

FALL 2016 Edition



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Improving Wellness; Enhancing Quality of Care

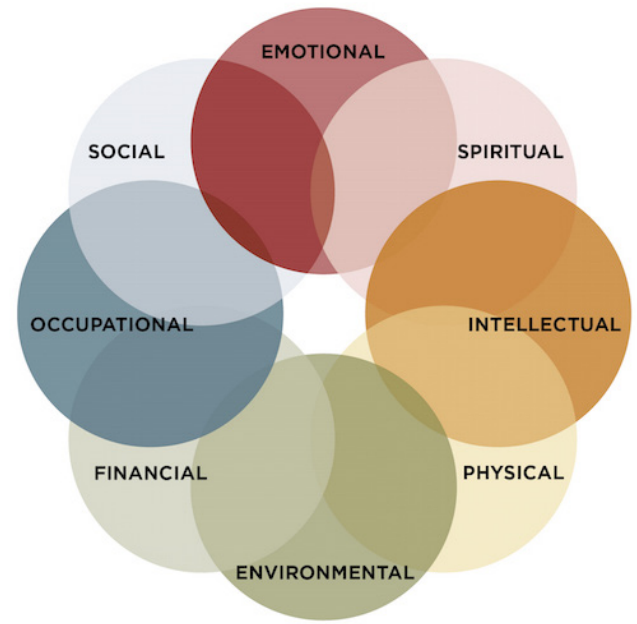
What does it take to improve your overall wellness? What is wellness and how do you define it? Merriam-Webster defines wellness as the quality or state of being in good health especially as an actively sought goal.

The Substance Abuse and Mental Health Services Administration (SAMHSA) defines wellness as being in good physical and mental health. Because mental health and physical health are linked, problems in one area can impact the other.

According to SAMHSA there are eight dimensions of wellness that can improve mental and physical health for people with mental and/or substance abuse disorders.

Each aspect or dimension of wellness is a component that contributes to a person's overall mental and physical wellness.

KEPRO's Health Care Quality Unit (HCQU) strives on a daily basis to provide guidance, tips and tools for caregivers and clinical practitioners caring for individuals with intellectual and/or developmental disabilities (I/DD).



WELLNESS

Image courtesy of The Substance Abuse and Mental Health Services Administration.

SAMHSA's Eight Dimensions of Wellness

1. **Emotional**—Coping effectively with life and creating satisfying relationships
2. **Environmental**—Good health by occupying pleasant, stimulating environments that support well-being
3. **Financial**—Satisfaction with current and future financial situations
4. **Intellectual**—Recognizing creative abilities and finding ways to expand knowledge and skills
5. **Occupational**—Personal satisfaction and enrichment from one's work
6. **Physical**—Recognizing the need for physical activity, healthy foods, and sleep
7. **Social**—Developing a sense of connection, belonging, and a well-developed support system
8. **Spiritual**—Expanding a sense of purpose and meaning in life

<http://www.samhsa.gov/wellness-initiative/eight-dimensions-wellness>

These resources include materials on improving wellness to provide the foundation to assist and enhance an individual's overall wellness, both physically and mentally. These activities improve the quality of care for individuals with I/DD and enable them to enjoy life to its fullest potential, which is KEPRO HCQU's top priority.

SAMHSA's National Wellness Week is held every year during the third week of September as part of the National Recovery Month to inspire individuals and communities to incorporate wellness into their lives. This initiative seeks to raise awareness and promote the importance of wellness, especially for individuals with behavioral health conditions as it has a direct impact on improving their health, quality of life and their overall happiness and satisfaction.

That is why this edition of **HCQU CARES** is centered on improving wellness. The articles in this issue explore wellness and provide information and guidance on four of the SAMHSA dimensions of wellness: physical, emotional, intellectual, and social.

To learn more about SAMHSA's eight dimensions of wellness or for additional wellness resources, visit <http://www.samhsa.gov/wellness-initiative/eight-dimensions-wellness>.



How to Help Individuals with I/DD Eat Healthy While Eating Out

Carrie Perrell, BSN, RN

People with intellectual and developmental disabilities (I/DD) may have multiple medical concerns including being overweight or obese. The additional weight a person carries can put strain on the body and make other co-existing medical conditions worse. Therefore, eating a healthy diet is important for maintaining or improving health.

According to governmental statistics 2/3 of adults in the U.S. are overweight or obese (Obesity Rates, 2014). This means many people may find it challenging to make healthy eating choices. As caregivers of people with intellectual disabilities you undoubtedly accompany them to various eating establishments. Knowing a few tips on how to choose foods that are healthier or at least lower in calories, equips you with the ability to help guide a person to healthier food selections, should they request this.

CHOOSING HEALTHY STARTS BEFORE YOU LEAVE HOME

The first consideration in helping a person make healthy food choices is knowing whether that person desires to have guidance or wishes to make a change. No one wants to be told what to eat. If a person is resistant to suggestions, then this isn't the time to implement change or to insist that healthy diet choices be made.

However, for those who are interested in making healthy choices, a caregiver can be of assistance by helping that person prepare even before leaving home. Many restaurants now have websites with their menus available. Larger chain restaurants not only have the menu available, but also provide the nutritional information for each food item. Before going to a restaurant, pull up this information on the computer. If computer access is limited, many restaurants have printed nutritional handouts that can be requested. Usually, information is available in regard to the fat, calories, carbohydrates and sodium content of a meal.

Help the person choose foods which will provide the desired amount of calories. If the person follows a 1,800 calorie diet, for example, and eats three meals a day, help that person select a meal which will provide approximately 600 calories. If the person has diabetes or is counting carbohydrates, help the person choose a meal which will provide the desired range as per his or her physician's orders. Being prepared before leaving home will assure that the individual will not have to make a quick decision at the restaurant.

FAST FOOD VS. TRADITIONAL RESTAURANTS

Fast food restaurants are known as a quick and convenient place to get a meal. However, it seems to be a commonly held belief that fast food is considered unhealthy food. This may be the perception as many of the menu items at fast food restaurants are high in calories and fat. A person who frequently eats fast food and chooses those food items would likely have a weight problem or be at risk for developing one.

However, even when eating in restaurants which are not considered fast food, it may be easy to order a meal which will provide an over-abundance of fat and calories. Think about the large portions that many restaurants serve. Again, this would likely have an undesirable effect on a person's weight and health.

So, what's a caregiver to do? Sometimes a person may simply want to have a burger and fries or other type of fast food. What about a traditional restaurant? Which is the better choice? Can a person make good choices at either? Sure, they can!

Consider the tips below to help a person make better choices at either type of eating establishment.

Some tips for dining out from the National Institutes of Health, the American Heart Association and the Mayo Clinic include:

- Avoid extras such as appetizers, bread and butter.
- Choose foods that are baked, steamed, broiled rather than fried.
- Ask for creams, sauces on the side so that you can control the portions.
- Select smaller portions (senior portions).

- Get a to-go box at the beginning of the meal and set aside a portion for lunch the next day.
- Select healthier side dishes (fruit, side salads with low-fat dressing).
- Watch the drinks (sodas, sweet tea, lattes, cappuccinos, are high in calories with no nutritional value.) Choose water or low calorie drink.
- Avoid supersizing the meal.

REINFORCING THE CONCEPT OF PORTION CONTROL

By choosing a smaller portion, a desired food can be chosen while limiting the intake of unnecessary calories, fat and carbohydrates. See the food table below; the difference between the calories of the small fries vs. the large fries is particularly eye-opening.

By choosing a smaller size a person can cut calorie intake by more than half! Imagine how much easier it would be to know that a small fry can be ordered rather than no fries at all while still staying within the desired calorie range. Note how many calories, carbohydrates and grams of fat can be added with a drink. Caregivers can provide pointers on how to enjoy certain foods while saving calories by making healthier choices, like choosing water to go with the meal.

