

BHN: Fuel Your Brain, Feel Your Best!



BHN Case Study 2016-3

Submitted by Tina Hornberger

The RDN uncovers a familial link that resulted in successful treatment when the patient's diagnosis was conditionally changed from Anorexia Nervosa to 3-methylcrotonyl-CoA carboxylase deficiency (3MCC Deficiency), an inherited metabolic disorder. The patient felt empowered once she understood the reasons for her eating habit and followed the dietary and supplement recommendations.

HIPAA identifiers, including unique patient characteristics were removed prior to submission and publication.

1. **Anonymous ID Number:**
2016-3

2. **Primary Behavioral Health Category*:**
 AD; ED; IDD; MH

3. **Age:** 17

4. **Gender:** Female

5. **Diagnoses:** Major Depressive Disorder, Post Traumatic Stress Disorder, Anorexia Nervosa

6. **Medical Conditions:** Recent hospitalization for intractable nausea and vomiting, History of abdominal pain with nausea/vomiting/diarrhea; history of dysfunctional uterine bleeding, history of costochondritis, history of GERD, history of headaches.

7. **Medications:** Rx: Zoloft, Trazadone; OTC: Multivitamin, Ibuprofen at mealtimes;
Added later: 1 g Carnitine/day

8. **Relevant Family History:** The patient had an extensive family history of mental health issues: bipolar disorder, anxiety disorder, schizophrenia, PTSD, Borderline Personality Disorder. Her mother and an aunt had been diagnosed with anorexia and bulimia. The patient later reported that her mother had been diagnosed with a metabolic disorder 6 years ago. She also had a brother that tested positive for the same metabolic disorder. The patient had also been tested and the results were negative.

9. **Relevant Laboratory Results:** IgA 26, (N: 60-337 mg/dl); Negative for celiac disease; blood carnitine level 25 nmol/mL (reference range: 34-77 nmol/mL)

10. **Nutrition Physical Exam:** Height: 60 inches; Weight: 94.8 pounds; BMI: 18.47; Wt History: Patient reported lowest weight in the past year was 88 pounds. Highest weight was 103 pounds and she tended to stay closer to mid 90's. She didn't weigh herself often because then she wouldn't eat for 2 days due to anxiety/stress about her weight. She usually weighed herself in response to someone else wanting to know how much she weighed. She reported some swelling in her knees, and stated the swelling was worse on the right side. Patient reported her goal weight is to be 115-118 pounds.

11. **Reported Diet & Supplements:** Patient with eating issues since age 5, which got worse around age 11 with both restricting and purging reported. She had a recent 1-week inpatient stay in the hospital for intractable vomiting. She states the last time she threw up was eight days ago. Until she was admitted to the hospital, typical intake up had been

Learning Objectives:

Upon completion of studying this case participant will be able to describe the nutrigenetics, symptoms, and dietary treatment of MCC (3-methylcrotonyl-coa-carboxylase-deficiency).



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From the Chair

Janice Scott, MS, RDN, CSP, LD



Spring is a time of renewal. The weather is warmer and we're coming out of our caves. It seems to me that winter makes many of us introspective and even the boldest of us – a little introverted. But spring – spring brings us hope and encouragement to see what the world has to offer and what we can offer to the world.

The BHN DPG represents registered dietitians that provide nutrition care for people at their most vulnerable. Behavioral health dietitians walk alongside men and women who may be unable to see a way out of their current situation. We often listen more than we speak, offer a compassionate word rather than a directive and share a level of understanding that might be born of personal experience.

Over this past year, I have met many members that offer nutrition insight that comes only from having lived it. BHN dietitians may be raising children with intellectual and developmental disorders and provide advice honed from days and nights of difficult feeding. Recovery from their own eating disorder allows other dietitians special awareness of the struggles faced by their clients. Dietitians working in mental health and addictions often work without recognition to help patients regain health and hope.

Nelson Mandela stated it best when he said, "Our human compassion binds us the one to the other - not in pity or patronizingly, but as human beings who have learnt how to turn our common suffering into hope for the future."

http://www.mandela.gov.za/mandela_speeches/2000/001206_healing.htm

This is the time of year for renewing our Academy membership. We join because we know the benefits we receive for our dollars. We are members of a large empathetic family that has made its mission to serve people. We encourage current members to renew their BHN DPG dues and new members to give us a try. You will be welcomed with open arms into one of the best DPGs in the Academy.

When you consider which practice group to invest in, you carefully look at member benefits and what you possibly have in common with practice group members. The executive committee of BHN wants you to know that the care provided by behavioral health members is exemplified by the highest principles. The Academy's Focus Area Standards of Practice and Standards of Professional Performance (SOP/SOPP) for both Intellectual and Developmental Disorders and for Mental Health and Addictions were researched, revised and vetted by expert members of our practice group. A 2018 update of the Mental Health and Addictions Standards is currently in process by the Quality Management Team and is due for publication online in September (full version) and printed in October (minus figures 1&2). The IDD SOP/SOPP are currently in the process of being updated. And in the coming year, our members will be collaborating to publish Focus Area SOP/SOPP for Disordered Eating and Eating Disorders.

Finally, to close this letter, this year and my term as BHN chair, I leave you with a quote from Queen Elizabeth II. "I know of no single formula for success. But over the years I have observed that some attributes of leadership are universal and are often about finding ways of encouraging people to combine their efforts, their talents, their insights, their enthusiasm and their inspiration to work together."

www.cnn.com/2010/WORLD/europe/07/06/england.queen.un.speech/index.html

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dry cereal in the morning and dry cereal at school. She would sometimes eat something for dinner, but sometimes there “wasn't much to eat in the house” – but usually that was just an excuse to not eat, not a true reality. Dry cereal was basically all she ate. She reported digestion issues lately – vomiting chunks of food or diarrhea with chunks of food. She usually would not eat much at school because if she did, she would get really tired and fall asleep. She prefers to drink ginger-ale. She doesn't like “diet stuff” and prefers regular ginger-ale. At home she drinks mostly water and tea with artificial sweetener. She reported drinking some milk at school but also reported some lactose intolerance. Reported controlling food very well at home but says food is controlling her now instead of the other way around. Prefers to refer to food issues as “Ana”. While in the hospital, prior to transferring to the inpatient psychiatric unit, she had been eating most of her meals and snacks.

12. Information from Consults/

Referrals: Patient admitted to inpatient Psychiatric Unit for suicidal thoughts, anxiety, depression and eating disorder. Extensive GI workups were inconclusive and she was referred to an outpatient eating disorder clinic. The patient admitted to purging behaviors in the past, but denied actively making herself throw up currently. Patient did have history of sexual abuse and reported that some of the motivation to stay thin was to avoid getting curves. Restricting food was also a way to cope with anxiety.

The treatment team consisted of psychiatrist, medical doctor, care coordinator (social worker), nurse, behavioral health specialist, and the dietitian (RDN) (consulted when the nutrition admission screen shows nutrition risk). The RDN was consulted to address eating disorder and purging.

