Practice Award. She is employed at North Florida/South Georgia Veteran Health System. Renee.Hoffinger@va.gov

Creating Understandable, Effective Tools for People with Intellectual and Developmental Disabilities

Joan Guthrie Medlen, M.Ed, RD, LD



Joan Guthrie Medlen

Creating understandable materials and education activities is key to successful nutrition coaching for people with intellectual and developmental disabilities (IDD) and those who support them. For many, the tools and techniques typically used to create “easy-to-read” health education materials will do. However, for some, these techniques require special attention.

The process is the same:

- Plan and research,
- Organize and create,
- Evaluate and improve,
- Inform and stay informed.

It is in the details of these steps that understandability is determined, for anyone, including people who experience intellectual and developmental disabilities. For consistency, this article will focus on what is different when creating materials for people with IDD using the same framework as the companion piece in this issue of the BHN Newsletter.

Step 1: Plan and Research

Define your target audience.

Though this is key to any good education tool, it is an imperative step for designing health communication materials for people with IDD. When designing materials for people with IDD or issues about them, you will find there are three distinct audiences:

- The person with IDD.
- The people who provide support (direct support providers, agency staff, family members).
- Health care providers.

Each of these requires a different scope, approach, and language use. Do not combine them. Once you have defined your audience, learn about them. Learn **with** them.

Discover your target audience's interests

When working with people with IDD and their families, it is essential to meet them where they are with regard to health education. More often than not

the pivotal information they seek is not what health care professionals expect. Taking the time to do interviews, focus groups, and observations takes time in the front end, but pays off ten-fold in the development of effective tools.

When gathering this information, capture the discussion using a Flip® Video or other small camera to review nonverbal messages and language use later. It is difficult to catch the nuances of non-verbal cues in the moment. These cues are often the missing piece in the conversation.

Create Learning Objectives

Whether you are making a brochure or designing a workbook, your product will be much more effective if you create learning objectives for your target audience. Writing learning objectives takes practice. Bloom's Taxonomy is helpful for writing appropriate, achievable learning objectives. (see <http://www.officeport.com/edu/blooms.htm>) Clearly written objectives using this method lead easily to measurable outcome.

For example, when writing learning objectives for tools designed for people with IDD, a useful and measurable goal is to identify, match, or categorize key words, tools, or concepts:

“Given appropriate visual cues, the learner will be able to identify labels with gluten-free symbols by matching the GF symbol to the GF symbol on the label.”

Step 2: Organize and Create

Making understandable tools for people with IDD is really a process of creating. The messages require careful thought to visual cues, simplicity, and clarity of both visual and text messages.

Key techniques for use of text in understandable materials can be found in the corresponding article. Here are some tips that are specific to the writing and design of tools for people with IDD:

Text

- Follow general rules for low literacy skills.
- When possible, use a font that has letters that are shaped like handwriting. Not handwriting fonts. For example, “a”

rather than “a” and “g” rather than “g.”

- Capitalize the start of a line in a bullet list (visual cue for the beginning).
- End bullet lists with a period (visual cue for the end).

Writing

- Use active tense.
- Be direct. Do not start sentences with a clause.
- Be familiar. Write in the first person. Use “I” and “you.”
- Keep it short. Stick to one, maybe two, discreet messages.
- Be positive. Focus on what to do rather than what to avoid.
- Keep the words small. Use the shortest, effective word to describe something.

Visual Cues

- Use images that have a purpose in the message.
- Use background free images.
- Images should convey a specific message.
- Use high resolution images.
- Use age appropriate images and language.
- Make good use of white space to organize the message.
- Avoid visual clutter and crowding.

Alternative Formats

- Consider formats other than print.
- Offer audio versions.
- Use video clips.
- Consider a hands-on activity.
 - Does this need to be in print or other media or can you offer a hands-on experience?
 - Can you describe a hands-on experience the person can do with support?
 - Can it be created as an iPod app?

Evaluate and Improve

You won't get it right the first time. It is impossible. Plan to evaluate the tool you make as you create it and also after

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Create Effective Tools

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you think you are done. Begin the process by using a Fry Readability Scale or SAM (see *How to Write Easy-to-Read Health Materials* following this article).

Use the gold standard: let your target audience test the tools you create. Choose the people who test your tools carefully. I have a cadre of young adults with Down syndrome who test my recipes. They are all very different in learning style and literacy skills. What they have in common is their ability to work with their parents, sibling, or friend and tell me what I need to change. Therefore, the person who supports them needs to be able to watch, let mistakes happen, and report what those mistakes might be. The more honest feedback you receive, both from the person with IDD and the people who support them, the stronger your tool will be. Be careful not to let the input from the support person over-ride the message from the person with IDD. I've found using a Flip® Video very handy for this purpose.

Remember, there is a vast range of skills and abilities for people with IDD.

More than any other demographic group, in my opinion. The skills and abilities of people with IDD are changing with each decade for the better. This also means that you must define your target audience very carefully. It is not possible to create a tool for the entire demographic labeled, "people with intellectual and developmental disabilities."

Inform and Stay Informed

When you create materials for people with IDD, share them! The Behavioral Health Nutrition Practice Group would love to see what you are making. For more information contact Diane Spear at newsletter@bhndpg.org.