It may be helpful to show this information to the individual in your care who is interested in watching calories, but doesn't want to give up certain foods. When teaching a person with I/DD about the differences in nutritional value of food, it may be helpful to only compare two similar items at one time. It can become too confusing to compare multiple items. Also, reinforce this concept by reviewing this information for short periods of time, but on multiple occasions. Follow the cues the person provides you. When he or she seems eager to learn, that is a good time to teach. When it appears the person is uninterested, this is the time to save the discussion for another day.

Food item	Calories	Fat	Carbs
Cheeseburger	300	12g	33g
¼ pound cheeseburger	540	27g	42g
Small fries	230	11g	30g
Large fries	510	24g	67g
Small strawberry shake	550	16g	90g
Large strawberry shake	850	24g	140g
Large Sweet Tea	280	0g	71g
Water	0	0g	0g



BE A ROLE MODEL

Maybe one of the most helpful things a caregiver can do is to be the role model of healthy eating. Most people understand that it is a lot easier to order healthy meals at restaurants when others at the table are doing the same.

SOME FINAL THOUGHTS

Caregivers often find themselves in situations where individuals may not be making the best choices. People who are armed with information can make choices based on what they know. The information you share or teach can empower them to make the best choices for themselves!

References:

- National Institutes of Health. Tip sheet: Eating Healthy When Dining Out: http://www.nhlbi.nih.gov/health/educational/lose_wt/eat/tips_dine_out.htm
- American Heart Association. (2015, May 15). Ordering Your Food, Retrieved from: http://www.heart.org/HEARTORG/HealthyLiving/HealthyEating/DiningOut/Ordering-Your-Meal_UCM_301471_Article.jsp#.V2BEVHI0zIU
- http://www.mcdonalds.com/content/us/en/food/full_menu/snacks_and_sides.html
- Mayo Clinic. (2017, February 27). Fast Food: Tips for Choosing Healthier Options. Retrieved from <http://www.mayoclinic.org/healthy-lifestyle/nutrition-and-healthy-eating/in-depth/fast-food/art-20047179>
- Obesity Rates & Trends Overview. (n.d.). Retrieved from <http://stateofobesity-rates-trends-overview/>

Healthy Eating Learning Tools for Individuals with I/DD

By Rebecca Trigger, RN

Caregivers face complex challenges promoting healthy eating for individuals with I/DD. Some examples of these challenges are provided in a recent article from the Centers for Disease Control and Prevention (CDC), which states, “People with disabilities can find it more difficult to eat healthy, control their weight, and be physically active (Challenges Facing People with Disabilities, CDC). This might be due to:

- A lack of healthy food choices.
- Difficulty with chewing or swallowing food, or its taste or texture.
- Medications that can contribute to weight gain, weight loss, and changes in appetite.
- Physical limitations that can reduce a person’s ability to exercise.
- Pain.
- A lack of energy.
- A lack of accessible environments (for example, sidewalks, parks, and exercise equipment) that can enable exercise.
- A lack of resources (for example, money, transportation, and social support from family, friends, neighbors, and community members).

Adding to the complexity, certain diagnoses have specific challenges. Not many studies have been done with data collection. Though an article from the National Center on Health, Physical Activity and Disability (NCHPAD) provides some specificity for individuals with Autism, stating, “Recent evidence suggests that some children with autism spectrum disorder (ASD) may have a higher than average need for nutrients due to digestive imbalances that may affect absorption.”

In addition, the article states, “A common symptom of Down syndrome is low muscle tone which causes a greater amount of fat mass and less muscle mass in the body. This increased fat mass, along with a higher prevalence of obesity, puts the Down syndrome population at a greater risk for type 2 diabetes and cardiovascular disease. Weight management is an important step in addressing these health concerns. Conditions that are common in individuals with Down syndrome include gastrointestinal problems, decreased immune system, hypothyroidism, and Alzheimer’s disease. These conditions can have a negative impact on their diet.”

The article further states, “Research has suggested that weight loss programs that include parental support appear to have greater success for adolescents and young adults with Down syndrome. So for parents and caregivers, it is important to not only educate about nutrition and physical activity, but to lead by example” (Nutrition for Persons with Intellectual/Developmental Disabilities, 2016).

Caregivers and individuals with I/DD also face being inundated by TV commercials, the internet, and store advertising, which further compounds healthy food choices. Processing all this information while standing in the aisle at the grocery store or reading the menu at a favorite restaurant can be a daunting and ineffective endeavor. Communication can be another issue with individuals who are nonverbal.

The good news is there are many resources available to educate an individual in their preference of learning. Utilizing various tools and resources can provide learning options to help caregivers with educating, as well as, with self-advocates learning healthy food choices. Practicing healthy food choices at home and utilizing visual tools and resources to assist an individual with I/DD in learning the principles of healthy eating can be inexpensive and fun!



When choosing a resource, think about the type of activity that most attracts and holds the individual's attention? Does the individual prefer to:

- Watch DVDs?
- Play games?
- Read books?
- Look at pictures?
- Hands on, building with items?
- Instructor-led?
- A combination of above?

An effective jump start towards healthy eating is scheduling a HCQU nutrition training with activities. For example, two HCQU trainings, Nutrition for staff and Eating Healthy for Self Advocates, explain the basics of nutrition and focus on food choices to manage and/or prevent certain disease conditions. Other HCQU topics focus on certain disease conditions such as, Diabetes and Heart Healthy Nutrition. Take a look at the HCQU website under training topics to preview the material to make an informed choice of the topic most suited for specific needs.

Activities that can be incorporated with HCQU nutritional trainings that utilize learning tools owned by the HCQU include:

- Explanation of the MyPlate method
- Practicing with the MyPlate placement
- Practicing building MyPlate with life size food props

A HCQU nutrition training accompanied with the hands-on activity of practicing the "MyPlate" method using the "MyPlate" placement, a dinner plate, and the paper food props of the HCQU will engage caregivers and self-advocates. Both will begin learning their way to healthy food choices. During the training, staff and/or individuals can choose to sit around the dinner table and practice filling their plate with the paper food choices for daily meals: breakfast, lunch, dinner and snacks. When all have completed creating their plate, each paper meal can be evaluated by the group by turning over the paper food and reading the complete nutrition label on the back. This method helps to encourage staff and individuals to work together in learning and advocating for each other with healthy food choices. Another easy tip of the "MyPlate" method is learning to mix different colors of fruits and vegetables at each meal to ensure adequate nutrients are being consumed.

The "MyPlate" method was developed by the United States Department of Agriculture. It's an easy to learn method using a placemat with a picture of a plate that is divided into 5 colorful food groups representing protein, vegetables, fruits, grains and dairy. This visual method provides an effective form of communication and enhances memory retention for individuals with I/DD. It can also be easily tailored to fit the nutritional needs of certain disease conditions.

The learning should be a continuing process enhanced by utilizing different methods to reinforce healthy food choices such as: participating in interactive nutrition games, tip sheets, picture cookbooks, picture cards, shopping cards and/or other resources from the reputable listings below. Caregivers will benefit, too, by the education to become more effective advocates and role models. By working together with effective learning methods we can all benefit by choosing healthier foods to consume.

For more information on specific nutrition topics please contact the HCQU at the website at <https://hcqu.kepro.com>.