13. Relevant Observations: Patient was eating 95% of meals. Her weight went from 94.8 pounds on admission to 95.9 pounds 2 days later. She was feeling constipated. She mentioned that her mom had to follow a special diet at home and didn't eat much meat. Her mom had been diagnosed six years ago with a metabolic disorder.

14. Nutrition Diagnoses: Disordered eating pattern (NB-1.5) related to controlling environment/anxiety/unknown cause, as evidenced by food intake

15. Guidelines or Criteria Utilized: Estimated nutrition needs: 35 g protein (0.8 g/kg), 1490-1780 kcal/day based on a sedentary (x 1) to low active (x 1.19) for activity level.

16. Nutrition Care Plan: Allow patient to select her food preferences from the menu, as she had been doing this already for two days with weight gain. The dietitian asked her to choose a variety of different foods from different food groups as patient's food history showed she tended to eat only one food: cereal.

17. Patient Response: Patient appeared motivated to make a change to eating habits. She set goals: to get to a healthy weight (115-118#); to eat without getting sick afterward; to be able to walk without losing her balance.

18. RDN Response/Expectation: This patient did not exhibit the typical relationship to food that is seen with patients with anorexia nervosa. While she did endorse some body image issues, she seemed eager to gain weight. After sleeping on this information for one night, the dietitian asked the patient for more information on the metabolic disorder that her mother had been diagnosed with 6 years ago. The patient reported that it was 3MCC deficiency. (3-methylcrotonyl-CoA carboxylase deficiency). 3MCC deficiency occurs when the body lacks the enzyme to break down the amino acid leucine.

The dietitian researched the symptoms and treatment of this

deficiency (*see also Supplementary Material*) and noted that the symptoms correlated closely with the patient's medical history and the patient's description of her eating habits. Symptoms of 3MCC include recurrent episodes of vomiting and diarrhea, excessive tiredness (lethargy), and weak muscle tone (hypotonia). Metabolic crisis can occur when a patient goes for a long time without food or if they eat too much protein. Sometimes symptoms do not show up until later in childhood. The patient's recent hospitalization with intractable nausea and vomiting could have been the result of a metabolic crisis. The patient's report of not eating at school so that she could stay awake matched the symptom of excessive tiredness.

19. Follow-up/ Progress: Follow Up #1: The dietitian printed out an information sheet about 3MCC deficiency and met with the medical physician. The medical physician was in agreement that the patient's symptoms matched the 3MCC deficiency symptoms and ordered lab tests to measure for blood levels of carnitine. The dietitian met with the patient and the patient reported that when her mother was diagnosed with this 6 years ago, that they had checked tests done at her birth and her brother had tested positive for this, but she had tested negative. However, she agreed that her symptoms very closely matched the symptoms described for 3MCC deficiency.

Medical Nutrition Therapy was reviewed and the patient was encouraged to limit protein intake. The patient declined counting grams of protein stating that she had tried to count calories in the past but found it cumbersome and not something she would continue. Also discussed the recommendation for carnitine supplementation: 1 gram of carnitine three times/day. Patient was in agreement that we would trial this approach to eating even though there was not a definitive diagnosis of her having 3MCC deficiency.

Follow Up #2: 3 Days later, the patient's weight was 96.2 pounds.

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Calorie counts showed that she was eating 2400-2700 kcals per day; 53-64 g protein per day. The patient reported much less post-meal pain than what was typical for her. She noted that she tried peanut butter, but immediately felt worse and had diarrhea. Otherwise, her body had adjusted and she was having one bowel movement per day and the swelling in her knee had subsided. She also noted that she was not feeling so tired after meals. She noted that she still had an urge to purge after meals but was not acting on it.

Final Follow-Up: Patient discharged from inpatient psychiatric unit 10 days later after having made significant progress with eating disorder symptoms. She was eating >2200 kcal/day, 40-55 g protein/day. Staff reported that she was free from the desire to restrict or purge food and she was focusing in therapy sessions on her emotions around some family issues. Her discharge weight was 98.2 pounds and staff reported that she was worrying about being able to keep the weight that she had gained as she did not want to lose it. The dietitian recommended that she follow-up with the same specialist that her mother saw for further 3MCC deficiency testing and treatment. After the patient was discharged, the lab test for blood

carnitine level finally came back and the patient tested low at 25 nmol/mL (reference range: 34-77 nmol/mL).

20. Lessons Learned from this Case:

On admission, neither the patient nor the mother included the 3MCC deficiency in the family history. It was only reported to the dietitian as a result of the dietitian completing a thorough food intake assessment. By doing a thorough assessment, the dietitian was able to give the patient the tools she needed to feel better physically and the treatment team was able to focus on the emotional issues that the patient presented. Dietitians are critical treatment team members. This patient was in many ways the anti-thesis of a typical patient with an eating disorder who stops listening to their body's hunger cues. Her symptoms and food restricting was an attempt to listen to the fact that her body could not metabolize protein. Once she understood why she would restrict food and that she could eat food as long as it wasn't high in protein, she became empowered. She had no trouble eating enough food to gain weight without extra staff encouragement.

Supplementary Material

3MCC Deficiency is a genetic inborn error of metabolism where one of the enzymes necessary for breaking down the amino acid leucine is lacking. This causes an increase in toxic byproducts

(3-hydroxyisovalerylcarnitine, etc.) if too much protein is consumed. L-carnitine supplementation is beneficial for ridding the body of these toxic byproducts. Carnitine also plays an important role in fat metabolism by transporting long-chain fatty acids into the mitochondria to be used to make energy. In 3MCC deficiency, the endogenous supply of carnitine is not enough for both breaking down toxic byproducts of incomplete protein metabolism and for metabolizing fat into energy. People with carnitine deficiency tend to consume a steady supply of carbohydrates in order to have energy.

Treatment for 3MCC deficiency is to follow a low leucine diet (essentially low protein) and to provide L-carnitine supplementation. Diagnosis for 3MCC deficiency is through urine organic acid analysis and blood levels of acylcarnitine.

Additional Resources:

http://www.kdheks.gov/newborn_screening/download/ACT/3MCC_Deficiency_Info_for_Health_Professionals.pdf

<https://ghr.nlm.nih.gov/condition/3-methylcrotonyl-coa-carboxylase-deficiency>

<http://www.newbornscreening.info/Parents/organicacid disorders/3MCC.html>

Rutledge SL, Berry GT, Stanley CA, van Hove JL, Millington D: Glycine and L-carnitine therapy in 3-methylcrotonyl-CoA carboxylase deficiency. *J Inherit Metab Dis.* 1995;18(3):299-305.



