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HCQU Staff

HEALTHY CONNECTIONS

THE QUARTERLY NEWSLETTER OF COMMUNITY HEALTH CONNECTIONS

SPRING 2011



Commonly Used Acronyms from the Office of Developmental Programs

AS
Asperger's Syndrome

ASD
Autism Spectrum Disorder

BSC
Behavior Supports Consultant

DD
Developmental Disability

(Continued on page 2)

Crisis

By: Mary A. Nau, Director, and Danna Haffey, Behavioral Health Consultant

The ID/DD world as of late is grappling with the unrelenting demon of dual diagnosis and psychiatric hospitalizations. It usually begins with an individual who is battling with something we can't see or understand. It appears to twist and distort and distress. The supporters begin to reach for resources in an attempt to maintain safety and restore stability. When their strategies don't yield positive results the vortex widens and now law enforcement or EMS become involved.



The situation escalates and the individual at the center of the crisis is further drawn into it typically landing him/her in an emergency department where s/he is either restrained, observed, questioned, medicated, admitted, or turned away. And the search for resolution goes on with more phone calls, meetings, consultations, medication

adjustments, new plans, new placements, new questions, and few answers. While progress is slow, there are a few insights that could make the difference for someone you support. The first is a growing body of research that reveals 75 percent of those with developmental disabilities who present at a psychiatric facility **have an underlying medical condition** that is either causing or contributing to the psychiatric presentation. Seeking a medical cause can help us find effective treatments and avoid inappropriate use of psychiatric medications and other restrictive behavior interventions. Most importantly, appropriate treatments are necessary to relieve the discomfort, pain, or illness to which a person is responding through his behaviors. It may take some investigating to determine the medical nature of a psychiatric presentation because many people can't say "I don't feel well," or "This part of my body hurts." Research suggests that the most common health

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(Continued from page 1)

ISP
Individual Support Plan

OVR
Office of Vocational
Rehabilitation

PaTTAN
Pennsylvania Training
and Technical
Assistance Network

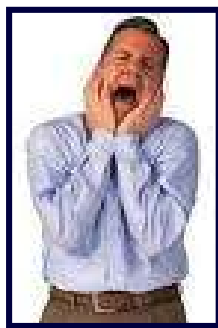
PPRT
Positive Practices
Resource Team

SEEP
Social/Emotional/
Environmental
Support Plan

problems associated with distressing behaviors are dental problems,



obstetric/gynecologic and prostate problems (cited by Mike Mayer, PhD, CRA). According to research published in the Journal of Intellectual Disability Research, June 2010, the most common medically



driven psychiatric presentations were constipation and gastroesophageal reflux disease (GERD).

If at any time a new behavior or a change in behavior is noted we should have the person medically evaluated to rule out any type of medical problem that may be causing or contributing to the behaviors we are seeing. It is important for caregivers to carefully report changes to the PCP and provide objective documentation so that s/he can make an accurate diagnosis. Medical problems certainly are not the only



cause of psychiatric presentations, but they clearly are worthy of ruling out first.

Examples of common presentations that can be medically driven:

- * Hitting self in the head might indicate a headache, toothache or infection.
- * Holding head and crying or moaning or wanting to be in the dark might indicate a problem with migraines.
- * Washing hands in the toilet or some other odd behavior may be due to confusion from a urinary tract infection.
- * Forcing self to regurgitate stomach contents may be due to acid reflux.
- * Placing sharp objects in mouth or back of throat may be due to acid reflux.
- * Rectal digging and smearing of stool can be due to constipation and/or hemorrhoids.
- * Masturbation in any environment may be due to urinary retention/infection, or erectile dysfunction due to medication side effects.
- * Sad demeanor may be due to a thyroid problem.
- * Agitation or aggression can stem from a thyroid problem.
- * Aggression, self injurious behavior, undressing may be attributed to a sensory integration disorder.
- * Lack of interest or withdrawal can be caused by sleep apnea.

Community Resource: Lions Club

By: Natalie Symons, Clinical Services Coordinator



Lions Clubs International

The mission of the Lions Club is to serve their community, meet humanitarian needs, encourage peace and promote international understanding. They are the world's largest service club with 1.35 million members. They conduct vision screenings to eradicate blindness, sponsor scholarships for children to attend schools, and provide nutrition and education to prevent diabetes. They have provided aid in war torn regions and to areas devastated by natural disasters. The Lions Club also provides aid and equipment to those in need. If you know of a person with a disability that could use medical equipment or adaptive devices, don't hesitate to call them. Their motto is "We Serve": To find out more about the Lions or to contact your local group go online at www.lionsclub.org.