References:

- "Challenges Facing People with Disabilities" March 30, 2016, <http://www.cdc.gov/ncbddd/disabilityandhealth/obesity.html>
- Nutrition for Persons with Intellectual/Developmental Disabilities, 2016, <http://www.nchpad.org/287/1802>
[Nutrition~for~Persons~with~Intellectual~Developmental~Disabilities](http://www.nchpad.org/287/1802)

Healthy Eating Learning Tools

Tool/Resource	Description	Website
HCQU Training: Nutrition for Staff & Healthy Eating for Self-advocates	Teaches nutrition using the “My Plate” method: includes activity with the “My Plate” placement and real size paper food items to practice food choices.	https://hcqu.kepro.com
United States Department of Agriculture (USDA): “Choose My Plate”	MyPlate offers ideas and tips to help you create a healthier eating style and improve health.	http://www.choosemyplate.gov/
American Academy of nutrition and Dietetics	The American Dietetic Association has informative articles and teaching aids that addresses the nutritional needs of individuals with I/DD.	http://www.eatright.org/
National Center on Health, Physical Activity and Disability (NCHPAD)	NCHPAD is a public health practice and resource center on health promotion for people with disabilities.	http://www.nchpad.org/ For NCHPAD article: “Nutrition for Persons with Intellectual Developmental Disabilities http://www.nchpad.org/287/1802/Nutrition~for~Persons~with~Intellectual~Developmental~Disabilities
NASCO Nutrition Teaching Aids	Shopping cards in vinyl pockets, prepared questions, 3 levels of difficulty.	http://www.attainmentcompany.com/shopping-card-packaging
NASCO Nutrition Teaching Aids	Great for beginners! Includes a cookbook with 62 step-by-step recipes, lesson plans, and two DVDs. Features recipe illustrations that are clear and easy to read. Each picture step has accompanying text. Laminated pages.	https://www.enasco.com/action/solr/select?q=look+and+cook+cookbook
Program Development Associates: Disability Training & Education Programs	Eat Right for a Long and Healthy Life DVD: 125 minutes of lessons, also including 25 Activity Sheets file.	https://www.disabilitytraining.com
Health Matters Program: A partnership between community and academia with a common aim to improve the health of people with I/DD.	Health Matters: The Exercise and Nutrition Education Curriculum for Individuals with Developmental Disabilities.	http://www.healthmattersprogram.org/products/
NASCO Nutrition Teaching Aids	“Nuts about Nutrition” Book Nasco offers many books for cooking and other resources. Their list of books range from youth to adult, beginner to more experienced cooks.	https://www.enasco.com/action/solr/select?q=books
Attainment Company	Look ‘n Cook Cookbook Step-by-step instructions for 62 traditional recipes with video.	http://www.attainmentcompany.com/look-n-cook-cookbook

Sleep Disorders and Sleep Deprivation: An Unmet Public Health Problem

By Pam Lodge, RN

Good nutrition, regular physical activity, and achieving and maintaining a healthy body weight are cornerstones of health at every stage of life, but what about healthy sleep?

According to the National Institutes of Health, 50 to 70 million Americans are affected by chronic sleep disorders and intermittent sleep problems that can significantly diminish health, alertness and safety. It is reported that an estimated 1 in 25 adult drivers (aged 18 years or older) report having fallen asleep while driving. The National Highway Traffic Safety Administration estimates that drowsy driving was responsible for 72,000 crashes, 44,000 injuries, and 800 deaths in 2013. However, these numbers are underestimated and up to 6,000 fatal crashes each year may be caused by drowsy drivers (Drowsy Driving, CDC).

Sleep problems can take many forms and can involve too little sleep, too much sleep or inadequate quality of sleep. A report released in 2006 by The Institute of Medicine, *Sleep Disorders and Sleep Deprivation: An Unmet Public Health Problem*, estimated that “hundreds of billions of dollars a year are spent on direct medical costs related to sleep disorders such as doctor visits, hospital services, prescriptions, and over-the-counter medications” (Sleep Studies). The report also discusses sleep problems and that lack of sleep can have an impact on personal and work productivity, as well as, contribute to behavioral and relationship problems.

Compounding the problem is the fact that most people know when to seek medical help for physical discomfort such as fever or pain, but sleep problems are often overlooked or ignored. In fact, the overwhelming majority of people with sleep disorders are undiagnosed and untreated.

According to a press release issued by the Centers of Disease Control and Prevention (CDC) in February 2016, more than a third of American adults are not getting enough sleep on a regular basis, according to a new study in the CDC’s *Morbidity and Mortality Weekly Report*. This is the first study to document estimates of self-reported healthy sleep duration (7 or more hours per day) for all 50 states and the District of Columbia (1 in 3 adults don’t get enough sleep, CDC).

Sleep Well, Be Well: A National Health Priority

Sleep has taken on the forefront of medical importance, as researchers try to understand its complex connection between brain function, the immune system, respiration, cardiovascular health, blood pressure, appetite, and mental health. Scientists are just starting to grasp the extent to which our health depends on the length and quality of rest we give our bodies; however, many experts have already come to understand that attention needs to be called to our sleep health, and the first steps are raising awareness.

Because of the importance to this issue The National Healthy Sleep Awareness Project was initiated in 2013 through a cooperative agreement between the CDC and the American Academy of Sleep Medicine. The Healthy Sleep project addresses the sleep health focus area of Healthy People 2020, which provides science-based, 10-year national objectives for improving the health of all Americans. The sleep health objectives are to increase the medical evaluation of people with symptoms of obstructive sleep apnea, reduce vehicular crashes due to drowsy driving and ensure more Americans get sufficient sleep.

The “Sleep Well, Be Well” campaign of the National Healthy Sleep Awareness Project is a reminder that sleep is one of the three pillars of a healthy lifestyle (National Healthy Sleep Awareness Project, American Academy of Sleep Medicine).

How much sleep is enough?

Sleep is defined as a periodic state of rest accompanied by varying degrees of unconsciousness and relative inactivity. The American Academy of Sleep Medicine and the Sleep Research Society recommend that adults aged 18 - 60 years, sleep at least 7 hours each night to promote optimal health and well-being. When an individual suffers from sleep deprivation, a condition that occurs if you don't get enough sleep, it may lead to physical and mental health problems, injuries, loss of productivity, and a greater risk of death. Sleep deprivation may be caused by specific sleep disorders that affects, disrupts, or interferes with the normal sleep pattern. To learn more about sleep deprivation and sleep disorders, visit the National Sleep Foundation's website at <https://sleepfoundation.org/>.

How do I recognize a sleep disorder in someone with an Intellectual Disability?

Impaired sleep quantity or quality in individuals with intellectual or developmental disabilities (I/DD) can have profound effects on daytime mood, behavior, cognition, general performance and physiology. When sleep disturbance is present in an individual with I/DD it impacts not only the individual's daytime functioning, but can also have an impact on all those who provide care for the individual.

It can be harder to diagnose a sleep disorder in I/DD individuals due to other symptoms or conditions that may exist. The stress that someone with I/DD may experience during the day makes it equally important for them to get the proper amount of rest. Due to differing characteristics with varied intellectual disabilities, it is even more important to monitor sleeping patterns. Many intellectually disabled individuals experience insomnia, sleepiness and night waking that may be associated with genetic disorders, syndromes or other disorders. Sleep apnea is also very common in people with Down's syndrome, but will often go unnoticed. Due to their intellectual disability the reporting of sleep disruption may rely on documentation by a caregiver. It is important that caregivers do not just assume that disruptive sleep is part of the intellectual disability, as an unnoticed sleep disorder could lead to long-term health conditions and should be treated as a separate condition. The change in behavioral patterns and sleepiness may be mistakenly documented as related to the intellectual disability or behavioral issues, but it is equally likely that the person could be suffering from a sleeping disorder. Changing sleeping patterns may be a much harder task to recognize and document in individuals with intellectual disabilities. Observations of any abnormal patterns within sleep should be assessed, documented, monitored and reported to a doctor (How do I Recognise a Sleep Disorder in someone with an Intellectual Disability?, UKHealthCentre).

Documenting sleep:

Documenting sleep is an important part of an individual's health record. Sleep disorders may have an effect on an individual's behavior pattern. Behaviors that increase in frequency or escalate with no apparent trigger could be a sign of poor sleep. Increases in self injurious behavior, increased aggression, a decreased activity level, or increased anxiety are a few examples of behaviors that can be exacerbated due to an unhealthy sleep pattern. Proper documentation can assist medical personnel in determining if an individual's sleeping pattern is healthy or whether a poor sleeping pattern could be the potential cause of increased negative behaviors.