CPE credit (1.0 hour) is available from BHN for the full text version of the article, BHN Case Study 2016-3 Access the article at <http://www.bhndpg.org/cpe-articles-quizzes>

CPE Questions for BHN Case Study 2016-3

- MCC is a genetic inborn error of metabolism resulting in the inability to breakdown
 - carnitine
 - leucine
 - proteins
 - sucrose
- Supplementary carnitine is needed to
 - act as a precursor for lactic acid catabolism
 - correct a deficiency of leucine
 - excrete by-products of excess protein consumption
 - increase the efficiency of glycogenesis
- Diagnosis of the nutritional problem was based on
 - Correlating Patient's symptoms with symptoms of MCC
 - Improvement of patient's symptoms following initiation of low protein diet.
 - Information from GI workups
 - a and b
- Which of the following is a symptom of MCC?
 - High carnitine blood levels
 - Increase appetite
 - Lethargy
 - Taste changes

Evaluation of Food-Related Programs for Individuals with Autism Spectrum Disorder: “The Snack Zone” Part 2

by Janice Goldschmidt

In Part 1 of this series, the nutritional trends for adults with autism were examined and *Active Engagement*, a program for teaching cooking skills to individuals with disabilities, was introduced as a form of hands-on nutrition education (HONE). Implementation strategies were illustrated through a description of The Snack Zone (TSZ), a community based snacking program.

In this follow-up article, there will be a discussion of the ways in which hands-on programs, such as *Active Engagement*, can best be evaluated for effectiveness (both in terms of participant assessment and program evaluation). This is a particularly important topic when working with populations that manifest cognitive and communicative deficits, as data collection strategies must be carefully considered.

Assessment and Evaluation on the Autism Spectrum

Evidence-based practice is the goal for all those working in health-related fields. The reality, however is that most empirical findings are organized around components that can be measured. In the context of individuals with autism, this has often meant quantifying discrete aspects of programs rather than determining how interventions are manifested in authentic behavior change.¹ In defining what metrics to assess, it is important to distinguish between the relatively straightforward use of biomarkers and the type of data that often results from behavioral interventions (e.g. level of program satisfaction).

The type of problems that arise for individuals with communicative and cognitive disabilities when they are drawn into the process of assessment or evaluation are diverse but include difficulties in discussing experiences, providing opinions or insight, or contributing any kind of quantitative estimation or measurement.² A significant proportion of those on the spectrum are non- or minimally verbal (less than 10 words). Because of these considerable challenges, traditional views of “participation” for this cohort seem somewhat problematic.

It becomes even more complicated in terms of defining the questions to be posed. What constitutes participation?

What is the definition of a “successful” intervention in the realm of snacking for individuals with autism? Is it simple attendance? Is it partaking of a snack? Is it not consuming when full? Is it socially interacting when present within a group? Even a cursory examination of the issue makes clear that reducing involvement to a discrete, measurable parameter transforms a rich experience into a restricted one.

One typical approach to this problem is to simply bypass communicative and cognitive challenges by gearing programs to the highest functioning cohorts. Though neither well studied – or readily acknowledged – there is a “disquieting research trend”³ in disability studies whereby most research protocols are designed specifically for those individuals who can appropriately communicate perspective:

“To have a perspective, one needs language. To have a perspective means to formulate an individual vision, opinion or narrative about the world that represents your experiences. Consequently, if you cannot speak or fill out questionnaires, you cannot produce a perspective.”⁴

Though some believe this skew in research towards higher functioning individuals is done merely for “convenience”,⁵ there is currently no consensus as to whether outcomes

addressing high functioning individuals are applicable – or appropriate – across the autism spectrum.

How, then, to design an assessment/evaluation process with appropriate data collection that is simultaneously rigorous and yet values the experiences of those with impairments? One of the most common means for assessing program outcomes in community-based health promotions is to have participants perform pre- and post-test activities, often in the form of questionnaires. The appeal of this approach is that it allows the attitudes or competencies developed during an intervention to be converted to scores, which can then be manipulated statistically. The communicative and cognitive deficits of many adults with autism would preclude them from participation in this type of activity. Consequently, if this form of evaluation is to be utilized, proxies (typically caregivers or support staff) must be used who can use experience or familiarity with the individual to approximate their response.⁶ Though relatively easy and inexpensive to implement, this is clearly not ideal and may compromise the data collected.⁷ It has also been noted that the closeness of the proxy relationship and the type of information collected is likely to affect outcomes.⁸

Another often utilized assessment technique is to judge skill acquisition through measurement of performance

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standards. This type of methodology has been used in a variety of programs that attempted to teach individuals with autism spectrum disorder or intellectual disability to prepare a frozen pizza,⁹ assemble cheese and crackers,¹⁰ or make a peanut butter and jelly sandwich.¹¹ In these contexts, the end-product was limited in scope and successful completion of the program task was well defined.

The advantage of such an approach is that it requires the researcher only to observe the behavior of interest for purposes of data collection. However, observing human behavior is time consuming, limits the sample size, and is difficult to accomplish in a group setting. Moreover, many food-related projects are not necessarily easy to demarcate or define, particularly where choice and individualization are involved. For example, an individual may successfully prepare the sandwich per program goals, but then refuse to eat it. Or a participant might eat a sandwich, if offered, but refuse to prepare it. How are these nuanced behaviors to be quantified in the assessment process?

In the field of special education, single-subject research designs (SSRD) are the most common means used for assessing outcomes. The advantage of this technique is that it allows measurement of distinct parameters for each participant so that an individual can serve as his or her own control.¹² For example, data could be collected on "Ben" during his time in TSZ to assess intake; perhaps he is often fixated on carrots to the exclusion of all other vegetables so the goal is to increase variety by having him try another option. At the same time, "Katie" refuses to eat any fruits or vegetables, so any form of intake would be a success. Perhaps "Laura" is a continual binge eater so not eating in the presence of a full stomach would be a program gain for her.

The advantage of the SSRD approach is that each person's skill advancement

or retreat can be measured by a different standard; the downside is that it still requires progress to be assessed along discrete and measurable metrics although food preparation is a rich and complex behavior involving many skill sets. Further, because it is necessary to continually observe the behavior of interest, SSRD often requires a clinical setting rather than a social group context. Though SSRD remains useful for assessment at the individual level, such as for measuring outcomes for goals in an Individualized Education Plan, this is not likely to be a meaningful approach for assessment or program evaluation in the realm of teaching food preparation skills.