Here are some other resources to hone your skills in the area of health literacy for individuals with IDD:

- Health Literacy for People with Intellectual and Developmental Disabilities (Blog). <http://healthlit.wordpress.com>. The blog is written by Joan Guthrie Medlen, M.Ed, R.D., L.D. and is a information sharing site for health care professionals interested in the topic.
- Health Literacy Discussion List: healthliteracy@nifl.gov or Julie

McKinney: julie_mckinney@worlded.org

- Visual Strategies for improving Communication, Linda Hodgdon, MA, CCC-SLP. Quark Publishing. (www.usevisualstrategies.com)
- *Creating Graphics for Learning and Performance: Lessons in Visual Literacy*. Linda Lohr, 2003. Merrill, Prentice, Hall; Ohio.
- *Visual Foods Photo CD*. Silver Lining Multimedia, Inc., 2005.
- iStockPhoto.com.

Creating understandable health education materials for people with IDD and those who support them is wildly rewarding. It takes time, it's true. But when that "A-Ha" moment arrives, it's priceless.

Joan Guthrie Medlen, M.Ed, RD, LD

owns her own practice, JEM Communications and Phronesis Publishing, which focus on creating practical tools and strategies for people with IDD. Joan lives in Oregon and is the mother of two adult men, one of whom has Down syndrome, autism spectrum, celiac disease, and is nonverbal. www.downsyndromenutrition.com

How to Write Easy-to-Read Health Materials

Medical concepts and language are very complex. People need easily understandable health information regardless of age, background or reading level. Here are guidelines to help you create easy-to-read health materials.

What are easy-to-read (ETR) materials?

ETR materials are written for audiences who have difficulty reading or understanding information.

How can you create easy-to-read materials?

Writing ETR materials for MedlinePlus is a process involving several important steps:

- **Plan and research**
- **Organize and write**
- **Evaluate and Improve**
- **Inform and Stay Informed**

Step 1: Plan and Research

Know your target audience.

Consider reading level, cultural background and attitudes, age group and

English Language Proficiency (ELP).

- **Include your target audience.** Bring members of the audience into early planning stages, if at all possible. This is especially important in cross-cultural communication.
- **Research your target audience.** Use tools such as surveys and interviews to learn about the need of the target group. If extensive research is not feasible due to time or budget constraints, contact other organizations who communicate regularly with similar target audiences.
- **Determine objectives and outcomes.** What do you want your target audience to learn? For example, if your objective is to show the proper use of asthma inhalers, emphasize the outcome of their proper use. A sample sentence might be: "Following the directions for your asthma inhaler may help you to breathe easier."

Step 2: Organize and Write

General Points

- Keep within a range of about a 4th to 6th grade reading level.

- Focus on a few key concepts.
- Use a clear topic sentence at the beginning of each paragraph. Follow the topic sentence with details and examples. For example, "Proper use of asthma inhalers helps you breathe better. Here are reasons why." Then give reasons.
- Examples and stories may help engage readers.
- Use the "you" attitude. Personalization helps the reader understand what he or she is supposed to do.
- Structure the material logically. Some users prefer step-by-step instructions. Others may find concepts arranged from the general to the specific easier to understand.
- Emphasize benefits of adopting the desired behavior. For example, "Following these directions will help you get enough medicine from the inhaler."
- Do not make assumptions about people who read at a low level. Maintain an adult perspective.
- Many who are challenged by English

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How To Write Easy-to-Read...

continued from pg 8

are extremely fluent in a different first language. Is your school French or Spanish or German good enough to read medical instructions?

Language and writing style

- Find alternatives for complex words, medical jargon, abbreviations, and acronyms. When no alternatives are available, spell complex terms and abbreviations phonetically and give clear definitions.
- Keep most sentences short. Use varied sentence length to make them interesting, but keep sentences simple.
- Use the active voice and vivid verbs. Here's an example:
Active: Amanda used her inhaler today.
Passive: The inhaler was used by Amanda today.
- Be consistent with terms. For example, don't use "drugs" and "medications" interchangeably in the same document.
- When possible, say things positively, not negatively. For example, use "Eat less red meat" instead of "Don't eat lots of red meat."

Visual Presentation and Representation

- Use colors that are appealing to your target audience. Be aware, however, that some people cannot tell red from green.
- Use pictures and photos with concise captions. Keep captions close to graphics.
- Avoid graphs and charts unless they actually help understanding.
- Balance the use of text, graphics, and clear or "white" space.
- Avoid words or sentences in all capital letters.
- Avoid italics.
- Use bolded subheadings to separate and highlight document sections.
- When possible, use graphics or spell out fractions and percentages.

Step 3: Evaluate and Improve

Always test your materials on a sample group from your target audience. Evaluate the feedback and revise your

material if necessary. Testing during the writing process can help ensure your audience is getting the message. For more information, see the pretest and revision section from the *National Cancer Institutes "Clear and Simple" publication*.

