



HCQU Staff

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# Healthy Connections

Community Health Connections

## QUESTIONS ABOUT THE ECONOMY, ID/DD SYSTEM, AND GOVERNMENT: A NEW OPPORTUNITY

By Natalie Symons, RN; CSC

Several years ago a friend of mine was working at a very large well known store. A terrible gravity defying balancing act happened in the bathroom. Let's just say that number two was left in the number one sink. Management was notified and they informed the employees that there was "A New Opportunity" in the bathroom. Since then the word "Opportunity" has had a different meaning for me. In the past years, I have had many new opportunities some have been shiny and terrific, others have been like the one in that bathroom. Each has come with an education and the ability to grow in some area of my life. I find that everyday a new opportunity exist for all of us



U.S. Congressman, Jason Altmire (PA-04)

in a faltering economy, recessions, and budget cuts. I thought it would be beneficial for our readership to hear from someone whom they have elected. I asked questions that I thought you would want to know. I didn't get exactly what I expected, but I am grateful for the experience and for the time that Congressman Altmire and his staff took completing their response. Below are the questions that were asked and then Congressman Altmire's response.

1. Have you had the pleasure of a personal or professional relationship with someone who has an intellectual or developmental disability (ID/DD). If so, could you please tell me about it?

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## OUR MOST VALUABLE RESOURCE

By Cheryl Parker, Behavioral Health Consultant

We work in a field which doesn't produce mass quantities of products, there are no conveyor belts, no great financial profits, our "product" is people, our "investment" is in people, and our work is about people. In any human service organization its greatest resource is people. Next to those we serve, the most important people in this field are Direct Support Professionals.

Alarminglly, the Direct Care Workforce Workgroup recently

reported to the Governor that by 2014, the state will need over an additional 24,000 direct care workers (this number includes CNAs and home health aides). In a field so dependent on its direct care workforce we must ask why there is a shortage of direct support professionals, and what can be done to recruit new staff and keep the skilled staff already working in the field. The Direct Care Workforce Workgroup also points to the importance of well trained professionals coining "quality

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## QUESTIONS ABOUT THE ECONOMY, ID/DD SYSTEM, AND GOVERNMENT: A NEW OPPORTUNITY

2. The ID/DD service system relies on government funding. What concerns do you have about the ability for community supports to continue to exist, let alone maintain quality and capacity, in the face of rapidly shrinking availability of dollars?
3. If forced to choose between these two options, which would you protect: failed companies or agencies or stabilizing services to those with ID/DD?
4. What economic strategy would you employ to deal with the serious emergency and critical needs waiting list for ID/DD services while availability of funds seems to be plummeting?
5. Do you support using savings from the closure of one or more state MR institutions to help fund elimination of the community-based services waiting list?
6. The US Supreme Court Atkins decision banned the use of capital punishment on people with mental retardation in 2002, yet it left it to the states how to implement their decision. What do you believe Pennsylvania's stance should be on this?
7. The US Supreme Court ruled in the 1999 Olmstead decision that the unnecessary institutionalization of a person with a disability is unconstitutional. Do you ever think that there is ever a "necessary" institutionalizing of a person with a disability? If so, what might that be?
8. In the face of an uncertain economic environment, what advice or final comments would you like to give to both professionals and families who provide care to individuals with ID/DD?

*"Throughout my life, I have been fortunate to work with and to know Americans with disabilities. Each of these individuals has inspired me with their unique talents and gifts and has contributed a great deal to my life.*

*As a Congressman, I am committed to standing up for the rights of Americans with intellectual and physical disabilities and supporting*

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## OUR MOST VALUABLE RESOURCE



**Lifesteps Butler Staff L to R: Dianna Pinkerton; Lauren D' Angelo; Bogie Goughler (Supervisor); Missy Corej**

care through quality jobs," as a need for statewide policy.

Staff retention is a major focus for many human service agencies. First of all, turnover can be extremely costly, but more importantly the effect of staff turnover

on the people we support can be devastating. As staff leave an agency, that organization loses key skills, experience, knowledge, and the therapeutic relationship forged with the people being supported. The burden of turnover is great to human resource departments, front line managers and peers. It requires time and effort to be spent on hiring and training new staff, while senior staff work long shifts and have to juggle their personal lives with the demands of too few staff to care for the people they support. Historically, workers moved from one agency to another seeking job satisfaction and higher wages, but now are leaving the profession altogether.

