

A publication of the National  
Alliance for Direct Support Professionals

# Frontline Initiative

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Healthcare  
Frontline Initiative

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## From hospice to fishing

Families, DSPs, and healthcare providers working together

*Frontline Initiative* interviewed Daniel and Joan Gacki and Kelly Stowell from Lifeworks Services, an organization that serves the community and people with disabilities as they live and work together in Minnesota. In partnership with her son Daniel, Joan shared their arduous journey to achieve health in the midst of a dire prognosis. Kelly provided support to Daniel and his family during this time. Her testimony demonstrates effective advocacy, leadership, and care.

Together, their stories and insights offer valuable lessons to be drawn upon in practice.

### Would you please describe the health crisis you experienced?

**Joan Gacki:** Last summer my son Daniel had pneumonia, and he was hospitalized twice. He seemed to be improving with antibiotics but in September he started going downhill again. We took him to

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Kayla Jetter, Kelly Stowell, Joan Gacki, and Daniel Gacki at Lifeworks.

# Frontline notes

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Welcome to our *Frontline Initiative* on Healthcare. According to the Centers for Disease Control and Prevention, 92.1% of children and 82.2% of adults have had contact with a healthcare professional within the past year. Direct Support Professionals (DSPs) are often the first to know when the person they support isn't feeling well or is in pain, and they often serve as an important liaison between the healthcare provider and the individual served. Because DSPs are responsible for facilitating the health promotion of the individuals they support, they must know how to balance their role in communicating the individual's medical needs to the healthcare provider, and advocating for the person they support to have maximum control over, and to improve, their health.

This issue approaches healthcare from multiple perspectives; it also provides useful information that is needed to support people with disabilities in making good choices related to their health. Joan and Daniel Gacki and DSP Kelly Stowell share their personal testimonies related to effective advocacy, leadership, and support in the midst of a dire prognosis. DSP Amanda Bruneau and Research Assistant Michael Bray describe the various roles of DSPs related to the healthcare of people they support. Self-advocate Zach Holler offers his important perspective

on the role of a DSP in promoting and respecting individuals' independent decisions related to their health. Dr. Seth Keller highlights the critical advocacy role of a DSP in the healthcare setting, and Dr. David Pavasko shares an important story about how having access to and obtaining proper dental care significantly improved one person's quality of life.

Being a DSP requires having awareness and basic understanding of health-related issues; in an overview of health considerations throughout the life course, Nancy McCulloh provides useful information that DSPs can use as a quick reference, and that supervisors can use to facilitate discussion at a staff meeting or training. Beth Marks, RN, PhD and Jasmina Sisirak, MPH, PhD describe a DSP's key role in observing and reporting early signs and symptoms of emerging health conditions. Megan Graf from Project HEALTH in Tennessee and Toni O'Brien from Dakota Communities in Minnesota describe two important organizational wellness initiatives for individuals with disabilities and their DSPs.

We hope you will enjoy this issue as you learn more about supporting individuals to live healthy lives.

~ The editors

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*Frontline Initiative* is available in alternate formats upon request.

# NADSP update

## The difference between helping someone have a good day or a great life

By Joseph Macbeth

So much has been happening with the NADSP over the past three months, it's hard to find a place to begin this article. It seems that when you're busy, things that you worked on just last week seem to fade away as you move on to your next project. So it's good to pause and reflect on our accomplishments, challenges and new directions for the coming year.

By now, most of you know that September includes "Direct Support Professional Recognition Week". As in previous years, we thank our members and partners who worked closely with state governors and legislators to introduce and pass a proclamation that makes it official in your state. September also marks the beginning of our new membership year. This means that throughout the summer, and ending in September, we've been trying to meet our ambitious membership goal of 2,500 individual and 150 organization memberships. I hope that we can count on you to spread this important message because our membership is what keeps us moving forward. You are why the NADSP exists.

In early June, our board of directors met for a day of strategic discussion and planning in Washington, DC with Max Chmura, President of S2S Enterprises. With Max's help, we confirmed a previous conclusion that the ultimate goal of NADSP is to improve the quality of life for people who have

intellectual and developmental disabilities (I/DD) by creating the most qualified and caring workforce possible. The board also concluded that quality in human service settings was defined, in many ways, at the moment of interaction between the person with disabilities and his or her DSP. This simple point will now become part of our everyday conversations — its simplicity speaks volumes.