Following are samples of readability assessment tools:

- **Fry Readability Graph.** A commonly used readability assessment tool. See the Iowa Department of Public Health's Fry Readability Graph page. (PDF File)
- **SMOG.** Less frequently used than the Fry Graph, but still widely used. See, for example, the *Harvard School of Public Health's SMOG Readability Formula page*. (PDF File)
- **Gunning FOG.** One of the first readability tools. It is widely used. See the *Iowa Department of Public Health's Gunning-FOG Readability page*. (PDF File)
- **SAM (Suitability Assessment of Materials).** A tool created by Cecilia and Leonard Doak. SAM assesses not only readability, but also usability and suitability elements.
- **Flesch Reading Ease / Flesch-Kincaid Grade Level.** Used in the Microsoft Word grammar checker.

For more information on readability, see *Harvard School of Public Health's How to Create and Assess Print Materials page*.

Readability software programs

These are examples of software programs. Other programs exist. Readability software may not be suitable for every ETR project. Note: NLM makes no endorsements in displaying these examples.

- *Readability Plus* (Windows and Mac)
- *Readability Studio* (Windows)
- *Stylewriter* (Windows and Mac)
- *InText* (Public domain software for Windows, English and German) Commercial version available as *TextQuest*
- *UNIX commands* to help identify readability and style issues

Step 4: Inform Us and Stay Informed

After you create ETR materials, we suggest you label them "easy-to-read." MedlinePlus will display materials as easy-to-read only if the sponsoring organization labels them. NLM does not evaluate materials for reading level.

Other Resources

Here are some lists of other materials that may be helpful.

Sites with easy-to-read health materials

- National Institute of Diabetes & Digestive & Kidney Diseases. *Easy-to-read publications page*
- National Institute on Alcohol Abuse and Alcoholism. *Easy-to-read publications page*

Guidelines and bibliographies for developing easy-to-read materials

- Center for Medicare Education. *Writing Easy-to-Read Materials* (PDF file)
- Centers for Disease Control. *Simply Put* (PDF file)
- Covering Kids & Families. *Health Literacy Style Manual*. October 2005.
- Doak CC, Doak LG, Root JH. *Teaching Patients with Low Literacy Skills*. 2nd ed. Philadelphia: J.B. Lippincott Co; 1996.
- National Cancer Institute. *Clear & Simple: Developing Effective Print Materials for Low-Literate Readers*
- National Library of Medicine. *Current Bibliographies in Medicine 2004-1. Understanding Health Literacy and its Barriers*
- Society for Technical Communication, Usability Special Interest Group. *Readability Research*
- University of Michigan Health Sciences Libraries. *Improving Health Literacy*

Date last updated: 21 August 2009
MedLine Plus U.S. [National Library of Medicine](#), 8600 Rockville Pike, Bethesda, MD 20894 [National Institutes of Health](#) | [Department of Health & Human Services](#). Accessed July 6, 2010.

BHNewsletter reaches 1500 members quarterly.

Do you have a product or service to publicize? Have you written an evidence-based article to share?

Contact
newsletter@bhndpg.org

Community/University Partnership Establishes Infrastructure to Improve Health Care for People with Disabilities

Printed with permission of Rehabilitation Research and Training Center on Aging with Developmental Disabilities at the University of Illinois at Chicago, RRTCADD_NEWS@LISTSERV.UIC.EDU, August 25, 2010 11:25 AM

Leveraging the power of American Recovery and Reinvestment Act funding, two community-based organizations serving people with developmental disabilities are collaborating with the NIDRR funded Rehabilitation Research and Training Center on Aging with Developmental Disabilities at the University of Illinois at Chicago (UIC) to form an inter-state consortium. This consortium will create statewide infrastructures to improve health for people aging with developmental disabilities in Illinois and New Mexico. The funding from the Eunice Kennedy Shriver National Institute of Child Health and Human Development provides \$1,000,000 in shared project support over three years. Key consortium collaborators include ARCA in Albuquerque, New Mexico and NorthPointe Resources in Zion, Illinois.

Beth Marks, RN, PhD, the Principal Investigator in the Department of Disability and Human Development at UIC says, "For people aging with developmental disabilities, little data exists on how to translate health promotion research into public health practice so that they have health equity. The development of strong statewide infrastruc-

tures through an innovative community-academic health center partnership can ensure the involvement of local stakeholders in planning culturally and linguistically appropriate research and bridge gaps in practice outcomes. By building capacity across communities we can better facilitate health care delivery by linking a hard-to-reach population through outreach and referral initiatives."

Through this consortium, community based organizations will assume a leadership role in generating research questions, actively participate in the development and implementation of research initiatives, apply the results in practical activities, and disseminate evidence-based products. ARCA and Northpointe Resources are well suited to facilitate the research to practice process by engaging local communities and tribal entities because they have a wealth of experience providing day-to-day services and translating and disseminating evidence-based health promotion practices. This three year project will build much needed statewide infrastructures to promote and maintain healthy lifestyles among people aging with developmental disabilities.

Project Title: Community-Academic Partnership: Building an Infrastructure to Improve Health for People Aging with DD

The project described was supported by Award Number RC4HD066915 from the Eunice Kennedy Shriver National Institute of Child Health & Human Development.