The Biggest Loser Sparks Healthy Lifestyle Changes

By: Kelly Fisher, RN; Physical & Behavioral Health Consultant



Sitting L to R: Tom, Stephanie, and Larry

Standing L to R: Georgia, Tracy, Audrey, Ken, David, and Marty

The Arc of Butler County has created a healthy competition in their Life Sharing Through Family Living Program. Ten self advocates have taken the challenge to make steps toward a healthier lifestyle. The group has agreed to engage in making healthier choices in what they eat/drink, as well as leading a more active lifestyle. In addition, the HCQU has had the privilege of offering trainings during their meetings. The group

members have all been actively participating and challenging each other. Some have chosen “buddies” for support in their goal of making healthier choices. Healthy incentives have been offered by the Provider.

Kelly: *What do you like best about the competition?*

Tom: I like winning the best!

Stephanie: I really am having fun.

Ken: I like having the opportunity to see people.

Audrey: I like the competition.

Kelly: *What have you done or changed that helped you lose the weight? What would you tell others who want to lose weight?*

Tracy: Eating healthier has helped me to lose weight.

Marty: Exercise. (Marty is walking three miles twice a week.)

Stephanie: Not eating things that aren't good for me. And now I watch my portion size.

Ken: Exercise is good. I shovel snow, cut grass, and go for walks. The weather doesn't matter to me. I can always find something to do.

Dave: I'm doing good. (Dave has been open to taking food suggestions from his supporter.)

Tom: Instead of taking two sandwiches in my lunch, I take one.

Larry: I take my medicine with water. I might think about eating less beef jerky.

Audrey: I think it's important to just think positively about the choices you are making.

The group has focused on making small consistent changes. Does this mean they can never have a cookie again? No. But limiting it to a portion size is important. Everything in moderation. The group has been very successful. Part of their success is their support of each other and their willingness to try something new while having fun doing it. Great job to each and every “winner” in this group.

Hospital Capacity Building



The weather outside was frightful, but that didn't stop the HCQU nurses from traveling throughout our 9 county region to network with local hospitals in January and February! During each hospital visit the nurses met with the Education Department and offered to provide trainings. The HCQU has 30 Nursing CEU accredited trainings that provide education around various topics, such as *ID/DD: Gaining Understanding, Communication at the Bedside with People with ID/DD, and Discharge Planning and Group Home Regulations*. These trainings will assist medical professionals in understanding the ID/DD system and providing the optimum in medical care to those with disabilities.

Shingles Vaccine

By: Margie Fend, RN; Health Services Consultant



Shingles (also known as Herpes Zoster) is a very painful skin rash often with clusters of blisters. Shingles rash usually appears on the face or body and symptoms can include fever, headache, chills and upset stomach. Shingles can last two to four weeks. The shingles vaccine is approved to protect your body from reactivation of the chickenpox

varicella-zoster, a virus that most people are exposed to during childhood. When you recover from chickenpox, the virus stays latent (not active) in your body. For unknown reasons, the latent virus sometimes get reactivated years later, causing shingles. The shingles vaccine prevents this reactivation. Some people can develop shingles despite vaccination. When it fails to suppress the virus completely, the shingles vaccine may reduce the severity and duration of shingles. The Zostavax (shingles) vaccine is a live vaccine given as a single injection, usually in the upper arm. Common side effects of the shingles vaccine are redness, pain, tenderness, and swelling at the injection site, and headaches. According to the Center for Disease Control, adults age 60 and older should get the shingles vaccine whether they've had shingles or not.

The shingles vaccine is **not recommended** for anyone:

- That has ever had a life-threatening allergic reaction to gelatin, or the antibiotic neomycin.
- That has a weakened immune system from cancers such as leukemia, lymphoma, or prolonged use of high dose steroids.
- Receiving cancer treatment such as chemotherapy or radiation.
- Who is pregnant or trying to become pregnant.

This vaccine does not protect from other types of herpes such as genital herpes or active shingles.

Check with your health care provider to see if the shingles vaccine is recommended for you. For more information on the shingles vaccine, visit www.cdc.gov.