Clearly greater insight is needed into human behavior when attempting to evaluate outcomes on the autism spectrum – particularly the motivations and experiences of participants.¹³ To get around problems of these types, serious consideration should be given to qualitative methods of analysis which have been used in a wide range of autism studies,¹⁴⁻¹⁷ typically involving interviews of high functioning individuals or of caregivers and support staff. Autobiographical accounts have also shed tremendous light on the experience of those with the capacity to comment on the world around them.¹⁸⁻²⁰ It should be noted that qualitative approaches need not be in lieu of quantitative approaches, but as an additional resource that can provide supplementary information on program experiences.^{21,22}

Built upon the premise of incorporating participant perspective, qualitative research emphasizes descriptive (often subjective) outcomes rather than predictive conclusions. Because of this capacity to reorganize and interpret data, qualitative methodologies are considered vital in the generation of hypotheses. Further, qualitative methodologies offer the researcher the ability to "develop an in-depth understanding of particular cases or circumstances."²³

Likewise, this type of methodology offers numerous advantages for researchers and practitioners working with the nonverbal or cognitively impaired. First, such approaches allow nonverbal actions to be considered as a form of communication. In the realm of food this is most readily manifested in the act of eating which signifies an expression of opinion.²⁴ Second, along with bypassing certain communicative issues, qualitative analysis is also useful in research contexts where an intervention affects each participant differently, leading to distinct outcomes. For example, among participants in TSZ activities, described in part 1, no two journeys were the same. Each individual struggled with highly individualized challenges that were, in turn, manifested in unique trajectories.

Qualitative data collection and analysis can be done through a variety of means, and can even be a tool in prescribed program evaluation.

- **Interviews** with caregivers and support staff regarding their observations and opinions can be a rich source of information as to the ways that individuals with disabilities respond to an intervention; this is particularly useful when gains are evident but disjointed, or where participant responses to program components seem illogical or contradictory.
- **Case studies** can also provide an appropriate methodology to capture behavior change, typically following a single individual through their progression, although multiple cases can also be examined. There are also a variety of case study formats that greatly expand the possibilities for use. These include methodologies that provide exploratory analysis, define program components, highlight social analysis or community structure, or compare or contrast research hypotheses.²⁵
- **Narrative approaches** offer a powerful framework for contrasting the ways that different students will progress through a program that

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is highly individualized. This type of approach offers the researcher the opportunity to focus on how program components are adapted by a range of participants rather than single out a particular journey. A narrative review of participation in TSZ, for example, demonstrates how no two individuals have the same experience in this snacking program.

- **Classic ethnographic techniques** can be useful in assessment as they allow for data collection as part of immersion in the program.²⁶ Ethnography is a tool of anthropology that puts an emphasis on “culture” or exposing how an individual fits into the larger social context. This is a particularly effective method for those researchers who want to interact within a program context, rather than just observe.

Thus, while quantitative analysis offers the ability to assess the effectiveness of specific metrics, qualitative analysis extends the opportunity to focus on differential and multi-component responses and opens up the possibilities for evaluating the nature of participation for nonverbal and cognitively impaired cohorts.²²

Unless there are specific constraints on assessment due to funding requirements, the reality is that all the methods described here can contribute to a better understanding of the behaviors of individuals with autism. In a given day in TSZ, for example, many participant actions can be observed – some positive, others not. No one assessment technique can capture meaning for those who cannot verbally express their experience. Having staff and caregivers complete questionnaires or answer open-ended questions; observing individuals as they respond to program stimulus (both in the short and long-term); and noting the nature of social interaction during program activities are

all viable means of gaining insight.

Having provided an overview of the difficulties of data collection for individuals with autism, it is also important to consider the differing types of formal program evaluation.

Program Evaluation

Program evaluation is undertaken not only to justify efforts but also to build a better practice, create accountability and to serve as a form of applied research.²⁷ As such, program evaluation strives to define stakeholder values and determine whether they are being addressed in the process of program implementation.

Often denoted by the acronym **SCREAM**, the evaluation should:

- measure **(S)trengths**
- honor **(C)ulture**
- acknowledge the limits of **(R)esources**
- follow all appropriate codes of **(E)thics**
- determine evaluation protocols under written **(A)greement** with all stakeholders
- **(M)easure** change across as many systems as appropriate²⁷

Another way to approach evaluation of program efficacy is through employment of “standards.” Standards can offer dimensions to assist in the development of evaluation tools and must be open-ended enough to be applied in very diverse contexts. The program evaluation standards typically employed include *utility, feasibility, propriety, accuracy and evaluation accountability*.²⁸

There are differing genres of program evaluation – including process, fiscal, impact, outcome, and formative or summative – all of which vary in terms of what is being assessed. Drum et al.,²⁹ argue that interventions for individuals with disabilities should prioritize process evaluations based on the belief that obtaining feedback from the disabled is vital to assessing the authentic effectiveness of programs

for this cohort. **Process** evaluations emphasize how a program works and seek to define the mechanisms that bring about success (or fail to). To be effective, however, such evaluations should establish “outcome measures appropriate for people with disabilities”.²⁹ Though laudable, working with those on the autism spectrum is more complex than providing a survey in braille or having an interpreter translate during an interview.²⁹

Other types of evaluation offer different insight into outcomes. A **fiscal** evaluation provides a view of the program as a function of participation and costs; is the financial investment paying off? An **impact** evaluation can look at the most telling indicators of success by focusing on the underlying beliefs, knowledge and attitudes of program participants. This, of course, requires that participants provide such insight, or have proxies who can do so. **Outcome** evaluations focus on health-related results (e.g., weight loss or improved hemoglobin A1C). However, assessment of physiological changes cannot be measured in the short-term and most interventions have neither the personnel nor resources to track participants for the extended time periods that are required to demonstrate a positive (or negative) effect on health. Lastly, while a **formative** evaluation addresses the implementation or creation of a pilot or new program, the **summative** evaluation assesses whether goals were met upon completion of the program.

This short overview demonstrates that both participant assessment and program evaluation require careful consideration when working with those on the autism spectrum. The challenges involve not only the need to sensitively consider data collection, but also ensure that hands-on teaching contexts are not reduced to one-dimensional concepts. The extent to which these types of issues will be significant impediments to program development will likely parallel funding needs and requirements.

Autism research in the last several

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decades has opened up to incorporate a multi-disciplinary perspective. This series has argued that nutrition professionals are uniquely positioned to contribute to this population and help to mitigate the many food-related pathologies they experience. One means for doing so is through the development of proficiency in food preparation, which can both foster important life skills and enhance nutritional status.

About the Author

Janice Goldschmidt, MS, RD, LDN has worked with individuals with autism for the last decade and has written and presented on her work in a wide range of professional formats. In her capacity as Director of Nutrition Services at Community Support Services, Inc. (Gaithersburg, MD) she is responsible for the development and implementation of nutrition-related cooking programs. In June, 2018, the American Association on Intellectual and Developmental Disabilities (AAIDD) will publish her first book entitled *Teaching Authentic Cooking Skills to Adults with Intellectual and Developmental Disabilities: Active Engagement*. She welcomes questions about her work and can be reached at jgoldschmidt@css-md.org.