For more information contact:

- Beth Marks, RN, PhD, University of Illinois at Chicago, Department of Disability and Human Development or Jasmina Sisirak, MPH, PhDc, Co-Principal Investigator (312) 413-4097 or bmarks1@uic.edu; (312) 996-3982 or jsisirak@uic.edu
- Elaine D. Solimon, CEO, or Leslie Hoelzel, Grant Manager, ARCA (505) 332-6700, esolimon@arc-a.org; (505) 332-6847, lhoelzel@arc-a.org
- Dina Donahue Chase, Senior VP Vocational Services, NorthPointe Resources (847) 872-1700, ddonohue@northpointeresources.org

From the Chair

continued from pg 2

BHN's Nominating Committee is busy right now trying to find the best fit to fill important positions. Under the leadership of Committee Chair, Sharon Lemons, MS, RD, LD, nominating committee members, Cary Kreutzer, MPH, RD and Patricia Novak, MPH, RD, work diligently throughout the year to find volunteers to fill long term positions for short term projects. Nominations are being accepted **right now!** So, if you or someone you know, would like to ramp up your involvement, contact one of these three awesome volunteers!

Other BHN volunteers that keep our DPG moving include our Treasurer, Janice Scott, RD, CSP, LD who makes sure that we are fiscally responsible and on track with our budget. Charlene Dubois, MPA, RD is BHN's secretary. Charlene manages the

business end of our activities, scheduling our monthly conference calls, sending out agendas, and taking the minutes of our meetings. Leslie Schilling, MA, RD, CSSD, LDN is BHN's DPG Delegate. Leslie is dedicated to taking the concerns of our members to the ADA House of Delegate's meetings to make our voice heard.

FNCE 2010 is right around the corner and we hope to see you there. See details about BHN's activities in this newsletter. Andrea Shotton, MS, RD, LDN, our Past Chair has been preparing for our Member Awards Reception by calling for nominations for Excellence in Practice and Distinguished Member awards in the four practice areas and overall for BHN. The award recipients are top notch and we hope you will come by the reception honoring them!

While we are all preparing for this year's FNCE, our Chair-Elect, Charlotte

Caperton-Kilburn, MS, RD, CSSD, LDN, is diligently planning FNCE 2011! True to our goal of meeting the needs of all our members, BHN rotates the practice area each year for FNCE topics. The practice area for 2010 is Eating Disorders, and 2011 is Mental Illness. If you have a topic or speaker in the area of mental illness that you would like to suggest, please contact Charlotte at nflperformance@yahoo.com.

As you can see, it takes some super people to do a whole lot of work! The good news is that we sure do have fun doing that work. There is always a place for BHN volunteers and we welcome **you** with open arms!

**Yours for good health,
Kathy Russell, MS RD**

Regaining a Sense of Self: Integrating Spirituality with Eating Disorders Treatment

Marci E. Anderson MS, RD, LDN, CPT

Spirituality is not a word most clinicians associate with the treatment of an eating disorder. That's why I was intrigued when The Renfrew Center Foundation (<http://www.renfrew.org/>) offered a daylong seminar entitled "Hungers of the Soul: Spirituality, Hope, and Forgiveness in the Treatment of Eating Disorders" in Cambridge, Massachusetts. Jennifer Nardozi, PsyD and National Training Manager presented the seminar.

My own spiritual practices have profoundly influenced my own feelings of self-worth and meaning in my life. I was curious to learn how integrating spirituality into my work with clients might benefit them. This article is a summary of core concepts I learned at the seminar and ways in which I have utilized spirituality in the work I do with my clients.

Losing a Sense of Self

By nature, an eating disorder prevents a person from developing their true selves. Rather than learning to recognize, communicate, and meet their own needs, people who struggle with an eating disorder lose their own identity. They tumble in the sea of their disease, allowing their behaviors to do the asking and communicating for them. What is left is often an empty, lost, undeveloped or undiscovered true self. Author and therapist Sheila Reindl, EdD, EdM discusses this perspective in her book, *Sensing the Self*. She states "the essence of recovering [from an eating disorder] is the development of a sense of self." (1)

Spirituality as Defining Self

Spirituality is not the same as religion. Spiritual practices are intended to help an individual develop their inner life. Examples of spiritual practices include, but are not limited to: meditation, prayer, attending religious services, creating positive rituals, listening to sacred music, spending time in nature, discovering creative expression (dance, art, writing, poetry), being of service to others, recovery focused letter writing, practicing yoga and deep breathing techniques.

Research Supports Integrating Spirituality with Eating

Disorder Treatment

Encouraging our clients to engage in practices which enrich and enlarge their spiritual lives gives voice to their inner most desires, their inner most and truest selves. We now have research which strengthens the case for incorporating spirituality into eating disorders treatment. Not surprisingly, there is a high correlation between religion and spirituality with better health. (2) Additionally, incorporating spiritual interventions into eating disorder treatment enhanced treatment outcomes, reduced eating disorder symptoms and psychiatric distress. (3) (4) More specifically, the authors noted that "improvements in spiritual well-being during treatment were significantly associated with positive gains in eating attitudes, less body shape concerns, and positive psychological and social functioning." (3)

However, it should be noted that religion may not always be a positive addition to treatment. Morgan, et al stated that their research showed that "in some of the cases, religious beliefs seemed to provide a containment of maladaptive behaviors, partly through prayer and through a sense of belonging to the religious community. In other cases, it proved difficult to separate the concept of a punitive God from the illness process." (5) It is important to discuss if, when, and how to incorporate spirituality into treatment with your clients, as discussed below.