Subsequent to our meeting in the nation's capitol, a few of us met in New York to create a framework for technical assistance seminars that will assist organizations in creating a culture of competence for their direct support workforce that focuses on building quality at that point of interaction. Along with this new NADSP technical assistance service, I am very happy to announce that our national certification in direct support practice will be streamlined and made much more accessible for busy DSPs. Currently, the second level of our competency-based certification will take someone 18-24 months to achieve the full DSP-C credential. Our new process will create an initial certification (DSP-C: Level -I) that can be achieved in only six months, by removing the requirement from eight work samples in a portfolio to four work samples. For those dedicated in making direct support as a long-term career, our new advanced certification (DSP-C: Level -II) will include the next four samples. We believe that having easy access



to a national credential that uses nationally-validated skill standards is one of the first steps in defining us as a true profession.

In the coming weeks and months, we'll be sharing more information about our technical assistance activities, changes in our direct support certification processes and other strategic initiatives. In the meantime, remember, quality is being measured every time that you report to work and begin to interact with the people who you support. I like to describe it this way; the difference between helping someone have a good day, and helping someone have a great life is in your hands. It's that simple. It's that important.

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*Joseph Macbeth is the Executive Director of NADSP. He can be reached at [jmacbeth@nadsp.org](mailto:jmacbeth@nadsp.org) or 518-449-7551.*

# The many roles of DSPs in the healthcare of people they support

By Amanda Bruneau and Michael Bray

Many DSPs help the individuals they support access important healthcare services. Their role is critical in connecting the people they support with healthcare professionals. DSPs are with the people they support daily. DSPs likely understand individuals' health histories, behavioral cues, and medication use. They can also model treating people with disabilities with dignity and respect in a healthcare setting.

Amanda Bruneau is a DSP working at Renaissance Community Homes for adults with developmental disabilities in Lenawee County, Michigan. Amanda has been a DSP since 2001 and has also held manager and program manager positions. She is currently working toward her RN degree and also works for a local nursing home.

Amanda has accompanied many of the people she's supported over the years to doctors visits. She says that her primary role in these visits has been that of an advocate. She describes, "Many people I support may know when they aren't feeling well. But they have difficulty clearly communicating this to the healthcare providers. That's when I can step in. I can provide observations from the home staff such as frequency of coughing or apparent energy levels." Amanda also helps the people she supports by providing healthcare providers with records of medications and previous vital signs.

Amanda believes that, "During a healthcare appointment, DSPs should make sure that the individuals they support are being heard. It is also important that the healthcare professional has enough information to make good decisions regarding care." By promoting self-advocacy and providing relevant healthcare information, DSPs can ensure that the individuals they support receive the proper healthcare they need.

Amanda has faced several challenges while supporting individuals in a healthcare context. Some of the challenges include completing paperwork and making sure that prescriptions are correctly filled. Amanda has also experienced being ignored or overly focused on by healthcare providers. Amanda uses different strategies to de-escalate situations when the people she supports are waiting to be seen. She shares, "Some people have a hard time sitting for thirty minutes to an hour in a crowded waiting room. I've supported many individuals who will pace the room or switch seats often. This always draws attention from the other patients in the waiting room. I try to redirect the individual or let the receptionist know we are stepping out for a few minutes to get some fresh air."

Some important lessons that Amanda has learned include —

- Try to schedule appointment times that work best for the person being supported. Ask the individual when he or she would like to set up the appointment and be respectful of his or her preferred daily routines and schedules.
- Be prepared for the appointment. Bring a folder with necessary medical history information and documentation. This could include a list of current medications or sleep patterns.
- Prepare the individual ahead of time for the appointment. Explain what will happen, who the doctor/healthcare provider is, and how long the visit might take.
- Have a plan. If the person you are supporting is experiencing difficulties with waiting, have things with you that you know they enjoy doing. It might also be helpful to identify the nearest exit where you can both go for a quick break.
- Remain calm! This is the number one rule for any DSP. The person you support and the healthcare providers will read your cues and body language. Try to stay composed and relaxed.

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*Amanda Bruneau is a DSP in Adrian, Michigan and currently a full time RN student. She is also the mother of a 12-year-old daughter.*

*Michael Bray, MA, is a Research Assistant at the Developmental Disabilities Institute (DDI) at Wayne State University in Detroit, Michigan. Michael can be reached at [mikebray@wayne.edu](mailto:mikebray@wayne.edu) or (313) 577-6684.*

# Be Connected. Be Well.

## Dakota Communities Culture of Wellness Initiative

By Antonia (Toni) O'Brien

Dakota Communities provides services to people with disabilities in Minnesota. Dakota Communities emphasizes the importance of recreation and inclusion in people's lives. We believe that people with disabilities should live and play alongside their families and neighbors.

At Dakota Communities we are creating a "culture of wellness" for the people we support and employees. One of our initiatives is the *Be Connected. Be Well.* program. *Be Connected. Be Well.* addresses seven essential dimensions of health and wellness —

1. Mental wellbeing
2. Physical wellbeing
3. Relationship wellbeing
4. Work/volunteer wellbeing
5. Play wellbeing
6. Spiritual wellbeing
7. Wellbeing of our world

Our program continuously improves supports within these seven inter-connected dimensions. Both people with Intellectual and Developmental Disabilities (IDD) and Direct Support Professionals (DSPs) receive supports and benefits. DSPs and the individuals we support are given access to health and wellness-related information. They receive resources on best practices to lead a healthier life. They also receive individual information that allows people to "know their numbers."