References Cited

- Mesibov, G. B., & Shea, V. (2011). Evidence-based practices and autism. *Autism*, 15(1), 114-133. doi:10.1177/1362361309348070
- Finlay, W., Lyons, E. (2001). Methodological Issues in Interviewing and using self-report questionnaires with people with mental retardation. *Psychol Assess*, 13(9), 319-335.
- Dykens, E. M., & Lense, M. (2011). Intellectual disabilities and autism spectrum disorder: A cautionary note. In D. Amaral, G. Dawson, & D. H. Geschwind (Eds.), *Autism Spectrum Disorders* (pp. 263-269). New York: Oxford University Press.
- Pols, J. (2005). "Enacting appreciations: Beyond the patient perspective." *Health Care Anal* 13(3): 203-221.
- Brereton, A. V., & Tonge, B. J. (2002). Autism and related disorders in adults. *Curr Opin Psychiatry*, 15(5), 483-487. doi:10.1097/00001504-200209000-00004
- Jones, I., Marshall, J., Lawthom, R., & Read, J. (2013). Involving people with communication disability in research in Uganda: A response to the World Report on Disability. *Int J Speech-Lang Pathol*, 15(1), 75-78. doi:10.3109/17549507.2012.743175
- Robinson, S., Fisher, K. R., & Strike, R. (2014). Participatory and inclusive approaches to disability program evaluation. *Australian Social Work*, 67(4), 495-508. doi:10.1080/0312407x.2014.902979
- Stancliffe, R. J. (2000). Proxy respondents and quality of life. *Eval Program Plann*, 23(1), 89-93. doi:10.1016/s0149-7189(99)00042-7
- Giere, S., Rudrud E., McKay, S. (1989). A functional approach to meal planning, preparation, and shopping skills. *J Intellect Dev Disabil*, 15(2), 81-97.
- Fiscus, R. S., Schuster, J. W., Morse, T. E., & Collins, B. C. (2002). Teaching elementary students with cognitive disabilities food preparation skills while embedding instructive feedback in the prompt and consequent event. *Education and Training in Mental Retardation and Developmental Disabilities*, 37(1), 55-69.
- Rehfeldt, R. A., Dahman, D., Young, A., Cherry, H., & Davis, P. (2003). Teaching a simple meal preparation skill to adults with moderate and severe mental retardation using video modeling. *Behav Interv*, 18(3), 209-218. doi:10.1002/bin.139
- Horner, R., Carr, E., Halle, J., McGee, G., Odom, S., Wolery, M. (2005). The use of single-subject research to identify evidence-based practice in special education. *Except Child*, 71(2), 165-179.
- Ogilvie, D., Craig, P., Griffin, S., Macintyre, S., & Wareham, N. J. (2009). A translational framework for public health research. *BMC Public Health*, 9. doi:10.1186/1471-2458-9-116
- Barnett, J. P., & Maticka-Tyndale, E. (2015). Qualitative exploration of sexual experiences among adults on the autism spectrum: Implications for sex education. *Perspect Sex Reprod Health*, 47(4), 171-179. doi:10.1363/47e5715
- Jones, J. L., Gallus, K. L., Viering, K. L., & Oseland, L. M. (2015). 'Are you by chance on the spectrum?' Adolescents with autism spectrum disorder making sense of their diagnoses. *Disabil Soc*, 30(10), 1490-1504. doi:10.1080/09687599.2015.1108902
- Preece, D., & Jordan, R. (2010). Obtaining the views of children and young people with autism spectrum disorders about their experience of daily life and social care support. *Br J Learn Disabil*, 38(1), 10-20. doi:10.1111/j.1468-3156.2009.00548.x
- Sciutto, M., Richwine, S., Mentrikoski, J., & Niedzwiecki, K. (2012). A qualitative analysis of the school experiences of students with asperger syndrome. *Focus Autism Other Dev Disabil*, 27(3), 177-188. doi:10.1177/1088357612450511
- Chamak, B., Bonniau, B., Jaunay, E., & Cohen, D. (2008). What can we learn about autism from autistic persons? *Psychother Psychosom*, 77(5), 271-279. doi:10.1159/000140086
- Davidson, J., & Smith, M. (2009). Autistic autobiographies and more-than-human emotional geographies. *Environ Plan D*, 28, 898-916.
- Elwin, M., Ek, L., Schroder, A., & Kjellin, L. (2012). Autobiographical accounts of sensing in asperger syndrome and high-functioning autism. *Arch Psychiatr Nurs*, 26(5), 420-429. doi:10.1016/j.apnu.2011.10.003
- Bolte, S. (2014). The power of words: Is qualitative research as important as quantitative research in the study of autism? *Autism*, 18(2), 67-68. doi:10.1177/1362361313517367
- Tomlin, G. S., & Swinth, Y. (2015). Contribution of qualitative research to evidence in practice for people with autism spectrum disorder. *Am J Occup Ther*, 69(5). doi:10.5014/ajot.2015.017988
- Kisely, S., & Kendall, E. (2011). Critically appraising qualitative research: a guide for clinicians more familiar with quantitative techniques. *Australas Psychiatry*, 19(4), 364-367. doi:10.3109/10398562.2011.562508
- Stafford, L. (2017). "What about my voice": Emancipating the voices of children with disabilities through participant-centred methods. *Child Geogr*, 15(5), 600-613. doi:10.1080/14733285.2017.1295134
- Yin, R. K. (2009). *Case Study Research : Design and Methods* (4th ed.). Los Angeles, Calif.: Sage Publications.
- Bailey-Goldschmidt, J. (2015). *Active Engagement: Development of Cooking Skills for Young Adults with Autism*. (Master's), University of Maryland, College Park, MD. (1592484)
- Brun, C. (2014). *A Practical Guide to Evaluation*. Chicago, IL: Lyceum Books, Inc.
- Yarbrough, D. B., Shulha, L., Hopson, R., & Caruthers, F. (2011). *The Program Evaluation Standards: A Guide for Evaluators and Evaluation Users* (3rd ed.). Thousand Oaks: SAGE Publications.
- Drum, C. E., Peterson, J. J., Culley, C., Krahn, G., Heller, T., Kimpton, T., . . . White, G. W. (2009). Guidelines and criteria for the implementation of community-based health promotion programs for individuals with disabilities. *Am J Health Promot*, 24(2), 93-101, ii. doi:10.4278/ajhp.090303-CIT-94

The Language of Hope: An Imperative for RDN and Psychotherapist Collaboration in Eating Disorder Treatment

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This article was adapted for BHN from a previous article: Siegfried, N. (2017). The role of hope in eating disorders recovery. 2017 Gurze/Salucore Eating Disorders Resource Catalogue. <https://www.edcatalogue.com/role-hope-eating-disorder-recovery/>

“Talking about hope makes me feel hopeless!” exclaimed a client during a group discussion on ways to build hope in eating disorder recovery. Hope is one of the most elusive, frightening, and yet essential components of treatment. Hope has been one of the most studied yet least understood aspects of recovery, and clinicians often underestimate its necessity to the recovery process. The message of hope is most often connected to the psychotherapy aspect of treatment; however, the voice of the registered dietitian/nutritionist (RDN) within an eating disorder treatment team wields significant power to decrease or strengthen hope in our clients. A united, focused collaboration between RDN and psychotherapist that weaves hope messages throughout the recovery journey can exponentially strengthen our clients’ ability to embrace hope as an essential component to their full recovery.