How to Incorporate Spirituality into ED Treatment

You may feel a little uncertain as to how to introduce spirituality into your practice. It's easier than you think.

1. Ask your clients about incorporating spiritual practices into their recovery. Explain that spiritual practices may help them find peace and develop creativity. It does not have to mean religion. The idea of practicing yoga may be much more appealing than attending Sunday Mass.
2. If you need a little guidance, consult a spirituality assessment or questionnaire (Google "spirituality assessment"). Or simply ask your clients when they feel most at peace. Some

may be able to identify when they feel most connected to themselves rather than to their eating disorder.

3. Based on their response, discuss ways they would like to integrate these interests into their recovery work. Let me share with you three unique clients that taught me the power of spiritual practices in their journey to recovery.
 - Mary struggled with restrictive eating and only felt comfortable eating an extremely limited number of foods. She also suffered from severe anxiety. However she had a love of horses and expressed feeling the most peaceful when at the stables. She suggested the idea of trying a new food when she went to the stable to visit her horse. She felt calm and confident as she fed both her horse his snack while nourishing her own body. Mary made tremendous strides as she enjoyed the peace in nature which allowed her space to challenge her fear of new foods.
 - Dora has battled a binge eating disorder for over 40 years. She is incredibly smart, warm, and generous. And among her many talents, Dora has a way with words. She is a beautiful writer and once told me that she feels her truest wisdom when writing. However, due to a slight learning disability, a traditional food journal felt overwhelming and confusing for Dora. So we decided on a once a week writing entry about a "food experience." Dora discovered tremendous insight into the function of her eating disorder which we used to guide our work together. This process has brought Dora tremendous peace and a sense of meaning in her life.
 - Amber aspires to complete her Masters Degree in Dance/Movement Therapy but her education is on hold as she works toward her own recovery. Bed time is a particularly stressful time for Amber as she struggles with night eating. She has found tremendous

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Integrating Spirituality

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peace and relaxation when she incorporates a 15 minute guided meditation on her iPod. This allows her to feel more grounded, less distracted, and better able to sleep soundly.

- Utilize current resources. Michelle M. Lelwica, ThD wrote "The Religion of Thinness: Satisfying the Spiritual Hungers behind Women's Obsession with Food and Weight" by Gurze Books, LLC (see <http://www.religionofthinness.com/about.html>). Dr. Lelwica provides practical tools to help clients develop their inner spiritual self through mindfulness practices. Additionally, spirituality seems to be a hot topic, as it is on the program at many conferences including The National Eating Disorders Association and The Renfrew Center Foundation.

One valuable lesson I have learned is that even though we are responsible for the nutrition piece of our client's care, we are working with the whole person. By utilizing spiritual practices as an adjunct to our work, we are helping our clients tap into and develop their true selves. When used sensitively in conjunction with appropriate medical care and therapy, clients may find greater hope and purpose in their recovery.

For further ideas, consider reading "Spiritual Approaches in the Treatment of Women with Eating Disorders" by Richards, Hardman, and Berrett and published by the American Psychological Association. See <http://www.apa.org/pubs/books/4317103.aspx> for details.

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About the Author: Marci E. Anderson MS, RD, LDN, CPT works in private practice in Cambridge, MA. She works exclusively in the field of eating disorders, helping her clients to find peace, fulfillment, and happiness with food. Marci maintains a blog at http://www.marciRD.com/_blog/blog. She can be reached at marci@marciRD.com

Cardiovascular and Metabolic Risk Profile and Acylation-Stimulating Protein Levels in Children with Prader-Willi Syndrome and Effects of Growth Hormone Treatment

de Lind van Wijngaarden RF, Cianflone K, Gao Y, Leunissen RW, Hokken-Koelega AC.

Dutch Growth Research Foundation, 3016 AH Rotterdam, The Netherlands. r.delindvanwijngaarden@erasmusmc.nl

Published: *J Clin Endocrinol Metab*. 2010 Apr;95(4):1758-66. Epub 2010 Feb 19.

PUBMED accessed Sept 13, 2010 <http://www.ncbi.nlm.nih.gov/pubmed/20173020?tool=MedlinePlus>

Abstract

CONTEXT: Reports on the cardiovascular and metabolic risk profile in children with Prader-Willi syndrome (PWS) and the effects of GH treatment are scarce. Acylation-stimulating protein (ASP) stimulates glucose uptake and triglyceride storage in adipose tissue.

OBJECTIVES: The aim was to study the metabolic and cardiovascular risk profile and ASP levels and to investigate the effects of GH treatment.

DESIGN: We conducted a randomized controlled GH trial. Infants and prepubertal children were assigned to receive GH (1 mg/m² . d) or to serve as controls for 12 and 24 months, respectively.

PATIENTS: Eighty-five children with PWS (mean +/- sd age of 4.9 +/- 3.0 yr) participated in the study.