Gardasil Approved for Anal Cancer (12/28/10 11:09:36 AM)

The FDA has approved Merck & Company's *Gardasil* (human papillomavirus [HPV] quadrivalent vaccine, recombinant injection) for the prevention of anal cancer and associated precancerous lesions due to HPV types 6, 11, 16 and 18 in patients 9 through 26 years of age. The vaccine is already approved in girls and women 9 to 26 years of age for the prevention of cervical, vulvar, and vaginal cancer caused by HPV types 16 and 18 and for the prevention of precancerous or dysplastic lesions caused by HPV types 6, 11, 16 and 18, as well as the prevention of genital warts caused by HPV types 6 and 11 in males and females 9 to 26 years of age.



Training in Your Pajamas

By: Leslie Dollman, MIS Administrator

Have you ever had a dream that you showed up to work or school in your pajamas? Chances are that you felt uncomfortable or embarrassed about being inappropriately dressed. Here at CHC, we think you should be able to get training in your pajamas without shame if you choose to, so we have been working hard to bring you **CHC-Online**, our new web-based training delivery system, designed to help meet your training needs.

CHC-Online delivers interactive training over the World Wide Web, enabling people to learn anytime and anywhere. All you need is a computer and access to the internet! We have just a few training modules currently available, but our ultimate goal is to have a wide variety of physical and behavioral health training topics so you can gain the knowledge and skills you need to best support people with intellectual and developmental disabilities.

Do you need training but don't have the time to drive to a location and sit through a two-hour course? Or maybe you're just the sort of person who prefers to learn at your own pace? Log on to www.hcqu.org and navigate to our web-based training page to browse our selection of fun, interactive, web-based training modules.

HCQU Happenings: To register, please visit our website at www.hcqu.org or call (724) 283-0990.

Asperger's/Autism and Sexuality: Knowledge and Skills Necessary for Successful Relationship Development (Nursing CEU)

Presented by: Lawrence R. Sutton, Ph.D.
Psychologist/Manager Western Region
Bureau of Autism Services, ODP

Date: April 14, 2011

Time: 1PM - 4PM

Location: The ARC of Crawford County - Meadville, PA

The Person Directed Framework: Partnering Through Feedback

Presented by: Guy Legare, M.Ps.
Management and Clinical Training
Consultant, PDSS Consulting, LLC

Date: April 20, 2011

Time: 8:30AM - 3:30PM

Location: The CDC - Butler, PA

Aging with a Mental Illness (Nursing CEU)

Presented by: Dr. Gregory Cherpes, MD
Medical Director, Community Health
Connections

Date: May 26, 2011

Time: 1PM - 4PM

Location: McGuire Memorial Homes - New Brighton, PA

David Hingsburger Conference with a TWIST - FREE 2-day Conference - CONSUMER FRIENDLY EVENT

Date: May 19 - 20, 2011

Time: 9AM - 3:30PM

Location: Succop Theatre Butler County Community
College - Butler, PA

Day 1: KEYNOTE - David Hingsburger

We will look at the basic ground rules we need to be together respectfully. This session will have role plays and maximum participation. **Afternoon breakouts include: Abuse Prevention (for people with disabilities ONLY); film festival; exercise; and other breakouts.**

Day 2: KEYNOTE - David Hingsburger

We will look at the importance of learning voice and allowing voice. For services to be truly client centered there needs to be a freedom from fear--of punishment, of correction, of patronization. Voice leads to change. It is important for all of us to find a space where we can be authentic to who we are in safety. **Afternoon breakouts include: Abuse Prevention (for staff and administrators ONLY); chef; sensory room; and more.**

Our Future, Our Lives...Endless Possibilities

Date: June 17, 2011

Location: Lutherlyn Camp - Prospect, PA
More information coming this Spring.

Can Your Bladder Really Burst?