The Direct Care Workforce Workgroup and other groups such as the National Alliance for Direct Support Professionals

have identified key areas where providers and the commonwealth may need to direct their attention:

- Access to full time work, affordable health care coverage and increased wages
- Appropriate training possibly to include credentialing
- Access to promotions within the agency and career advancement
- Availability of job counselors and peer mentors to offer support and quality training on the job
- Involvement in the decision making process, being heard and valued
- Well-trained supervisors to offer guidance, support, and encouragement
- Well-trained administrators with a core value of strengthening the therapeutic, respectful relationship between the person being served and his/her direct supporters

As the Commonwealth considers how to address workforce shortages, those of us working within the field can consider now to protect our most valuable resource, **Direct Support Professionals**. Remember, we all want to be seen, heard, and known as full human beings.

## TIPS FOR WORKING WITH DEAF INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

By Pam Maciejewski, Center for Community Resources

When working with Deaf individuals there are variety ways to communicate depending on their intellectual level and their native language. Ask their parents or caregivers what is their normal communication mode. \*Several examples of Deaf communication modes are showing pictures, gestures (pointing things, etc.), basic sign language, American Sign Language (ASL) - use interpreters if you do not know ASL, writing notes back and forth if higher functioning, lip-reading. Remember not all Deaf has English as their primary language.



Pam Maciejewski

General top five tips on how to communicate with a Deaf individual:

1. Relax. Be yourself; do not go overboard when meeting a Deaf individual. Get the Deaf person's attention and make eye contact. To get their attention, tap the person on the shoulder or wave your hand.
2. Speak slowly and normally, but do not exaggerate. Use facial expression and gestures while talking and they should match the words being spoken. Do not move around while talking. Avoid standing in front of lighting and make sure there's enough light so that the individual can see your face clearly. Do not cover your mouth or have objects in your mouth while talking. Talk to the individual

themselves, not who they are with. (interpreters, parents, etc.)

3. If the person does not understand you say the first time, try to rephrase your statements (for example, "What would you like to drink?" could become "Would you like water or pop?") Please stay on the same topic of conversation. If you change topics, notify the Deaf individuals. NEVER pretend you know what they are saying. Ask for clarification or write things down.

4. If the Deaf individual asks for paper and pen, please provide it to them. Keep sentences short and simple. If they ask for other means of communication, try to accommodate them the best you can (computers, cell phones, emails, etc.)

5. Let the Deaf individual know about their environment and surroundings. For example, if someone's at the door or the phone rings, please let them know and excuse yourself. Do not carry on conversation in front of them without including the individual.

If you have any more questions about Deaf, please contact Pam Maciejewski at Center for Community Resources (CCR). You can email at [pmaciejewski@ccrinfo.org](mailto:pmaciejewski@ccrinfo.org) or call 1-866-937-1951.

## SLEEP...WHAT'S THAT?

by Kelly Fisher, RN; Health Services Consultant

Have you ever felt this way? Have you looked at the alarm clock at 1am, 2am, and 3am and thought, "If I can only fall asleep now, I could get...hours of sleep." It happens to all of us. It affects our thoughts, our mood and our physical health. How often do we think of this with the people we support? How would you know if the person you support is having problems with sleep? What factors could come into play that could interfere with discovering sleep difficulties? If a person goes to their bedroom at 9pm and stays there until 6am does that mean they are sleeping the entire time? It may be difficult for some of the people that we support to communicate to us that they are having a hard time sleeping. Is the person's bedroom conducive to sleep? Are there bright lights on? Is the room too hot or



too cold? Does the person have a roommate that is snoring all night? Observation is key! If you or the person you support takes more than thirty minutes to fall asleep, has sleep disturbances, snores or has sensations in the extremities you may want to consider talking to a doctor as this may indicate a sleep disorder. This may also be exhibited in behavioral changes and daytime sleepiness. Lack of sleep may play a role in strokes, asthma, immune system issues, seizures and mental health disorders. Sleep plays a vital role for all of us that is often times overlooked or neglected. May your eyelids be heavy and your sleep be long. But, if this is not the case and you would like to know more about sleep disorders, please feel free to contact the HCQU!