MAIN OUTCOME MEASURES: We measured fat percentage (fat%) with dual-energy x-ray absorptiometry, blood pressure, fasting insulin and glucose levels, serum lipids, and ASP levels.

RESULTS: Mean +/- SD fat% was 28.4 +/- 6.2 in infants and 36.9 +/- 8.5 in prepubertal children. Fat% sd score (SDS) was above 2 SDS in 95% of prepubertal children. In addition, 63% of infants and 73% of prepubertal children demonstrated at least one cardiovascular risk factor, defined as hypertension or dyslipidemia. The metabolic syndrome was demonstrated in 5% of all children. Mean +/- sd baseline ASP was 107 +/- 45 nmol/liter (normal < 58 nmol/liter) and correlated with fat mass and TG levels. GH improved fat%SDS and the HDLc/LDLc ratio

($P < 0.0001$ and $P = 0.04$). GH had no effect on mean ASP levels in this population.

CONCLUSIONS: Many children with PWS had dyslipidemia and high ASP levels. GH improved fat% and high-density lipoprotein cholesterol/low-density lipoprotein cholesterol, but not ASP. High ASP levels may prevent complete normalization of fat%SDS during GH treatment but may contribute in keeping glucose and insulin levels within normal range.

For more information on Prader-Willi Syndrome Growth Hormone Deficiency and Treatment: <http://www.pwsausa.org/GH/index.htm>

STUDENT CORNER. . . .

Set Yourself Apart – Consider the Global Market

By Stephanie Joppa, Student Assistant Newsletter Editor

According to The National Geographic-Roper 2002 Global Geographic Literacy Survey, among 18-24 year olds in the United States, 87% cannot locate Iraq on a map, 83% cannot locate Afghanistan on a map, 58% cannot find Japan, and 11% cannot find the United States.

This is a poor and somewhat shocking statistic. While I am not necessarily advocating going to any country on the U.S. Department of State's "Travel Warning" list (which includes Afghanistan and Iraq), studying abroad can increase one's hiring potential in a number of ways beyond improving their geography, and is a great idea for today's students. With the economy down and few openings in nutrition available, students looking to graduate and obtain jobs in this field must set themselves apart. What makes them special? What makes them eligible to compete in the global market?

Studying abroad is an excellent response to those questions. Nationally,

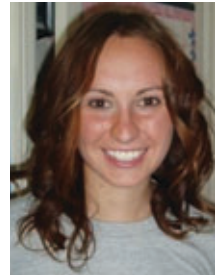
only about 1% of students study abroad. Students who do, however, report increased confidence and maturity, communication and language skills, the ability to think on their feet, and a long-term impact on their world-view. With the phenomenon of globalization, these skills are vital.

Furthermore, skills gained from studying abroad can be extremely applicable to the field of nutrition. For example, spending time on a lifestyle block in New Zealand learning how to grow food in a sustainable manner will help students learn about the "green revolution" we are seeing. Spending time in France or Italy, etc. will help students appreciate culinary cuisine at its finest. Being abroad in any country will help you learn about other customs, dietary habits, and differing cuisines. It is almost guaranteed to open up your mind to things that you would never have experienced while at home. Immersing yourself in another

culture will also help you relate well to others, including potential clients.

The trend in globalization demands that we are not merely citizens of the United States, but of the world. Our generation is responsible for knowing how to interact with a wide variety of people and cultures. Studying in another country enables you to compete with the best and the brightest in the field of nutrition.

About the Author: Stephanie Joppa is a pre-med student at the University of North Dakota with a double major in French and minors in nutrition and psychology. She is currently studying abroad at the Université de Caen Basse-Normandie, France during fall semester, 2010. Stephanie.Joppa@und.nodak.edu



Stephanie Joppa

BHN Webinars Planned

Watch for BHN webinar opportunities to gain knowledge and interact with nutrition professionals on behavioral health issues.

November 18, 2010 Addictions and Eating Disorders: Finding Balance in Recovery
1:00pm CST



Speaker: Mary E. Kuester, MA, RD, LD

Webinar Description: Many people who struggle with eating disorders struggle with substance abuse and visa versa. The BHN November 18, 2010 Webinar will explore the relationship between substance abuse and eating disorders including current research on brain chemistry,

neural pathways and common risk factors. We will also discuss the role of the dietitian in screening, assessment and treatment for these populations. Community and school based prevention programs will also be evaluated.

December 8, 2010 PKU and Motivational Interviewing
11:00am CST



Speaker: Eileen Stellefson Myers, MPH, RD, LDN, FADA

Webinar Description: Providing education and resources to patients and families with PKU may not be enough for them to follow their strict diet. Motivational Interviewing is a style of communicating and interacting that increases the likelihood of compliance while

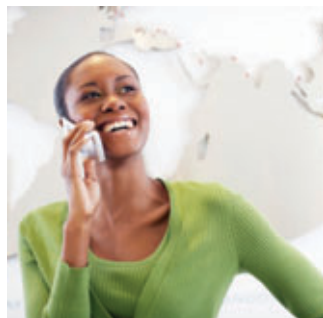
decreasing the RDs frustration. In this webinar, you will learn how to incorporate motivational interviewing into your assessment and counseling of patients and families with PKU.