What is Hope?

“Hope is a salve to the soul. It is the small voice that whispers us through the inevitable pain of humanness to remind us that there is a “try again” after every failure, a get-back-up after being knocked down, and a being-found after being-lost.”¹ Hope holds relatable and buildable properties that are often described as vertical and horizontal. Vertically, hope has been considered a “Velcro construct” in which other positive emotions stick to it and build on top of it.² In other words, hope attracts other positive emotions, and when clients feel hope, they are more likely to feel joy, peace, and contentment. Horizontally, hope broadens perspective. During times of distress, our range of vision narrows so that we are unable to see possible solutions. Hope expands our view and reveals possibilities that were previously hidden, and

as a result can provide a sense of optimism, relief, and empowerment.

Hope and Eating Disorders Recovery

In mental health treatment, a lack of hope is a predictor of suicide attempts and completions;³ depression,⁴ physical illness, and mortality.⁵ Alternatively, the capacity for experiencing hope predicts decreased attrition rates,⁶ abstinence in drug and alcohol recovery,⁷ and improved quality of life.⁸ In eating disorders treatment, hopelessness has been identified as a risk factor for dropping out of treatment⁹ and a predictor of co-morbid depression and suicidality.¹⁰ Recently, as part of a larger study, improvements in hopelessness, as measured on the Beck Depression Inventory-2,¹¹ across the course of treatment predicted improvement in eating disorders symptoms, as measured by the Eating Disorder Risk Composite Score on the Eating Disorder Inventory (EDI-3).¹² Specifically, clients who had improvements in hope from admission to discharge were more likely to have improvements in their eating disorder symptoms from admission to discharge.¹³ At the time of this article, there have been no studies that have investigated hope as it directly relates to nutrition rehabilitation or to the role of the dietitian. It is the position of the authors that hope is a neglected concept in nutrition therapy. RDNs can benefit from the findings about hope in recovery for other disorders and with other providers, and apply these to their practice to enhance the recovery of their clients.

Building Hope through Authentic Connection:

When clients enter treatment, they are often disconnected from themselves and others. Authentic connection with

the treatment team is the pavement upon which hope is built, opening the passageway out of suffering. Through the safe connection to the psychotherapist and the RDN, clients can reconnect to hope, develop connection to self, and enhance recovery. This connection can be developed through consistent use of neutral, shame-reducing language and interactions that restore the clients’ hope in their capacity to change.

The therapeutic relationship has been identified as critical to client success in treatment. In fact, research suggests that the therapy relationship is as important as the type of intervention used in terms of patient outcomes.¹⁴ Hope has been identified as the foundation of the therapeutic alliance.¹⁵ *By accepting the client without judgment, the psychotherapist and RDN demonstrate optimism and hope that the client has the capacity for change.* “Hope bonding” is a term that has been used to describe the “formation of a sound, hopeful therapeutic alliance.”¹⁶ To strengthen the therapeutic alliance, the RDN can join the psychotherapist in co-leading process groups in which the client(s) share what the eating disorder represents, the top ten beliefs that the client holds about the eating disorder, or similar topic. The psychotherapist is the lead but the joint presence of the RDN reflects the interwoven nature of intangible emotions and tangible food and body. Likewise, the psychotherapist can join the RDN in co-leading nutrition therapy groups in which the client(s) explores feelings of judgement and shame around specific foods, the lack of trust in the body’s healing process, or comparable discussions. The RDN is the lead but the joint presence of the psychotherapist models a trusting relationship of mutual respect and support for the unique but similar roles that nutrition and thoughts/emotions play

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within disordered eating behaviors. Sessions or groups that actively reflect the collaborative partnership between psychotherapist and RDN elevate the authentic connections with the client and prevent splitting that often occurs if only individual sessions are provided. The fibers of connection between a client and the treatment team may be strands of hope that attach a client to the psychotherapist and RDN, ground the client in therapy, and move the client through recovery.

Clinicians have been referred to as “hope brokers” or “hope ambassadors” in the therapy process. As treatment providers we hold hope for our clients when they have none and guide them to the pathways toward hope on their road to recovery. If we as clinicians do not have hope for a client’s recovery, that client will not recover. Attempting to provide treatment without hope is the equivalent of blocking the exits during a fire. Alternatively, when clinicians infuse hope into the client relationship and into the recovery process, it is as though they clear the smoke and reveal the exits out of suffering.

Building Hope through Interactions that Reflect Capacity to Change

One specific strand of hope is recovering the client’s belief that change is even possible, and capacity to change still exists. The RDN can support the therapeutic interventions by guiding the client in building small successes through lateral moves, a nutrition intervention strategy that has been successful with clients in all levels of care. A lateral move is simply a small goal that the client is willing to attempt for the sole purpose of experiencing change only. For example, if a client is “stuck” in a long-standing habit of eating a specific type and size of apple every afternoon at a certain time of the day, a lateral move is being willing and attempting to eat a different type of apple at the same time of the day. No calorie or size variation, no change in the type of food consumed (both

fruits) and no alteration in timing. The completion of this challenge is to build success in “change” itself. The willingness to change, the ability to accept change, and the completion of that change will begin restoring confidence that the client is still capable of change. The experience of change is celebrated for what it signifies – change is possible, for this specific client, in this specific stage of recovery.

Building Hope through Language that Reduces Shame

Individuals who operate from a shame-based perspective are more likely to make internal attributions for negative life events (e.g., “that happened because I am a bad person”) and are more likely to believe that future negative events will occur (e.g., “bad things happen to bad people”).¹⁷ Clients with eating disorders may internalize seemingly innocuous comments or messages through a shame-based lens. For instance, “you look healthy!” may be internalized through a shame filter as “you look fat!” Research supports that authentic connections that provide empathy and compassion have a direct impact on hope by decreasing shame.¹⁸ The language we use as clinicians, both psychotherapist and RDN, also has the power to directly impact hope in a negative or positive way. Because many of our clients are receiving messages through a lens of shame, psychotherapists and RDNs may need to be especially cognizant of their language to bypass the shame filter so that clients may be more receptive.

A team of reviewers and editors for the International Journal of Eating Disorders (IJED) discuss the potential power of language to hurt or help our clients in an article published in the April 2016 edition of IJED. In their words, “we hope that our list will contribute to improved clarity in scientific thinking about eating disorders, and that it will stimulate discussion of terms that may need to be reconsidered in our field’s vocabulary to ensure the use of language that is respectful and sensitive to individuals who experience an eating disorder”.¹⁹ They propose re-thinking the use of “sufferer” or “struggling with an eating disorder”.¹⁹ Experiencing

suffering from an eating disorder and throughout recovery is a common and realistic occurrence; however, this specific language can be emotionally-charged and perceived as an expression of disapproval or belittlement. The alternative verbiage suggested is “treatment-seeking” or “exhibiting an eating disorder or related symptoms”.¹⁹

This team also discusses the word “refeeding” and supports its use within the medical term “refeeding syndrome,” a potentially life-threatening condition. However, they suggest the verb use of “refeeding” may create shame or embarrassment to our clients if perceived as “an image of an animal being fed, or of being a young child,” and offer the alternative terms “re-nourishing” or “nutritional rehabilitation”.¹⁹ The collective experience of this review team united in their observations of written language that has potential to belittle or shame, and reasoning concludes that our verbal words used with clients and within treatment teams have the same potential.