When individuals have a shift from baseline, caregivers begin to explore areas of the individual's daily activities and signs/symptoms of a physical illness. One area that often is unexplored is the individual sleep pattern. Observation of sleep is an important piece of documentation when ruling out possible causes to an individual behavioral pattern or a possible sleep disorder. Caregivers may want to consider how and when they are charting sleep patterns. Charting an individual's sleep pattern on a regular basis is recommended, especially if there is a concern with an individual's health and wellbeing. However, it can be a difficult task for caregivers to observe and document sleep patterns.

The following is an example of a sleep chart that caregivers may consider using to assist when determining if an individual's sleep pattern is healthy.

SLEEP Chart

Name: _____ Start Date: _____

MORNING							
Week Day:	Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7
Went to bed at:	AM/PM	AM/PM	AM/PM	AM/PM	AM/PM	AM/PM	AM/PM
Got out of bed at:	AM/PM	AM/PM	AM/PM	AM/PM	AM/PM	AM/PM	AM/PM
Fell asleep:							
Early	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
After awhile	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
With trouble	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Woke up:							
_____ times							
_____ minutes							
Total Hours Slept							
Was woken up by: (Discuss with individual what woke her/him up, including noises, lights, discomfort, room temperature, stress/worrying, pets, illness, etc. Record responses so these may be addressed to prevent recurrence.)							
When awoke this morning, he/she reported feeling: (Ask individual and record response(s))							
Rested	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Somewhat Rested	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Still Tired	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Notes: Record all other factors affecting sleep (i.e. excitement over days of event/upcoming events; menstrual cycle; possible illnesses; etc.)							

Caregivers can also use the following questions when documenting sleep patterns:

- How long did it take to fall asleep?
- Did the individual wake up?
- How long did it take for the individual to fall back asleep if awakened?
- Is the individual easily aroused?
- Is the individual's breathing pattern even and non-labored?
- Is the individual waking up during the night? If so, how many times?
- Does the individual appear to be in a comfortable position? (For example, is their head raised?)
- Is the individual snoring or making noise when they are sleeping?

Observing the answers to these questions over time can assist in determining a pattern of sleep and whether or not the sleep pattern is healthy.

Sleep Hygiene: Tips on Bedtime Rituals

- **Fixed bedtime and awakening time** - Keeping consistent times for sleeping and waking can help the body maintain a healthy balance.
- **Bedtime rituals** – Create habits with bedtime rituals like brushing teeth, reading a book, or listening to soft music. However, be sure to avoid loud music/noise, playing video games, using your cellphone, or watching T.V.
- **Relaxation techniques** – Use relaxation techniques to prepare your body for sleep. Try breathing exercises, yoga, or meditation. Avoid cleaning tasks, playing video games or games that involve physical activity.
- **Avoid daytime naps** – Limit sleeping time during the daytime hours as this helps create better sleeping patterns at night. (Note: Document if I/DD individual is sleeping during daytime hours.)
- **Avoid caffeine 4-6 hours prior to bedtime** – Be sure to limit coffee, soda, and sugary drinks before bedtime.
- **Avoid heavy, spicy, sugary foods prior to bedtime** – Be sure to limit the amount of snack foods prior to bed, such as chips and salsa, cookies or cakes.
- **Avoid exercise prior to bedtime** -- Avoid activities that involve strenuous activity prior to bed.
- **Make sure to have a comfortable bed** -- Avoid a mattress that is unsupportive, too small or too hard/soft.
- **Keep a cool, dark, quiet bedroom** -- Avoid over lighting a room, make sure temperature is comfortable, and avoid loud noises.
- **If awakened during the night, read or listen to music** - Avoid watching T.V., or getting on your cell phone.

Following a consistent routine for bedtime can assist individuals and caregivers in a healthy sleep pattern.

Sleeping is an important part of every individual's health and well-being. Research has shown that inadequate sleep in individuals with intellectual disabilities can cause problems with brain function, the immune system, respiration, cardiovascular health, blood pressure, appetite, and mental health. Impaired sleeping patterns in individuals with intellectual disabilities can also have a profound effect on an individual's behavior.

Documentation and sleep hygiene are an important part of caring for individuals and ensuring that they are achieving the proper amount of healthy sleep each night. For more information on healthy sleep, please contact the Southwestern PA Healthcare quality unit at <https://hcqu.kepro.com>.

References:

- Sleep Studies. (n.d.). Retrieved July 01, 2016, from <https://sleepfoundation.org/sleep-topics/sleep-studies>
- National Healthy Sleep Awareness Project, American Academy of Sleep Medicine (n.d.). Retrieved July 01, 2016, from <http://www.sleepeducation.org/healthysleep>
- Drowsy Driving: Asleep at the Wheel, CDC (2016) from <http://www.cdc.gov/features/dsdrowsydriving/>
- 1 in 3 adults don't get enough sleep, CDC (2016). Retrieved July 01, 2016, from <http://www.cdc.gov/media/releases/2016/p0215-enough-sleep.html>
- How do I Recognise a Sleep Disorder in someone with an Intellectual Disability?, UKHealthCentre (n.d.). Retrieved July 01, 2016, from <http://www.healthcentre.org.uk/sleep-disorders/faq-recognise-intellectual-disability.html>
- Drowsy Driving: Asleep at the Wheel <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1281388/>
- Sleep problems in children with developmental disorders J R Soc Med. 2001 Apr; 94(4): 177–179 <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1281388/>
- Medical Daily, Sleep Well, Be Well' Campaign Says Sleep Is 'Life Changing'; Why We Should All Get A Good Night's Rest May 24, 2014 02:08 PM By Samantha Olson, <http://www.medicaldaily.com/sleep-well-be-well-campaign-says-sleep-life-changing-why-we-should-all-get-good-nights-rest-284384>

Vitamin “D” ficiency: A New Concern

By Cheryl Pursley, RN, CDDN

One billion people! That is the estimated number of people worldwide with low levels of Vitamin D. In fact, doctors are seeing the reappearance of rickets, a disease that weakens the bones that was basically eliminated years ago after foods were enriched with Vitamin D (Vitamin D and Health, Harvard). Unfortunately studies also reveal that people with developmental disabilities with low levels of Vitamin D have an increased risk of more health issues than the general population (Grant, et al).

Benefits of Vitamin D

Vitamin D helps the body absorb calcium to maintain strong bones. New research indicates that Vitamin D is not only valuable for bone growth, but offers numerous other benefits as well. Mounting evidence shows Vitamin D:

- Improves neuromuscular function which reduces the risk of falls and increases functional ability,
- Reduces the risk of several types of cancer such as colorectal, breast, and aggressive prostate cancer,
- Lowers cholesterol and triglyceride levels impacting cardiovascular disease,
- Protects the central nervous system against the threat of Alzheimer’s disease and dementia,
- Improves insulin sensitivity, possibly reducing the risk of developing type 2 diabetes,
- Reduces oral health issues such as periodontal disease and cavities; and
- Decreases the risk of autoimmune diseases and respiratory illness (Grant, et al).

Sources of Vitamin D

The 3 sources for obtaining Vitamin D are sunlight, food and supplements.

Food

Mother Nature provides very few foods with Vitamin D. Most of the foods providing Vitamin D in America are found in fortified foods such as milk.

Food	IUs per Serving*	Percent DV**
Swordfish, cooked, 3 ounces	566	142
Salmon (sockeye), cooked, 3 ounces	447	112
Tuna fish, canned in water, drained, 3 ounces	154	39
Orange juice fortified with Vitamin D, 1 cup (check product labels, as amount of added Vitamin D varies)	137	34
Milk, nonfat, reduced fat, and whole, Vitamin D-fortified, 1 cup	115-124	29-31
Yogurt, fortified with 20% of the DV for Vitamin D, 6 ounces (more heavily fortified yogurts provide more of the DV)	80	20
Margarine, fortified, 1 tablespoon	60	15
Sardines, canned in oil, drained, 2 sardines	46	12
Liver, beef, cooked, 3 ounces	42	11
Egg, 1 large (Vitamin D is found in yolk)	41	10
Ready-to-eat cereal, fortified with 10% of the DV for Vitamin D, 0.75-1 cup (more heavily fortified cereals might provide more of the DV)	40	10
Cheese, Swiss, 1 ounce	6	2

(Vitamin D, NIH)

Sunlight: Expose or Cover-Up?