Fall 2010 HOD Meeting

HOD Member Input Form



House of Delegates



Let delegates hear from you regarding the issues below so your voice can be heard at the **Fall 2010 HOD Meeting** (November 5-6, 2010 in Boston, MA). Member input is needed to help inform the knowledge foundation for governing the profession.

Please respond to the following questions by Wednesday, October 27, 2010. BHN Delegate contact information is below.

Health Reform – Next Steps

➤ Tell your delegate what is going on in your state in regards to health reform.

HOD Proposal: Establish an ADA Multidisciplinary Category

Quadrant 4: What are the advantages of keeping the membership categories as they are currently (no change)?	Quadrant 2: What are the advantages to adding a multidisciplinary membership category?
Quadrant 1: What are the disadvantages of not adding a multidisciplinary membership category (no change)?	Quadrant 3: What are the disadvantages to adding a multidisciplinary membership category?

HOD Delegate Contact Information

Leslie Schilling, MA, RD, CSSD is the delegate for BHN and can be contacted at leslie@schillingnutrition.com 901.628.8102 cell, 901.761.5933 fax. For more information on these topics, visit www.eatright.org/hodmegaissues.

Proposed Revision of Medical Criteria for Evaluating Mental Disorders

Federal Register Document

2010-20247 Filed 8-18-10; 8:45 am

The Social Security Administration has proposed revisions to the Medical Criteria for Mental Disorders as it appears in the Federal Register on August 19, 2010. The intent of the proposed changes is to update the criteria for eligibility for benefits under titles II and XVI of the Social Security Act (most notably Social Security Income and Social Security Disability Insurance) so that applications will be evaluated based on the most current diagnostic criteria, assessment strategies, and understanding of the course of the disability. The proposed revisions reflect the adjudicative experience and advances in medical knowledge, treatment, and methods of evaluating mental disorders that have occurred since we last revised; mental disorders listing for children was last revised on December 12, 1990 and for adults on August 28, 1985. The proposed revisions include 12.02 Dementia and Amnesic and Other Cognitive Disorders, 12.04 Mood Disorders, 12.05 Intellectual Disability/Mental Retardation (ID/MR), 12.10 Autism Spectrum Disorders and the inclusion of 12.13 Eating Disorders.

The proposed revisions are open for comment, received no later than November 17, 2010. You may submit

comments by any one of three methods:

- Internet Federal eRulemaking portal at <http://www.regulations.gov>. Use the Search function to find docket number SSA-2007-0101.
- Fax comments to (410) 966-2830; Be sure to state that your comments refer to Docket No. SSA-2007-0101.
- Mail your comments to the Office of Regulations, Social Security Administration, 137 Altmeyer Building, 6401 Security Boulevard, Baltimore, Maryland 21235-6401.

The electronic file of this document is also available on the date of publication in the Federal Register at

<http://www.gpoaccess.gov/fr/index.html>.

Are You Seeking a Great Opportunity?

BHN is offering the opportunity to get involved in the future of Behavioral Health Nutrition. If you want to advance skills in the following areas, now is the time!

Nominations needed for the 2011- 2012 Officers, beginning June 1, 2011:

- Chair-Elect
- Treasurer
- Nominating Committee

Volunteers needed to fill non-elected positions:

- Publications Chair
- Sponsorship Chair
- Eating Disorders Resource Professional
- Intellectual/Developmental Disabilities Resource Professional

If you would like to volunteer or nominate another BHN Member, please contact Sharon Lemons, RD, LD, Nominating Committee Chair at slemons@prodigy.net.

Deadline for officer nominations is October 15, 2010.

A Call for Action!

Cinde Rutkowski, MA, RD, FADA
BHN Public Policy Liaison

It's that time again - mid-term elections. National, state and local campaigns are in full swing. The media is actively focusing on the candidates and their positions on the issues as they see them affecting their constituency. Who are the candidates on your ballot in November? What are their positions on legislation that will affect you as a Food and Nutrition Professional? Are you willing to make a phone call, write a letter or send an e-mail to the candidates to learn their views? Will you continue communicating with them regarding the issues that affect you, your Dietetic practice and the health of your patients/clients? The time for action is NOW.

The Legislative and Public Policy Committee (LPPC) of the American Dietetic Association guides the establishment of ADA's policy regarding legislative, regulatory and public policy issues at both the national and state level. The LPPC reports to ADA's Board of Directors and the House of Delegates. The Committee meets once a month via conference call and at the annual FNCE and Public Policy Workshop events.

The LPPC collaboratively receives information, positions and guidance from other ADA committees, Task Forces, working groups, teams and DPGs to fulfill its responsibilities to the ADA membership. The LPPC consists of twelve ADA members, the President-elect, Speaker of the House, ADAPAC Chairman and others who serve as Ex-officio members as needed; however, this year, the LPPC currently sits eight voting members and three Ex-officio members. The current Public Policy Priority Areas that the LPPC has defined for ADA are Aging, Child Nutrition, Food and Food Safety, Health Literacy and Nutrition Advancement, Medical Nutrition Therapy and Medicare/Medicaid, Nutrition Monitoring and Research.