## **ADDITIONAL MONEY FOR SPECIAL NEEDS DENTAL CARE**

**By Carol Oslosky, RN; Health Services Consultant**

On December 3rd, Community Health Connections hosted one of our guest speakers series. Erin Guay from PA Health Law Project spoke on Medical Assistance in Western Pennsylvania. Erin shared much information on accessing physical, behavioral, and dental health services for consumers covered by medical assistance.



**Erin Guay**

Here's some information that may be of interest:

- An additional \$125 can be paid to dentist up to 4 times per year for providing care to those with special needs; i.e., behavioral concerns. Dentists may not be aware of this.
- For those with dual eligibility (having both Medicare and Medicaid) - always show both cards. Being able to report

that this was done when there are billing difficulties or appeals are being reviewed may insure payment that would not otherwise be made.

- There is a Medical Assistance Transportation Program (MATP). This is non-emergency transportation. Consumers must be registered with their county to receive this service. You can check out the DPW website for more information. <http://www.dpw.state.pa.us/partnersproviders/medicalassistance/advocatesstakeholders/matp/default.htm>

If there are concerns about health coverage that are not being addressed through the insurance providers, PA Health Law Project may be able to help. They provide assistance to persons with disabilities, older adults, and those with low income. The helpline number is 1-800-274-3258.

## **MANAGING SEXUAL RISK FOR THOSE WE SUPPORT: A CRITICAL AREA OF NEED**

**By Cheryl Parker, Behavioral Health Consultant**

There are few complexities of behavior that we are unwilling to acknowledge and support within the ID/DD system. Throw any constellation of difficulties our way, and we are ready to consider the needs of the person and we can address them using the positive approaches paradigm. That is until we hear the words "problematic sexual behavior." It is often difficult for many within our field to acknowledge the need to address healthy sexuality, let alone problematic sexual behavior. Yet, many if not most organizations support at least one person with complex needs in this area. There is growing awareness of the need for specialized supports to address sexual risk, but this continues to be a daunting subject for many. The reasons are many, from misunderstanding and myths to fear for community safety and already overextended budgets, pressures which will no doubt continue to mount in these precarious times. Unfortunately, since many agencies already provide supports to people at risk the need to develop those very specific supports cannot go unmet.

To address these specific needs and to better equip our staff with information and supports to share with providers, CHC recently collaborated with Mr. James Haaven, internationally recognized author and consultant who works specifically with organizations to manage sexual risk for people with ID/DD. Mr. Haaven spent a day with our staff and the directors of several agencies, and has since continued to collaborate with CHC on the development of a training to address this critical area of need for education.

Some important points to consider regarding this serious issue are tendencies to over/underestimate risk, attempts to contain as opposed to safely manage risk, and a need to collaborate with outside agencies and systems. One of the most important points on which Mr. Haaven and many experts in this arena will agree, is the need to focus on healthy sexuality first and foremost, not just for those with problematic sexual behavior but all those we provide supports to. Education and the ability to express healthy sexuality are critical factors in abuse prevention and can also be important in relationship to risk management.

We also have to be willing to engage in community partnerships, question our assumptions and stay alert. Best practices in risk management reveal the need for providers to acknowledge that risk is dynamic and can increase or decrease in response to what WE do. Assuming that problematic sexual behavior is simply "counterfeit deviance" and turning the other cheek will often result in increased risk and possibly devastating effects. The other tendency is to assume that risk is always high and attempt to contain and control, which again raises risk and can create dangerous situations.

Supporting a person to manage risk entails a thoughtful approach, a cohesive team and well trained staff. With an effective risk management plan, it can be done well and the person and community can be safe.

## HCQU HAPPENINGS

**Jill Morrow, M.D.**

**Date:** March 20, 2009

**Time** 10am - 12pm

**Location:** The CDC

112Woody Drive  
Butler, PA 16001

**Topic:** What is Happening with the Chromosomes?



**Our Future, Our Lives...Endless Possibilities**

**Date:** May 8, 2009

**Time:** 9am - 3pm

**Location:** Lutherlyn Camp

PO Box 355  
Prospect, PA  
16052



More information to follow at a later date.