Vitamin D is known as the sunshine vitamin because exposure to the sun triggers the body to make vitamin D. The amount of sunlight to produce Vitamin D has not been established due to the variables of cloudiness, shade, and skin color. However, some researchers suggest “approximately 5-30 minutes of sun between 10 a.m. and 3 p.m. at least twice

a week to the face, arms, legs, or back without sunscreen usually lead to sufficient vitamin D synthesis” (Vitamin D, NIH). Since exposure to the sun increases the risk of skin cancer, it is still important to take precautions and limit the amount of exposure by wearing protective clothing and using a sunscreen. Unfortunately, sitting by the window exposing the skin to sunlight does not produce Vitamin D. Due to the many variables concerning sunlight exposure, and the insufficient food sources, Vitamin D should be gained through supplements.

Supplements

Since food does not provide enough Vitamin D and sun exposure is inconsistent, supplements may be needed. The amount of Vitamin D required each day is still being disputed between many health organizations. The Institute of Medicine (IOM) recommends 600 IU per day for children and adults, the Endocrine Society recommends 2000 IU, and the Vitamin D Council suggests 5000 IU (Vitamin D Council). The person’s physician is the best source of information on the amount of Vitamin D supplement needed. Blood work can be performed to diagnose a Vitamin D deficiency.

Who is at Risk for Low Levels of Vitamin D?

- Females tend to have lower vitamin D levels than men.
- Older adults do not make Vitamin D from sunlight as efficiently as they age and their kidneys are less able to convert Vitamin D to its active form.
- People with dark skin have more pigment called melanin which lowers the ability to produce Vitamin D from the sun.
- Crohn’s and celiac disease prevent the absorption of fat which is needed for Vitamin D to be absorbed and used.
- Milk allergies, lactose intolerance, and a vegan diet may cause a deficiency in Vitamin D.
- People who wear long robes and head coverings for religious reasons are at risk for low levels of Vitamin D.
- Nursing home residents and children who stay indoors at day care centers have limited exposure to the sun, causing a deficiency.

(NIH)

Vitamin D Deficiency in People with I/DD

Research shows that people with I/DD are prone to low levels of Vitamin D due to reduced exposure to the sun from excessive use of sunscreen and from staying indoors. People with I/DD are also more prone to being overweight. Body fat binds to Vitamin D and prevents it from entering the blood, so a higher dosage is needed. Medications including the anti-seizure medications Phenobarbital and Dilantin affect metabolism of Vitamin D which decreases calcium absorption (WebMD).

Supporting People in Your Care

Caregivers can support people with I/DD by encouraging dietary intake of foods high in Vitamin D. Walking outdoors in the sun not only boosts the production of Vitamin D, but is great exercise benefiting people with I/DD and caregivers. Advocate for people in your care by enlightening the doctor of the approaches caregivers are taking to encourage the intake of Vitamin D and asking questions about the Vitamin D levels.

The new reports on the value of Vitamin D are exciting. Low levels of Vitamin D are a health care dilemma with an easy remedy. Vitamin D improves the health and welfare for everyone, however, people with I/DD can particularly reap the benefits.

References

- Vitamin D and Health. (n.d) retrieved May 12 2016, from Harvard T.H.Chan School of Public Health website: <https://www.hsph.harvard.edu/nutritionsource/vitamin-d/>
- Grant, W. B., Wimalawansa, S. J., Holick, M. F., Cannell, J. J., Pludowski, P., Lappe, J. M., May, P. (2015, February 27). Emphasizing the Health Benefits of Vitamin D for Those with Neurodevelopmental Disorders and Intellectual Disabilities. Retrieved June 22, 2016, from <http://www.google.com/url?url=http://www.mdpi.com/2072-6643/7/3/1538/pdf&rct=j&frm=1&q=&esrc=s&sa=U&ved=0ahUKEwjhsuP-yLnNAhVh7oMKHYxZBSU4ChAWCBQwAA&usg=AFQjCNG5AbvMBiqUNQXKBC2h1em3Fpx6ew>
- How do I Get the Vitamin D my Body Needs? (n.d.). Retrieved June 29, 2016, from <https://www.vitaminCouncil.org/about-vitamin-d/how-do-i-get-the-vitamin-d-my-body-needs/>
- Vitamin D. (n.d) retrieved May 12 2016, from National Institute of Health website: <https://ods.od.nih.gov/factsheets/VitaminD-HealthProfessional/>
- DeNoon, D. J. (n.d.). The Truth About Vitamin D. Retrieved June 30, 2016, from <http://www.webmd.com/osteoporosis/features/the-truth-about-vitamin-d-drug-interactions>



Distress Tolerance and Emotional Wellness

By Erin Sass, BA

Emotional wellness is an important aspect in supporting people with Intellectual and Developmental Disabilities (I/DD) and is attainable with caregiver assistance. Having emotional wellness helps people cope with negative emotions and frustrating situations. It helps the everyday stressors seem less of a big deal and more serious challenges less overwhelming.

At some point every person has to tolerate unwanted emotions, frustrations, and pain. It's not always possible for a person to immediately change his/her life for the better – move, get a new job, or end a relationship. Avoiding the pain and frustrations can lead to further problems. Marsha Linehan, Ph.D., creator of Dialectical Behavior Therapy (DBT), points out in her Skills Training Manual for Treating Borderline Personality Disorder, that posttraumatic stress disorder and chronic long-term grieving both result from avoiding cues that cause emotional discomfort. “The more people attempt to avoid and shut emotional pain off, the more it comes back to haunt them” (Marsha Linehan). She further suggests that suppressing emotional pain or trying to get rid of painful thoughts leads to dwelling on painful events, resulting in even more painful thoughts. Using distress tolerance skills can help people tolerate, experience, and accept their emotional pain.

DBT distress tolerance skills differs from other approaches in that it focuses not on changing distressing events and thoughts, rather it helps people to tolerate, accept, and find meaning in them. Distress tolerance skills include four sets of strategies - distracting, self-soothing, improving the moment, and pros and cons (Psychcentral.com).

Distracting strategies aim to reduce emotional stimulation, or distract the person. The distracting skills can be remembered by using the phrase “**ACCEPTS.**”

- **Activities** – Distract the person under distress by offering activities the person enjoys, provide the person with undivided attention, and ask the person if they'd like to go out for lunch/dinner, or ask if they'd like to play a game on the computer.
- **Contributing** – Doing things for other people refocuses the attention from oneself onto another person. Ask the person if they'd like to make something for a friend or caregiver, ask if they'd like to help with dinner or run an errand, or offer some chores with which they could help.
- **Comparisons** – Help the person make a comparison between their life and someone's less fortunate as this may help the person see their own life in a more positive way.
- **Emotions** – Encourage the person to feel different emotions. Watch movies or read stories that provoke emotions other than what the person is feeling.
- **Pushing away** - Encourage the person to physically or mentally leave the situation, or block it from one's mind. Help the person to visualize putting the problem on the shelf or in the closet and walk away from it.
- **Thoughts** – Help the person to generate other thoughts, different from the problem. Count from 1-10, count backwards, count colors looking out the window, or play I Spy or 20 questions.
- **Sensations** – Use the person's senses as a way to distract them from the distress. Offer an ice cube or freezer pack to hold, listen to very loud or very quiet music, smell different citrus fruits or spices, have a taste test, or offer a stress ball.

Self-soothing skills focus on comforting, nurturing, and being kind to oneself. Using any object, food, or sound, caregivers can encourage people in their care to use their ***five senses*** to self-soothe. Allow each sight, sound,

smell, touch, and taste come in and go, not dwelling on any one thing for too long.