Participants learn about their current health and wellness through individual diagnostic testing and evaluation. They receive

information on their Body Mass Index (BMI) and metabolic rate. They also assess strength, flexibility, and lifestyle habits. They are able to benchmark their current emotional and psychological wellness. Participants are then given access to health coaches and volunteers. They can also access training. These are resources that assist with program implementation. Participants are provided with a new menu system. They have opportunities to play the Wii or work out at a local health club. There are even opportunities to engage in pet therapy and horticulture therapy.

Each person who receives our services has participated in one of more aspects of our wellness initiative. Initial results demonstrate success! Participants lost an average of 13.6 pounds during the twelve twelve-week evaluation period. They dropped their BMI an average of 5.4 points. Average waist circumference decreased by 1.7 inches. Over half of the participants who completed the twelve-week program met their goals. Their goals are focused on fitness, body composition, and lifestyle. Many participants have also noted growth in self-confidence and self-esteem. Overall, participants report higher energy levels. They express a sense of pride in attaining goals and making healthy choices. A quote from Patsy gives

us great insight into the popularity and value of the program. She said, "This can't be exercise because it is too much fun!"

One unexpected feature of the wellness program is its growing popularity. As people get involved, their friends and housemates are motivated to get involved. This brings new meaning to our understanding of 'contagious' wellness. Mike and Tom are a good example of this. Mike cooks from the new menu system and lost almost 60 pounds. Mike's housemate, Tom, saw Mike's successes. Now Tom is involved in his own cooking. Wellness at Dakota Communities is becoming viral!

We believe partnering DSPs with the people we support results in "well people = well employees". We are proud to have created a program that becomes the shared culture at Dakota Communities. Healthy living is not a one-time event. Wellness is infused in every aspect of the services we provide. The concept of wellness has reached far beyond our initial ideas. Wellness is integrated into the lives of everyone associated with the organization.

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*Antonia (Toni) O'Brien is a Certified Therapeutic Recreation Specialist Service Coordinator and Director of Community Life for Dakota Communities in Minnesota. Contact Toni at [tonio@dakcom.org](mailto:tonio@dakcom.org).*



**Dakota Communities**  
*people with disabilities realizing potential*

# Project HEALTH

## Helping every ability learn to be healthy

By Megan Graf

Mark Buckner is a 47 year old that enjoys hip-hop music, watching the news, and hanging out with his friends. Mark happens to have Down Syndrome. Mark lives at home with his mother and attends a state-funded day program during the week. Mark has lost 22 pounds in less than two years. Mark has been sharing his story of improved health and is an inspiration to many. *Sports 4 All Foundation* recently named Mark the 2012 Spokesman of the Year.

*Sports 4 All Foundation* is a nonprofit based in Nashville, Tennessee and serves individuals with disabilities. Kris Salisbury is a devoted mother of a daughter with a developmental disability. Kris was appalled when she noticed that her daughter's friends did not have the right equipment for competing in athletic events. They tried to compete in jeans and frequently did not have athletic shoes. They were often without the sport-specific equipment they needed. Kris noticed the same issue on several occasions and decided to take action. Kris formed *Sports 4 All Foundation* in 2005. *Sports 4 All* has dedicated its efforts to provide sporting equipment to agencies supporting people with disabilities.

*Sports 4 All* has worked hard to equip athletes of varying ability levels. But a more significant problem exists. People with disabilities generally have limited opportunities to participate in health-enhancing activities. *Sports 4 All* took action against this injus-



Pam Brooks, center (in chair), takes time to smile with her friends at a Project HEALTH community class

tice and created *Project HEALTH* (Helping Every Ability Learn To be Healthy) in 2008. The goal of *Project HEALTH* is to provide adaptive fitness and nutrition classes for people with disabilities.

*Project HEALTH* works to break down barriers to fitness and health often faced by people with disabilities. Some of these barriers include transportation, limited finances, and existing health condi-

tions. Through community classes offered in a variety of neighborhoods, *Project HEALTH* has been able to provide free adaptive fitness classes to over 800 Middle Tennesseans like Mark, the Spokesman of the Year.