Examples of Hope Language

In contrast to the often-used term, weight restoration—which is valid but also may conjure an image to our clients of a process that is controlled by an authority who takes on the role of restorer—*nutritional rehabilitation* implies a joint effort by a team in which both parties work within a partnership with unique responsibilities for a common goal. Reflecting a mutually beneficial collaboration between clinician and client, nutritional rehabilitation is like physical therapy/rehabilitation in the following ways:

- The sooner the client starts after surgical repair or physical injury, the quicker the client returns to normal activity.
- The physical therapy literally hurts as the wounded area is asked to move, and it is counterintuitive to agree to move when instincts say, “stop.”
- Movement requires constant and consistent support from the physical therapist, and the therapist’s work is critical for best results.
- Physical therapy must begin with simple and repetitive exercises that

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progress to more individualized movements as healing occurs.

- Choosing to stop therapy before full healing has occurred due to the assumption that “I don’t need this anymore” when some progress becomes evident increases the risk of re-injury and complications.

Engaging the client as an equal partner in the therapeutic relationship, reflecting on these commonalities between physical and nutritional rehabilitation, can help the client embrace the slow yet healing process and affirm the mutual benefit of continued collaboration. The belief that “I am an equal partner in my healing process” can reduce feelings of shame, isolation and inappropriate blame, maintaining an underlying foundation of hope.

Failure to complete treatment is common, yet significantly increases the risk of poor outcomes. Hope has been found to contribute to treatment completion.⁶ Predictors of premature termination of treatment include low treatment credibility, early therapy alliance and self-transcendence.²⁰ Specifically, Jordan and colleagues found that credibility and warmth of the treatment team increased length of care. Interestingly, mutual patient and client exploration, or regular conversations in which both the client and the clinician check in and share perspectives of progress and reflect on the session content together, reduces premature termination by the client. Finally, self-transcendence, or “enlightened vs objective” and “idealistic vs practical” self-reflection, also strengthened the relationship and increased length of treatment.²⁰ Enlightened and idealistic are words that reflect hope, since hope can be defined as a feeling that what is wanted can be had and a belief that events will turn out for good versus calamity.

More Examples of “Hope” Language

As the psychotherapist works with the client to discover underlying reasons for and meaning of the fear

and avoidance of hope, the RDN has the privilege to guide the client to view the body changes that occur during recovery in a new light that reflects hope versus shame. “What is my body telling me now?” conversations not only remove the surprise factor around inevitable body changes, but also begin neutralizing the relationship between food and body. For example, the fluid retention that occurs when the binge/purge cycle decreases or stops can add to shame and loss of hope if seen as “my body’s fault” or “my food’s fault” due to the assumption that any weight change is gain of body fat and food consumed is the enemy. Guiding the client to ask, “What is my body telling me now?” begins opening the door to a new perspective in which the body is a partner and all body changes have occurred as its attempt to help, and support life, versus harm, and destroy life.

Choosing the word “energy” instead of calorie can prevent the immediate emotional flooding that the client’s perception of “calories” usually triggers. Choosing the word “fuel” instead of food, and thus “fuel groups” instead of food groups, offers an opportunity for the client to begin healing a negative relationship with food, opening the door to connect a purpose to food that exists in a more neutral space than “calories” alone. Adding the word “foundation” to the word “fat” when discussing dietary fat choices at meals and snacks allows a moment in which the client can think about the purpose of fats to build the foundation of brain, nerve and hormone cells (and in fact, the structure within every cell membrane). This moment of time in which the thoughts of dietary fats have a chance to exist in the brain without immediate emotional flooding reduces shame and strengthens hope that food is not the enemy.

Concluding Thoughts:

Avoiding hope can often be a protective mechanism for our clients, for if they do not hope then they will not be disappointed. Essentially, they live by the motto “don’t get your hopes up, you’ll just get let down.” But hope is necessary to the process of recovery. It may appear elusive and mysterious, but the treatment team can hold hope

for the client as they work together to change the language around and perception of the healing process, which in turn allows the clients to begin holding hope on their own. Although the work is not quick or easy, hope in eating disorder recovery is restored through authentic connections between treatment team and client, as well as psychotherapist and RDN, using neutral language that prevents immediate emotional flooding and reduces shame, and guiding the client to see, believe and experience that change is possible. Ultimately, hope is essential for recovery to occur; therefore, as clinicians in the eating disorder field, creating hope for our clients is not just a goal – it is our mission.

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References

1. Siegfried, N. (2017). *The role of hope in eating disorders recovery*. 2017 Gurze/Salucore Eating Disorders Resource Catalogue.
2. Peterson, C., & Seligman, M.E.P. (2004). *Character, strengths, and virtues*. New York: American Psychological Association.
3. Klonsky, E. D., Kotov, R., Bakst, S., Rabinowitz, J., & Bromet, E. J. (2012). Hopelessness as a predictor of attempted suicide among first admission patients with psychosis: A 10-year cohort study. *Suicide Life Threat Behav*, 42(1), 1–10.
4. Brothers, B. M., & Andersen, B. L. (2009). Hopelessness as a predictor of depressive symptoms for breast cancer patients coping with recurrence. *Psychooncology*, 18(3), 267–275.
5. Everson, S., Goldberg, D., Kaplan, G., Cohen, R., Pukkala, E., Tuomilehto, J., Salonen, J. (1996). Hopelessness and risk of mortality and incidence of myocardial infarction and cancer. *Psychosom Med*, 58(2), 113–21.
6. Geraghty, A., Wood, A., & Hyland, M., (2009). Dissociating the facets of hope: Agency and pathways predict dropout from unguided self-help therapy in opposite directions. *J Res Pers*, 44, 155–158.
7. Mathis, G., Ferrari, J., Groh, D., & Jason, L. (2009). Hope and substance abuse recovery: The impact of agency and pathways within an abstinent communal-living setting. *J*