- **Vision** – Buy a beautiful flower for the person and talk about the details of it, watch a flame on a candle, go to an art museum, people watch, or beautify one area of the person's house.
- **Hearing** – Listen to the birds, focus on the sounds in the environment – mowers, trucks driving by, kids playing, etc. Help someone play an instrument.
- **Smell** – Offer different spices to smell, bake cinnamon bread, or go to a department store and smell perfumes/colognes.
- **Taste** – Have a good meal with a variety of food choices, sample different flavors of ice cream, suck on a mint, or make a smoothie with the person's favorite fruits.
- **Touch** – Take a warm bubble bath, offer a hand massage, play with sand, or walk in the grass barefoot.

Improve the moment requires replacing negative thoughts/events with more positive ones. This distress tolerance skill helps people feel more confident and courageous. These skills can be remembered more easily by the word **"IMPROVE"**.

- **Imagery** – Use imagery to help the person visualize leaving the negative situation and entering a safe, secure place. The caregiver and the individual can create this place together. If flashbacks occur, going to a safe place in the person's mind can be helpful. Imagine relaxing scenes. Help the person to imagine the negative thoughts melting away.
- **Meaning** – Find something positive in the negative situation. Give the negativity a purpose, or meaning. Focus on the positive aspect.
- **Prayer** – This refers to asking for strength, being open to a higher power. This can take the feeling of weight from overwhelming emotions off the person.
- **Relaxation** – Encourage muscle relaxation by tensing and relaxing each muscle group, starting from the feet working all the way up to the head, take a warm bath, listen to soothing sounds, get a massage, breathe deeply, and smile.
- **One thing in the moment** – Encourage the person to focus their attention on only one thing in the moment, help keep the person's mind in the present – not on what you'll do later or what happened in the morning, but right now. When staying in the moment, be mindful of the experiences of all five senses.
- **Vacation** – Help the person take a brief vacation. Build a fort or use a tent and pretend to go camping for 20 minutes. Or better yet, go camping. Rent a hotel room for a night and don't worry about the chores and other daily demands, have breakfast in bed or have a lunch picnic. Do something out of the ordinary.
- **Encouragement** – Teach the person to be their own cheerleader. Repeat "You can get through this," "You can do it," "It won't last forever."

Thinking of pros and cons is about making a list of the positive and negatives of tolerating and not tolerating distress. The intention here is to get people to see that tolerating distress has more positive outcomes than not tolerating or accepting the reality of distress.

Emotional wellness is an important aspect of everyone's life. Distress Tolerance skills can help people tolerate and accept the negative events that have occurred and the overwhelming emotions left behind. These skills are not a quick fix. It requires patience, guidance, and positive supports from each caregiver. Practice these skills often to help each person improve their emotional wellness.

References

- Linehan, M., Ph.D., (1993). Skills Training Manual for treating Borderline Personality Disorder. New York: The Guilford Press.
- An Overview of Dialectical Behavior Therapy. (n.d.) Retrieved from <http://psychcentral.com/lib/an-overview-of-dialectical-behavior-therapy/>

Health Literacy: Obtaining the Information

By Marjory Grieser, RN

Health Literacy is the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed in order to make appropriate health decisions (Center for Health Care Strategies, Inc. 2013). The ability to read, write, and effectively communicate are essential to achieving health literacy. As many as half of the adults in the U.S. have limited literacy skills, and up to 9 out of 10 people have limited health literacy skills (Health Literacy Basics, www.health.gov).

It is a skill that is owned by each person who needs health information, and people with I/DD will most likely require supports in attaining health literacy. Caregivers are in a unique position because in helping someone to achieve health literacy, they need to understand and apply information that matches the person's skill level and interest. Caregivers can think of health literacy as the ability to obtain, process, and understand basic health information with the intent of explaining it to another individual in a way that he or she will understand. Health literacy can be achieved through collaboration between the caregiver, the individual and the health care professional. This approach encourages the individual to be part of the care team and may foster the person's ability to make informed health care decisions.

In 2008, the United States Department of Health stated that it is not the lack of knowledge, but ineffective communication techniques that can contribute to poor health literacy. Individuals with I/DD may have deficits in reading, writing, and expressive and receptive verbal communication skills. It is essential for caregivers to identify and use the best methods of communicating health information to individuals in their care. It is also important to find out what the person wants to know about the health topic, as there can be a wealth of information that may be overwhelming to the person.

Kim, a 28-year-old who enjoys working at McDonald's and watching crime shows on TV, was scheduled for a skin biopsy to evaluate a lesion on her back. Caregivers talked with Kim regularly for 2 weeks about what to expect at the procedure, so that she was well prepared for completing the test. The night before the test Kim woke up, crying hysterically. Caregivers offered safety and reassurance, and eventually Kim was able to tell them what was wrong. She said, "I am so afraid. I don't want to have an autopsy. You have to be dead to have an autopsy!" Caregivers immediately understood that Kim had biopsy confused with autopsy. They used pictures and simple language to teach Kim the difference between these procedures. Kim was relieved, and stated she was glad she wasn't getting what she had seen on TV. This is a very good example of what can happen when health literacy skills are limited.

Health Care Literacy Skills Suggested Topics

- Osteoporosis
- Diabetes
- Obesity
- Gastro-Esophageal Reflux
- Seizure Disorder
- Dysphagia
- Urinary Tract Infection
- Aspiration Pneumonia
- Head Injury

This article is the first in a series of three, and its focus is on obtaining health information. The articles are meant to help the caregiver break down the barriers of health literacy while keeping in mind, the individual's needs, the individual's priorities and the individual's understanding of the health care topic.

Barriers Caregivers May Face when Obtaining Health Information to Share with People who have I/DD

- **Health care provider lack of knowledge about people with I/DD/attitudes towards this population**

Sometimes health care providers have not been trained in how to best work with people who have an intellectual disability. Consider this example: Beth, the caregiver, accompanies Kim, an individual with I/DD to the doctor's office for an appointment about a bad rash on Kim's arm. Upon entering the room, the physician greets Kim, but directs all conversation to Beth, stating that since Kim has I/DD she can't understand what the doctor is saying, nor can she consent to the recommended procedure. This approach removes the opportunity for Kim to be an active participant in her health care and to receive information from the doctor; it does nothing to increase Kim's health literacy. In this situation, the best action Beth could take is to inform the doctor that Kim can and does learn when information is presented in a simple way using words that Kim relates to, and encourages the doctor to talk to Kim. This is a non-confrontational way for the caregiver to educate the doctor about best practices when working with someone who has I/DD. Beth may want to consider modeling an effective communication approach for the doctor, using the information the doctor wants to share. This will increase Kim's ability to obtain the needed health information.

- **Lack of access to internet at work site**

Many searches for health care information start on the internet. If internet service is not available or is unreliable, the caregiver may want to consider visiting the library for internet access. Caregivers may also want to consult subject matter experts, such as a doctor who has experience working with people who have I/DD, a nurse at the provider agency, or staff from the HCQU. In addition, the University Center of Excellence on Developmental Disabilities website at www.aucd.org is also a very helpful resource.

- **Too much information available on the topic**

In helping a person with I/DD to obtain health information the first questions to ask is "What does the individual want to know?" This can help to narrow the focus of the information obtained, as presenting too much at once or presenting information that is not meaningful for the person can be overwhelming, and will not increase his or her health literacy. The second point of consideration for caregivers is "What do I, the caregiver, need to know to answer the individual's questions?" When doing an internet search, look for specific answers to specific questions; in other words, don't research the entire topic. For instance, to learn what a skin biopsy is, type in 'what is a skin biopsy?' in the search box, rather than biopsy. The more specific the request, the more specific the information obtained will be. Health literacy will improve if the caregiver can focus on obtaining information for one question or two questions at a time. As the caregiver, you want to provide basic, concrete, accurate information, answering specific questions.

- **Computer skill level of person who wishes to search the internet independently for information**

Some people with I/DD may wish to independently search for health information online. They may require assistance in both identifying the best way to look for information and in using website features such as the website search page or dropdown boxes. Caregivers may want to make themselves available for education and support during web browsing sessions as needed. Encourage the individual to allow supervision, promoting safety while navigating the internet. Visit websites that are known to be credible and easy to navigate; a list of useful websites is included below. If the person has difficulty seeing the webpage because the print is small, caregivers may need to assist the person to increase the font size or use the zoom function in the browser.