By: Carol Oslosky, RN; Health Services Consultant

Can your bladder really burst? Interesting question. First, let's look at how the bladder functions. Your kidneys work continuously producing urine which travels down through tubes called the ureters. From the ureters, the urine enters a stretchy pouch made of muscle called the bladder. The bladder can expand enough to hold around 475ml (16 ounces) of urine comfortably. The maximum most bladders can hold is about 800ml (about 26 ounces) and you'd be pretty uncomfortable. As your bladder fills with urine, you notice a feeling that you need to urinate. As it gets fuller and fuller the feeling intensifies until you now know you've really "got to go". So what happens if you "hold it" and don't go for a long time? Will your bladder actually burst? No--that's not likely. It's far more likely that you'll "pee your pants". The idea that your bladder will burst is largely a myth. Burst is a pretty dramatic term. Rupture might be more accurate. There have been reports of bladders rupturing with heavy alcohol users. It may be due to alcohol depressing the urge to urinate and allowing the bladder to fill beyond its limit. Also, it is likely the result of a trauma that occurred while under the influence of alcohol. In general, a full bladder is far more likely to be damaged with trauma than an empty one. Think about stepping on a very full balloon and then on one that is only partially full. Which one do you think will pop easily? Some other conditions where a bladder might rupture would be a major trauma like a pelvic fracture, damage from radiation or a bladder wall weakened by a tumor or surgery that removed the tumor. Holding urine for extended periods increases the possibility of a urinary tract infection. Moral to the story--When you've "got to go"--find a restroom. Avoid the discomfort and possible urinary tract infection.

Are Our Food Choices Making Us Sick?

By: Kelly Fisher, RN; PBHC

Everyday we make a choice about what we put in our body. In an earlier issue, we discussed the consumption of sugar. But wait. What about those of us who prefer the salty side of life. Well, researchers at the University of California say cutting back our daily salt intake by just three grams, just over a teaspoon, could prevent 32,000 strokes and 54,000 heart attacks a year! But, what about those of you who say, "I never add salt to my food." You may be surprised to know that the majority of salt we consume comes not from that salt shaker but from the foods we eat. The Western society diet primarily focuses on processed foods. In order to preserve processed foods, manufactures add salt. The average American consumes ten grams of salt a day. Recommendations from the World Health Organization suggest our intake should be only five. So where do we start? According to the Mayo Clinic you can begin by eating more fresh foods and less processed foods. Remember to shop the outside perimeter of the store. This is where you will find all the fresh foods. The center isles are typically all processed foods. Other options include using low salt items, limit high salt condiments, use herbs, spices or other flavorings. Look at labels when shopping. Know the "hidden" names for salt such as monosodium glutamate, baking soda, baking powder, disodium phosphate, sodium alginate and sodium nitrate or just nitrate. Just a note on those salt substitutes, we often over use them to achieve the taste we desire. In addition, because many of them contain potassium chloride persons who have kidney problems or taking medications for congestive heart failure or hypertension may have problems with potassium retention. Finally, the taste for salt is an acquired taste so it can be unlearned. Decrease your salt intake gradually and your taste buds will adjust. So the next time you go grocery shopping or prepare a meal look at the nutrition label. You will be amazed!



What's On Your Label?: "Phenylketonurics - Contains Phenylalanine" "Aspartame"

By: Christina Irwin, RN; Health Services Consultant

Products Containing Aspartame

Aspartame is found in about 6,000 products around the world, including:

- Carbonated Soft Drinks
- Powdered Soft Drinks
- Chewing Gum
- Confections
- Gelatins
- Dessert Mixes
- Puddings and Fillings
- Frozen Desserts
- Yogurt
- Tabletop Sweeteners

Aspartame can also be found in pharmaceuticals such as vitamins and sugar-free cough drops.

www.aspartame.org

What does "Phenylketonurics - Contains Phenylalanine" mean?

Phenylketonurics is the term used to refer to someone that has the metabolic disorder Phenylketonuria, (PKU). PKU is a condition, tested for at birth, in which the person cannot break down proteins. Those that have the disorder need to be aware of products that have phenylalanine, which is found in all products that contain protein. If someone with PKU continues to consume too much protein they are at risk for a decrease in their intellectual functioning, muscle aches and pains, and in extreme cases, even seizures.

How is this related to Aspartame? Phenylalanine is one of the ingredients that make up aspartame. Aspartame has come into the media spotlight for speculation that it is causing adverse side effects in consumers - unrelated to PKU. Many studies have reported the ill affects of aspartame. This can include tumors, cancer, or side effects with vision, hearing, neurological, cardiovascular, reproductive, GI, etc. (The list is very long.) Aspartame is also linked to overeating. For more information about health consequences of aspartame check out: www.aspartame.mercola.com/, www.livestrong.com/aspartame-side-effects/.