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- Groups Addict Recover*, 4, 42–50.
8. Weis, R., & Speridakos, E.C. (2011). A meta-analysis of hope enhancement strategies in clinical and community settings. *Psychol of Well-Being* 1, 1-5.
 9. Steel, Z., Jones, J., Adcock, S., Clancy, R., Bridgford-West, L. and Austin, J. (2000). Why the high rate of dropout from individualized cognitive-behavior therapy for bulimia nervosa? *Int J Eat Disord*, 28, 209–214.
 10. Miotto, P., DeCoppi, M., Frezza, M., Preti, A., (2003). Eating disorders and suicide risk factors in adolescents: An Italian community-based study. *J Nerv Ment Dis*, 191(7), 437-443.
 11. Beck, A.T., Steer, R., and Brown, G. (1996) *BDI-II, Beck depression inventory: manual* San Antonio, Texas: Psychological Corp.
 12. Garner, D. M. (2004). *Eating Disorder Inventory-3. Professional Manual*. Lutz, FL: Psychological Assessment Resources, Inc.
 13. Siegfried, N., Bartlett, M., & Goodwin (2015). Improvements in hopelessness in treatment for eating disorders. Presented in N. Siegfried, & M. Bartlett, Hope brokers: Clinicians as agents of hope in eating disorder recovery. Workshop presented at the 2015 International Association of Eating Disorder Professionals Symposium, Phoenix, AZ.
 14. Norcross, J. & Lambert, M. (2011). Psychotherapy relationships that work. *Psychotherapy*, 48, 4-8.
 15. Frank, J. (1968). The role of hope in psychotherapy. *Int J Psychiatry*, 5, 383–395.
 16. Lopez, S. J., Ciarlelli, R., Coffman, L., Stone, M., & Wyatt, L. (2000). Diagnosing for strengths: On measuring hope building blocks. In C. R. Snyder (Ed.). *Handbook of hope: Theory, measures, and interventions* (pp. 57-85). San Diego: Academic Press.
 17. Williamson, I., Sandage, S., & Lee, R. (2007). How social connectedness affects guilt and shame: Mediation by hope and differentiation of self. *Pers Individ Diff*, 43, 2159-2170.
 18. Brown, B. (2007). *I thought it was just me*. London: Penguin Books.
 19. Weissman, R.S., Becker A. E., Bulik, C.M., et al (2016). Speaking of that: Terms to avoid or reconsider in the eating disorders field. *Int J Eat Disord*, 49(4): 349-353.
 20. Jordan, J., McIntosh V., Carter F., et al (2017) Predictors of premature termination from psychotherapy for anorexia nervosa: Low treatment credibility, early therapy alliance and self-transcendence. *Int J Eat Disord*, 50, 979-983.

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We now have a “**BHN Member Spotlight**” section on our home page. Check it out! Get in the spotlight and submit your bio using the template provided.

The IDD SOP/SOPP update group is looking for authors and reviewers. It's a great way to discover your specialty and work as a team. If you would like to help please contact Diane Spear at spear.nutrition@gmail.com

The Nominations Committee is pleased to announce BHN election results!

The following officers will assume duty on June 1, 2018:

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by Sue McLaughlin, MOL, BS, RD, CDE and Renee Hoffinger, MHSE, RD, LD

on page 7 of the Winter 2014 BHNNewsletter

Legislative Update



As your public policy advocacy leader (PAL), I wanted to share how important it is to respond to every Action Alert that you receive from the Academy or your DPG or Affiliate. For a bill to be passed in the House or Senate (or both), there is a very long process of items being added or taken away in order to get more legislators to sign on to each bill and ultimately to get enough votes to pass. If you think you have already taken Action, the new Action Alert is due to changes. We are so fortunate to have a group in Washington who stay on top of the changes and provide us with the talking points we need. WE all just have to use a few clicks on our computers! If you have ever responded to an Action Alert, it prepopulates that info the next time. It couldn't be any easier. In Texas, we also have a public policy team for legislation at the state level.

Currently we are asked as a member of the Academy of Nutrition and Dietetics, to please urge our policymakers to support legislation that protects and values nutrition programs in the farm bill. It is important for members of Congress to hear from their constituency. As vital decisions are made regarding health care in the upcoming weeks, the voice of every member is critical. **Take action today!**

Here is why:

Some Farm Bill Programs Expire September 30

The last farm bill, passed by Congress in 2014, provided mandatory funding for numerous food and nutrition programs. While some of these programs are assumed to continue after the 2014 farm bill expires September 30, others have a more uncertain future. A notable nutrition program without assured mandatory funding is the [Food Insecurity Nutrition Incentive](#). FINI is a grant program that provides financial incentives for SNAP participants to purchase fruits and vegetables.

The Congressional Research Service published a [report](#) of the 39 farm bill programs that receive mandatory funding that do not have assured funding beyond Fiscal Year 2018, and will require new budgetary authority to continue.

Action Required: Farm Bill

There's still time to make your voice heard:

Farm Bill: Congress is currently working on the 2018 farm bill, which is the primary legislation that authorizes many of our nation's food and nutrition programs. The farm bill includes nutrition assistance programs that help people access nutritious food; nutrition education programs that empower people to make lasting, healthy choices; and nutrition research that addresses the nutrition-related health concerns we face as a nation. We are asking Academy members to take action and urge Congress to support the important nutrition programs in the farm bill that contribute to the health of all, especially those most susceptible to experiencing insecurity. Learn more about the Academy's farm bill priorities [here](#).

Please realize that if action is not taken before September 30, the bill can "just die" or basically go away.

For more information on Current Legislation click on each of the titles below.

- [Breastfeeding in the Workplace](#)
A program summary, explanation, and resource list for the Breastfeeding in the Workplace program.
- [Farm Bill](#)
The Farm Bill is a critical piece of legislation that determines not only what farmers grow, but what is available in the United States food supply. Farm policies have existed in the U.S. since the establishment of our country.
- [Food Insecurity Among Active-Duty Service Members and Veterans](#)
Active duty military personnel, veterans and their families are part of a growing number of people using government food assistance programs to help make ends meet.
- [Gestational Diabetes Act](#)
The National Diabetes Clinical Care Commission will focus on improving diabetes care delivery, patient outcomes, and cost effectiveness of care.
- [Medicare Diabetes Prevention Act](#)
Medicare Diabetes Prevention Act would allow participation in the National Diabetes Prevention Program to be a covered benefit under Medicare.
- [National Diabetes Clinical Care Commission](#)
The National Diabetes Clinical Care Commission will focus on improving diabetes care delivery, patient outcomes, and cost effectiveness of care.
- [Older Americans Act](#)
Signed into law in 1965, the Older Americans Act is the primary vehicle for delivering social and nutrition programs to older individuals.
- [Preventing Diabetes in Medicare Act](#)
The Preventing Diabetes in Medicare Act will help to prevent cases of diabetes in the Medicare population by allowing medical nutrition therapy to be provided by a dietitian or nutrition professional for individuals with diabetes, prediabetes or a renal disease, or an individual at risk for diabetes.
- [Prevention and Public Health Fund](#)
The Prevention and Public Health Fund was authorized in the Affordable Care Act to address a critical gap in our nation's investment in public health.
- [Preventive Health Savings Act](#)
A wealth of research has highlighted the role that prevention can play in improving Americans' health and reducing the financial burden of these chronic diseases on our health care system.

Carol Bradley, PhD, BCBA, RDN, LD, FAND
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Vision: Optimizing the physical and cognitive health of those we serve through nutrition education and behavioral health counseling.

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