### RN Continuing Contact Hours Training Day

**Date:** April 1, 2009

**Time:** 8am - 3pm

**Location:** CHC

120 Hollywood Dr., Suite 201  
Butler, PA 16001

Everyone is invited, however, Registered Nurses who attend trainings on this day will receive 6 hours of continued education hours for attendance. When registering please state that continuing education hours will be needed.



**Dr. Gregory Cherpes**

**Date:** April 16, 2009

**Time** 1pm - 3pm

**Location:** The CDC

112Woody Drive  
Butler, PA 16001

**Topic:** Self-Injurious Behaviors



**David Hingsburger Conference - FREE 2-day conference**

**Date:** June 11 - 12, 2009

**Time:** Day 1 & Day 2: 9am - 3:30pm  
Day 1 Evening: 5pm - 7pm

**Location:** Succop Theatre Butler County  
Community College  
107 College Drive  
Butler, PA 16001

**Day 1:** Communication: Who's Listening

**Day 1 Evening:** Movie Presentation: Ethics of Touch

**Day 2:** If You Do That One More Time: Behavioral Approaches

#### Overnight Accommodations:

Fairfield Inn & Suites Butler

Phone: (724) 283-0009

Online: <http://www.marriott.com/hotels/travel/PITBT?groupCode=DHCDHCA&app=resvlink&fromDate=6/10/09&toDate=6/12/09>

\*When reserving a room, please convey that you are attending the David Hingsburger Conference.

To register for any of the above or Spring 2009 Syllabus classes, please visit our website at [www.hcqu.org](http://www.hcqu.org) or call **(724) 283-0990**.

## QUESTIONS ABOUT THE ECONOMY, ID/DD SYSTEM, AND GOVERNMENT: A NEW OPPORTUNITY

*organizations like Community Health Connections, which play a vital role in helping these individuals reach their full potential and enjoy long, healthy lives.*

*Social service organizations across the country – including many of those that serve Americans with disabilities – are currently facing tight budgets as our nation's economic recession places ever greater demands on our state and federal governments. As our government works to strengthen our economy and help American families through this recession, I believe we must also continue to honor our commitment to provide service organizations with the funding they need to help all Americans, including Americans with disabilities.*

*Congress is currently putting together an American recovery and reinvestment plan that will rebuild our economy, create new jobs, and*

*strengthen support for families who are struggling to make ends meet. This stimulus package is set to provide states with more than \$80 billion in increased funding for Medicaid, which will help to ensure Americans with disabilities continue to receive the funding and support they deserve. Additionally, this package is also set to include \$13 billion in education funding to help states continue to provide children with mental and physical disabilities with the support they need to succeed in school.*

*As we work through this current economic crisis, we must also continue to look for ways to strengthen funding and support for Americans with disabilities in the future. I am hopeful that in upcoming budgets, we will work to provide more funding for organizations which support Americans with disabilities so that everyone will have access to the services they need and deserve.*

## Community Health Connections

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Butler, PA 16001

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### A NOTE FROM THE DIRECTOR

By **Mary A. Nau, Director**

Dear Valued Readers,

There was a news item out of Westmoreland County. But, it happens everywhere. No county is exempt. Below I've summarized an article from the January 7, 2009 Tribune Review:

A bus driver was charged with sexually assaulting six mentally disabled female passengers over a three-year period. The victims ranged in age from 27 to 52 years old. The assaults began in January 2005 and ended in November, when one of the alleged victims complained to authorities about what happened to her aboard the bus. This driver did not have a prior criminal record.

According to police complaints, all six victims were picked up by the bus or van at their residences and were delivered to therapy or training facilities in the morning and then returned home in the afternoon.

"During either the morning trip to the victims' place of therapy or training facility, or the trip home to residences, the bus driver would pull the bus off the road, into a parking area or other area, and sexually molest, fondle and assault one or more of the victims."

It was reported that one witness interviewed said the assaults "have been going on for years."



**Mary Nau**

At Community Health Connections, we wanted to respond in a meaningful way. Inside this issue you will find a brochure we developed specifically in response to this event. As we conducted research to put this brochure together, I was staggered at some of what we learned. What we learned, we are now sharing with you. Please take a look inside. If you would like more of these brochures please call our offices at 724-283-0990. Make your request to any of our staff and we'll be glad to send more copies to you. Those we serve will be glad you did.

Best regards,

Mary A. Nau, Director