Are those studies accurate, should I be concerned about Aspartame? According to www.aspartame.org this product is safe for all consumers including children, pregnant women, diabetics and those with seizure disorders. Many other websites agree with this information and feel that there are many false facts and emails circulating.

To determine if there is a concern with using aspartame, speak with your doctor or health care provider. Be sure to investigate both sides of the information that is presented, then make an informed decision before using a product that contains aspartame.

UPMC of Pittsburgh's Adult Down Syndrome Center

By Christina Irwin, RN; Health Services Consultant

The Down Syndrome Center in Pittsburgh is a wonderful, comprehensive resource for families and caregivers of those with Down Syndrome (DS). They provide a lifespan approach to a unique syndrome that affects one per 733 live births in the United States (CDC). Many centers for DS across the country only treat specific age groups. However, the DS Center in Pittsburgh is able to treat pediatrics, adolescents and adults. This is made possible by funding from the Down Syndrome Association of Pittsburgh. They fully fund the adult center for those with DS which allows the clinic to use other funding for the pediatric side.

The main office of the DS Center is at Children's Hospital of Pittsburgh, but adults looking for treatment will be seen at UPMC Montefiore by Dr. Peter Bulova. I have had the privilege to meet Dr. Bulova and to hear him speak on topics related to DS and have been thoroughly impressed with his knowledge of the field.

When first visiting the DS Center, each patient is given an hour with the doctor to review all medical history and to discuss any concerns that may be occurring. This is an excellent resource for patients who have many health and behavioral concerns.

The DS Center also works with medical students and residents to help dispel myths of DS, especially those with DS who are aging. Residents will quite possibly see a 60 year old doing better medically than a 16 year old. By working with doctors of the future, the DS Center is helping prepare the residents for what they will see in their practice with not only DS, but other disabilities as well.

Another feature of the DS Center is that they are working with Western Psychiatric Institute and Clinic of UPMC to conduct a research to study the early onset of Alzheimer's disease and DS. This study is currently open and looking for participants to help find the connection of these two diseases found on the same chromosome. If you, or someone you know is interested in participating, please contact the DS Center.

The Down Syndrome Center is located in the Oakland Medical Building at 3420 Fifth Avenue, Pittsburgh, PA 15213. The phone number is (412) 692-7963 and you would choose option 4 to speak with the adult center. More information can be found on the website at www.chp.edu/CHP/downsyndrome. There is also a wonderful page on the DS Center website that provides online resources for those looking for information regarding Down Syndrome.



L to R: Peter Bulova, MD, Director of Adult Down Syndrome Center; Sheila Cannon, Program Director; Susan Van Cleve, CRNP, DNP (no longer with team); Kishore Vellody, MD, Medical Director of Down Syndrome Center (Pediatrics)

Did You Know...

- * There are over 4 million people in the world with Down Syndrome
- * The average life expectancy of a person with Down Syndrome in 1990 was 30 years of age. Currently, the average life expectancy is 50 years of age.

Resource: http://downsyndrome.about.com/od/downsyndromebasics/a/DSFacts_ro.htm

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A Note From The Director



Dear Valued Readers,

My brother Nick lives across the state in a group home. He's been living in the same home for ten years. Nick's housemates have changed and staff have too, many times over. What is consistent and unchanging is the gratitude my family and I have for those staff who care. There is a saying we often think of here at the HCQU that goes, "People don't care how much you know until they know how much you care." Nick happens to have some very caring staff in his life. He has absolutely no interest in how much they know. He has every interest in how much they care. His house supervisor has become my personal hero and I have no doubt that he is Nick's hero too, and for good reasons. There are two other staff whom I see on weekends when I'm able to make the trip. One is a woman who is a senior and the other is a very young woman. They keep Nick safe...that shows they care. They work hard...that shows they care. They take time to talk to me about Nick...that shows they care. They talk to Nick...that shows they care. They hem his pants...that shows they care. They cook instead of heating up unhealthy food...that shows they care. They manage to clean up the sticky floors left over from the day before...that shows they care. High staff turnover probably will never change, but if you are a direct care professional who shows you care in the day-to-day faithful delivery of your support, you are special to us and we are convinced that your worth exceeds all other disciplines in the field of ID/DD combined. Thank you for all you do and all the care you show every day.



Nick

Kindest regards,

Mary