- **Lack of materials designed specifically for people with I/DD**

When searching for information, carefully regard educational material for children. The information can be helpful, but the caregiver will be responsible for using and explaining information in an adult manner. Consider visiting the HCQU website and downloading the Rehearsal Guides. These guides have been developed to promote health literacy and are found to be very helpful. Rehearsal Guides show specific pictures that are associated with the dialogue which, the direct support professional reads to the individual with I/DD.

The individual with I/DD associates the language with the picture to make the information memorable. The website, Books Beyond Words, <http://booksbeyondwords.co.uk/#/resources-dl/> offers obtainable, downloadable material. Pictorials can be very helpful. Pictures provide “memory pegs” through which the reader can connect with the story (Understanding Emotions and Books Beyond Words: A neuroscience perspective. SEND Magazine, May 2016.). Obtaining this type of information can empower the individual and help to build a dialog between the health care provider, the caregiver and the adult with I/DD. Another internet resource, Seeds Educational Services, www.seedseducation.org offers a similar style of information beneficial for communicating. The HCQU website offers self-advocate training and education, as well. This information can be downloaded from the website, <https://hcqu.kepro.com>. The printouts are designed to promote a conversation and assist the caregiver to facilitate a conversation with the individual.

In addition to the websites already mentioned, www.seeability.org has easy to read books which offer support for individuals going to the optometrist or, if they’d like to learn about common visual problems or assistive technology. The National Institutes of Health, www.NIH.org, offers information on many health topics and health maintenance topics such as tips for healthy summer habits and, the information is in an easy to read and easy to comprehend format. Also, www.autismspeaks.org provides safety, diet and nutritional guidance. For the caregiver, The American Academy on Intellectual and Developmental Disabilities, www.AAIDD.org, offers information on finding dentists and other medical clinicians, and offers the caregiver different methods to advocate for the individual.

Look for the second article in the next newsletter, to learn more on increasing the ability of the individual with I/DD to process health care information.

References:

- University of Minnesota Data on the Estimated Number of People with IDD by State. Sheryl A. Larson. Retrieved from www.nasddds.org on June 28, 2016
- Promoting Health Literacy for People With Disabilities and Clinicians Through a Teamwork Model. Journal of Family Strengths, 2015. Retrieved from www.digitalcommons.library.tms.edu on June 27, 2016.
- Medlen, J. (2010). Creating Understandable, Effective Tools for People With Intellectual and Developmental Disabilities.
- Health Literacy Fact Sheets. Retrieved from www.health.gov on June 27, 2016.
- Everyday Words for Public Health Communication. Centers for Disease Control and Prevention, retrieved on 6.28.16 from: <http://www.cdc.gov/ccindex/>
- Understanding, Emotions and Books Beyond Words, May 2016. SEND Magazine retrieved from www.sendmagazine.co.uk on July 21, 2016

The Relationship between Intelligence, Health & I/DD

Brian J. Leech, MS

An increasing amount of research has shown that intelligence and health have a strong and positive relationship (Gottfredson and Deary, 2004; Arden, Luciano, Deary, Reynolds, Pedersen, Plassman, McGue, Christiansen, & Visscher, 2015; Hambrick, 2015). Findings so far suggest that a higher IQ score generally relates to a longer lifespan, but researchers are still unsure of why this is the case (Gottfredson and Deary, 2004). Some evidence points towards genes for good health and intelligence occurring together, while other ideas imply that intelligence allows people to successfully adapt to challenges throughout their lives in a healthy way (Arden, et. al., 2015; Gottfredson and Deary, 2004). What does all of this mean for people with intellectual and/or developmental disabilities (I/DD)?

While individuals with I/DD are enjoying longer lifespans, the level of the intellectual disability can affect the length of a person's life: an Australian study showed that for those with mild I/DD, the average life expectancy was 74 years; those with moderate I/DD had a life expectancy of 67.6 years; and individuals with severe I/DD had a life expectancy of 58.6 years (Bittles, Petterson, Sullivan, Hussain, Glasson, & Montgomery, 2002). While issues with physical health and genetic conditions can affect lifespan lengths, intelligence also seems to play a role in one's longevity, possibly due to a person's ability to monitor their own health and to follow recommendations and best practices for a healthy lifestyle (Gottfredson and Deary, 2004). In this case, caregivers may be vital not only to extend an individual's lifespan, but also to help improve the person's quality of life by helping him or her follow healthy practices and understand various treatments.

Medical and psychiatric professionals define intellectual disability in a certain way, and it can be helpful for caregivers to understand this definition. Intellectual disability is defined in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition as a condition that affects the individual's ability to function in three distinct areas (APA, 2013). These areas include: conceptual, which deals with academic skills such as reading, writing, and critical thinking; social, which deals with how one interacts with and understands others; and self-management, which includes being able to take care of the activities of daily living (bathing, cooking, keeping a house clean, having a job) (APA, 2013).

What can caregivers do to help an individual with I/DD maintain a high quality of life and adapt to changes and/or challenges along the way? There are some general recommendations that can be useful in helping an individual maintain health and independence while compensating for issues in cognitive ability.

- 1. Use variety to teach tasks and concepts** – When learning how to accomplish a task (or learning about a new topic) it may be helpful to watch videos, to talk to professionals for basic explanations about the topic (i.e. asking a doctor to explain bipolar disorder), attend trainings, or even use pictures to illustrate steps or ideas (Government of South Australia Department of Communities and Social Inclusion, 2013).
- 2. Teach tasks in the places where they will be done** – If an individual is learning how to self-administer medication, it may be a good idea to work on that task in the area of the home where the person will usually be taking medications; this can help the individual to associate the area with the activity and could serve as a reminder for what to do and how in the future (Government of South Australia Department of Communities and Social Inclusion, 2013).
- 3. Break tasks or ideas into smaller parts** – A helpful way to teach new concepts to those with I/DD can involve breaking an idea down into smaller parts (Reynolds, Zupanick, & Dombeck, 2013). For instance,

teaching an individual how to do laundry independently may be achieved by breaking the task down into sorting clothing first, then moving on to loading the washing machine after mastering the first step.

- 4. Set up consistent daily schedules** – Repetition can be very helpful in learning new information, especially for those with I/DD (Government of South Australia Department of Communities and Social Inclusion, 2013). One way of doing this is to use pictures to highlight what will be happening throughout the day (Government of South Australia Department of Communities and Social Inclusion, 2013). It is also important for caregivers to work with individuals in creating their own schedules. Not only does this give the person a chance to exercise control over his or her life, it also may help the person to focus on completing tasks and practice how to order ideas in a sequential manner.
- 5. Label cupboards/drawers/cabinets in the home to help the person find needed items** – Caregivers can use either pictures of items or write out the names of items that are located in specific areas of the home (i.e. a picture of a dinner plate on the cabinet where the dishes are located) (Sanford School of Medicine, n.d.). This may reduce the stress of an individual trying to remember where certain items are and allow more mental energy to be devoted to learning and completing other tasks.
- 6. Encourage the person to have fun through games and activities** – Playing games and trying new activities (or enjoying activities the person is already interested in) can help to keep a person engaged and thinking about his or her world (Huckans, Pavawalla, Demadura, Kolessar, Seelye, Roost, Twamley, & Storzbach, 2010). Anything that stimulates thinking and problem-solving and is fun to do can count – from puzzles, to art projects, to trips to a park and even video games. The idea is not to build mental skills, but rather to help the individual develop focus and use his or her cognitive abilities while also enjoying the benefits of simply having a good time (Huckans, et. al., 2010).

The suggestions provided here are only a small sample of ways that caregivers can help those with I/DD to use their intelligence as a way to boost both life expectancy and quality of life. Being aware of the possible link between intelligence and lifespan can shape how treatment teams respond to the challenges and needs of an individual with I/DD in a more holistic way.