To learn techniques on speaking effectively as the food and nutrition expert that you are, click on the *Take Action* link at the Public Policy section on the ADA Member Center page. (<http://www.eatright.org/members>) Advocacy Tutorials, Recorded Webinars, Grassroots Advocacy: How ADA's Affiliate Structure Works, Congressional Materials, Congressional Visits FAQs, ADA Stance on Scope of Practice and the ADA Grassroots Report are available. You can also access the *Grassroots Manager* to find ADA LPPC initiated Action Alerts to help you stay in touch with your Legislators on key legislation regarding food and nutrition issues. Consider it your all-access pass to your elected officials and other VIPs in the political arena. This direct link to legislators is extremely important...they want to hear from you!

Remember to vote on November 2nd!

50 Year ADA Members to be Recognized!

BHN is pleased to honor members Thelma Anderson, RD, CD, and Carol Nealon, RD, for fifty years of ADA membership, having joined the American Dietetic Association during or prior to 1960. In recognition of their 50th year of membership, the honored members receive complimentary registration to attend the Food and Nutrition Conference and Exposition (FNCE) in Boston and receive special recognition at an honor ceremony.

BHN Members who over the past fifty years or more have been members of the American Dietetic Association will also receive special recognition at BHN's member reception and awards during FNCE. Plan to join in this special time to honor such dedicated dietitians and nutrition professionals!

BHN's 50 years and over ADA members are:

- Laverne Anderson, RD, Michigan, 1947
- Thelma Anderson, RD, CD, Indiana, 1960
- Betty Brigman, RD, California, 1959
- Virginia Casteen, MBA, RD California, 1950
- Harriet Cloud, MS, RD, Alabama, 1946
- Rita Connelly, Retired RD, Texas, 1953
- Shirley Ekvall, PhD, RD, LD, Ohio, 1957
- Barbara Gaffield, MS, RD, Virginia, 1949
- Dorothea Meagher, RD, LD, Oregon, 1950
- Carol Nealon, RD, Massachusetts, 1960
- Elaine Sasso, RD, Illinois, 1958

Are you looking for opportunities to satisfy your CPE requirements?

Find professional development resources at Shop ADA, available on the **Eatright.org** web site.

You will find the following resources and more:

- **Face-to-Face Learning »**
- **Live Teleseminars »**
- **Individual Online Learning »**
- **Audio Recordings »**
- **Books and Publications »**
- **Webinars »**

The following link will provide you with a list of current CPE opportunities

<http://www.eatright.org/Shop/Categories.aspx?id=381>

Free CKD Nutrition Materials from NKDEP Now Available

<http://nkdep.nih.gov/professionals/ckd-nutrition.htm>

The National Kidney Disease Education Program (NKDEP) has developed a suite of materials to help registered dietitians provide effective Medical Nutrition Therapy (MNT) to chronic kidney disease (CKD) patients who are not on dialysis.

The purpose of MNT for CKD is to maintain good nutritional status, slow progression, and treat complications.

Some of the therapeutic interventions for CKD are similar to those required for optimal care for diabetes and hypertension—the two leading risk factors for CKD. Many interventions can be initiated by RDs in the primary care setting, before a referral to a renal specialist.

These free, downloadable, and reproducible materials are designed to distill key information about CKD and diet for RDs and their patients. The patient materials are written below a seventh grade reading level.

BHN: Setting the Standard for Nutrition in Behavioral Healthcare

Vision: Impact the nutrition of the behavioral health populations we serve.

Mission: Empower BHN members to be the experts in

- Intellectual and Developmental Disabilities
- Eating Disorders
- Mental Illness
- Addictions

- Goals:**
1. The public recognizes, trusts, and chooses our members as the experts in behavioral health nutrition.
 2. Members and prospective members view BHN as essential to their professional success.

ADA website: <http://www.eatright.org>

BHN practice standards:

BHN website: <http://bhndpg.org>

<http://bhndpg.org/moa/practice/index.asp>

Behavioral Health Nutrition Executive Officers 2009-2010

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Student Liaison Committee Chair

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A complete list of BHN Executive Committee members and volunteers is available at www.bhndpg.org

BHN PUBLICATIONS

The Adult with Intellectual and Developmental Disabilities

This resource tool is designed to provide an overview of nutrition in individuals with intellectual and developmental disabilities. The resource guide is contained on one CD-ROM as a 209 page PDF file.

BHN Member Price: \$28.00



Psychiatric Nutrition Therapy

This resource guide is intended for anyone working in the 4 practice areas within Behavioral Health Nutrition: mental illness, eating disorders, addictions, and those with intellectual and developmental disabilities who also require psychiatric care. The resource guide is contained on one CD-ROM as a 170-page PDF file.

BHN Member Price: \$28.00



Nutrition & Addictions

This is a 244-page manual of information about addiction and drugs of abuse, including legal, illegal and pharmaceutical drugs, alcohol, nicotine, caffeine, and more. Patient educational handouts on nutrition and recovery topics are also included.

BHN Member Price: \$24.95



To order, visit

<http://www.bhndpg.org/publications/index.asp>

Revision of the Psychiatric Nutrition Therapy Publication is Planned
BHN members interested in joining the workgroup should contact Sharon Lemons at slemons@prodigy.net.