References:

- American Psychiatric Association, & American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders: DSM-5. Washington, DC: American Psychiatric Association.
- Arden, R., Luciano, M., Deary, I. J., Reynolds, C. A., Pedersen, N. L., Plassman, B. L., ... Visscher, P. M. (2015). The association between intelligence and lifespan is mostly genetic. *International Journal of Epidemiology*, 45(1), 178-185. doi:10.1093/ije/dyv112
- Bittles, A., Petterson, B., Sullivan, S., Hussain, R., Glasson, E., & Montgomery, P. (2002). The Influence of Intellectual Disability on Life Expectancy. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 57(7), M470-M472. doi:10.1093/gerona/57.7.m470
- Gottfredson, L. S., & Deary, I. J. (2004). Intelligence Predicts Health and Longevity, but Why? *Current Directions in Psychological Science*, 13(1), 1-4. doi:10.1111/j.0963-7214.2004.01301001.x
- Government of South Australia, Department for Communities and Social Inclusion. (2013, July). Disability information. Retrieved from https://www.sa.gov.au/_data/assets/pdf_file/0007/17359/intellectual-disability-promoting-daily-skills-adults.pdf
- Hambrick, D. Z. (2015, December 22). Research confirms a link between intelligence and life expectancy. *Scientific American*. Retrieved from <http://www.scientificamerican.com/article/research-confirms-a-link-between-intelligence-and-life-expectancy/#>
- Huckans, M., Pavawalla, S., Demadura, T., Kolessar, M., Seelye, A., Roost, N., Twamley, E., and Storzbach, D. (2010). A pilot study examining effects on self-reported cognitive problems, psychiatric symptoms, functioning, and compensatory strategy use in OIF/OEF combat veterans with persistent mild cognitive disorder and history of traumatic brain injury. *Journal of Rehabilitation Research & Development*, 47 (1), 43-60.
- Intellectual Disability Rights Service. (2016). Information about intellectual disability: What is it? Effects of intellectual disability. Retrieved from <http://www.idrs.org.au/education/about-intellectual-disability.php>
- Reynolds, T., Zupanick, C. E., & Dombeck, M. (2013, May). Effective teaching methods for people with intellectual disabilities. Retrieved from <https://www.mentalhelp.net/articles/effective-teaching-methods-for-people-with-intellectual-disabilities/>

Peer Support Specialist

By Elizabeth Hobbs, BA

Finding personalized support for persons who have mental illness can be a challenge. Peer Support Specialists can help meet that challenge. A Peer Support Specialist, also called a “Peer Specialist”, is a person who has had a life changing experience who works with others to assist with mental health issues and other life effecting issues. Often the life changing experience is living with a mental illness.

A Peer Specialist has moved through the recovery (from mental health) process and has an understanding of that process due to their first-hand experience. In brief, Recovery or the Recovery Process is the belief that people can and do recover from mental illness and that all people must have opportunities to participate fully in the process and services aimed at improving and supporting mental illness. Due to the life altering experiences, a peer specialist is able to provide unique insight, has knowledge, and skills that professional education cannot replicate. That said, Peer Support Specialists are required to complete government and state certification requirements.

In Pennsylvania the requirements include:

- Experience: has received mental health services for a serious mental illness. A serious mental illness is defined in the mental health bulletin OMH-94-04.
- Education: a high school diploma or general equivalency degree (GED).
- Activity: within the past three years has maintained a job or volunteer position for 12 months, or has earned 24 post-secondary education credits.
- Training: has completed and passed Certified Peer Specialist training.



There are two providers in Pennsylvania who provide Peer Specialist training. They are The Institute for Recovery and Community Integration and Recovery Innovations Consulting.

How can Peer Support Specialists help?

Peer Specialists perform a wide variety of tasks. But all are focused on assisting their peers. Peer Specialists typically use the recovery approach to help the person that they are assisting to build a personalized plan for recovery.

This plan is drawn up by the person being supported, with their goals for recovery being central to it. The plans focus on the overall health and well-being the person, including but not limited to mental health. Aspects of the plan often include:

- Health care and maintenance of health
- Stable / long-term residential needs
- Medication, therapies and supportive services (support groups)
- Education needs/goals and/or vocational development/meaningful activity
- Improvements in relationships – personal, family, and/or friends
- Community connections

The plan may also include a timetable for monitoring, and/or a plan for re-involvement when needed to balance the health and overall quality of life for each individual.

As quoted in a study “Peer support is not like clinical support, nor is it just about being friends” (MacNeil C. & Mead S. 2003). It fills a gap in services while building a bridge to them.

Peer specialists might help to:

- Support an individual in advocating to obtain effective services. For example, a Peer Support Specialist might support a person in their search to find a mental health therapist.
- Discover and put into words their goals for recovery. For example, an individual might not have considered community support. The Peer Specialist would be able to explain it for the person’s consideration and give an idea of what that might consist of.
- Support the person regarding their treatment. For example, the Peer Specialist might help the person come up with a system to ensure that they have taken their medications if this was a need for them.
- Model effective coping techniques and self-help strategies. For example, the peer specialist might model and practice relaxation techniques with the individual.
- Help the person with monitoring their progress of recovery. For example, an individual might doubt that they are improving. A peer specialist could provide feedback on the overall progress such as reminding the person that they have had fewer hospitalizations.

Peer recovery support specialists can be found in an increasing variety of settings, including community-based recovery centers. In some counties support can be available for up to four hours a day. For many, support is for a few hours at a time, for one to two times a week. Support ends when the person is consistently meeting their goals that they have set. Support can average two and half to three years.

Funding for peer recovery programs comes from a combination of federal and state agencies, as well as, local and national charities and grant programs. The person’s behavioral health insurance may also pay for this service. Counties may have varying requirements to receive peer support services, such as having an order prescribing this specific support from a licensed professional of the healing arts. Licensed professionals include: Psychiatrist, Psychologist, Primary Care Physician, Nurse Practitioner, Physician Assistant, or Doctor of Osteopathy.

Looking for a Peer Support Specialist or want to refer someone for peer support? Your county’s mental health services may be the best place to start. The Pennsylvania Mental Health Consumer’s Association (PMHCA) in association with the The Pennsylvania Peer Support Coalition maintains a database of service providers of Peer Support Specialists. The data base can be accessed at http://www.pmhca.org/db/Find_PSC.html.

References:

- Depression and Bipolar Support Alliance. 2016. Learn about Peer Specialist. http://www.dbsalliance.org/site/PageServer?pagename=education_training_learn_about_peer_specialists
- Greene ARC incorporated. 2016. Peer Support. Brochure
- International Association of Peer Supporters (iNAPS). What is a peer supporter? <https://inaops.org/definition-peer-specialist/>
- Pennsylvania Peer Support Coalition. Peer Support Specialist: What is a Peer Support Specialist? <http://www.pmhca.org/projects/ppsc.html>
- Recovery Innovations Consulting, <http://riinternationaltraining.com/>
- The Institute for Recovery and Community Integration, <http://www.mhrecovery.org/>
- MacNeil, C. & Mead, S. (2003). The Standards of Peer Support, <http://papeersupportcoalition.org/wpcontent/uploads/2015/09/UnderstandingWhatUsefulHelpLooksLike.pdf>

NOTES:

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Stay Tuned for a New Resource!

The Southwestern Pennsylvania Health Care Quality Unit (HCQU) will be adding a new resource to our website in the coming months! We've partnered with Staywell- Krames to offer our clients, customers and members access to more than 6,000 HealthSheets and Medication References.

With access to more than 4,000 topics relating to health and medication, Krames Online provides you with the ability to find answers to most questions, both big and small. Simply click on the search function to begin.

The new resource will be available on our website at <https://hcqu.kepro.com/Home.aspx>, under 'Other Resources' in the near future!

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Southwestern Pennsylvania Health Care Quality Unit

8775 Norwin Avenue, Suite 103

North Huntingdon, PA 15642

Toll-Free: 888.321.5861

Office: 724.864.0715

Fax: 724.864.3750

<https://hcqu.kepro.com>