*Project HEALTH* classes incorporate fitness, nutrition, fun, and friendship into an inclusive hour of health-improving activities. A key component in the success of the

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Mark Buckner, right, accepting the *Sports 4 All Foundation* Spokesman of the Year Award

# Advocating in a healthcare setting

## The critical role of DSPs

By Seth Keller, MD

Being healthy affects a person's quality of life. A person with a disability may experience additional health issues that are inherent to his or her disability. Some of these common health issues include seizures, low muscle tone, and swallowing difficulties. Each of these medical problems can cause daily challenges, which may make a person feel sick and not able to be happy and enjoy life.

The person receiving support may not be able to explain or describe how he or she feels. The person being supported may act differently and sometimes his or her behavior may change for the worse. This may be because he or she is experiencing pain or confusion due to sickness or discomfort.

**DSPs can be a major help to the people they support, especially when it comes to health.**

The medications that are given by the healthcare provider are used to help heal an illness. But sometimes the treatments prescribed can cause side effects.

How would a person who has difficulty communicating tell you that his or her stomach hurts? How would he or she tell you that about feeling dizzy or nauseous? The person may not be able to.

But, the Direct Support Professional (DSP) and family member will know something is wrong.

DSPs can be a major help to the people they support, especially when it comes to health. DSPs will know if the person is not feeling well. They will know if the person is taking prescribed medication, brushing his or her teeth, eating the right food, exercising, and going to doctors' appointments. They will also know where to get the individual's important health information.

The healthcare provider may not really know how to speak to the person receiving support. The office staff may not appreciate that sitting a long time in the waiting room may be difficult or scary for a person receiving support. The doctor or nurse may not understand that people with disabilities have real feelings and purpose. Healthcare providers may even direct all of their conversation towards the DSP and not talk to the person directly. The DSP must be the one to explain the correct ways to speak to a person with disabilities. It may be surprising to you, but doctors and nurses do not get special training on how to speak or care for someone with a disability. They may be ignorant, but ignorance doesn't mean they don't care or aren't nice.

Finally, the healthcare provider may not have a lot of time for an office visit. Therefore, it is very important that the DSP come prepared for each visit. The DSP must know what health issue is the most important to talk about during the visit. The DSP must know



how the person he or she supports is feeling and if the health condition is better, worse, or the same. How is the medication working? Is the person experiencing possible side effects?

Keeping healthy is a team effort. The DSP is often key. The person with the disability is the most important member of the team. Everyone else, including the family, doctor, nurse, friends, and DSP, must work together to support the individual in being healthy and having an enhanced quality of life.

*Seth Keller, MD, is President of the American Academy of Developmental Medicine and Dentistry and serves as a consulting Neurologist to New Jersey State Developmental Disability Centers as well as a member on The Arc of New Jersey, Mainstreaming Medical Care Board. Dr. Keller lives in New Jersey and can be reached at 609-261-7600 or [sethkeller@aol.com](mailto:sethkeller@aol.com).*

# Home healthcare support

## Insights from a self-advocate

By Zach Holler

I require a tracheostomy tube, or a trach. A trach is a surgically made hole that goes through the front of my neck and into my trachea (windpipe) to help me breathe. I use homecare nurses to help me clean and care for the trach. I am a client of homecare services and an employee in an Independent Living Center. I'm going to share a person-first perspective of what it is like to receive healthcare support in my home.

I do not consider the Direct Support Professional (DSP) as a healthcare liaison. I consider DSPs to be providers of direct support. As someone living independently, I believe the person receiving support is the expert of his or her own medical needs. Therefore, the person receiving support is the liaison that coordinates services and manages DSPs. Communication between the DSP and healthcare providers is important because it keeps all team players on the same page. However, it is critical that the person receiving support be aware of and involved with the communication.

It is important for DSPs to be aware of their boundaries when supporting someone during a healthcare visit. The person receiving support is, and should be, the primary communicator. The DSP is there to provide information as needed to help the person communicate effectively. For example, I am unable to gather visual details such as color and texture of respiratory secretions. This is important information to a pulmonologist. A

care provider helps me to get this information so that I may share it with my doctor.

DSPs may support people who have challenges with communicating their needs and desires or have difficulties with speech. It is important to take time to become familiar with a person's speech patterns and nonverbal communication such as facial expressions and body language. Some people may also use alternative communication devices like a speech-generating device or a communication board. It is important to care for this equipment and respect the person's need to use the equipment because it helps him or her perform basic functions. When supporting a person who has significant challenges with communication, it is extremely important for a DSP to consult with the person's legal guardian or representative before making any healthcare decisions.

So what should a DSP do if the person they are supporting is making a seemingly unhealthy choice? It is important for DSPs to be able and willing to go with the flow. A person receiving support may have the day planned before the DSP arrives. It is not uncommon for a person receiving support to make a choice contrary to the opinion of the DSP, such as having a soda rather than a glass of water. DSPs can give information and advice as they feel is needed to assist in decision-making. That's about as far as it goes. I encourage DSPs to not take it personally if the person being supported chooses to ignore advice. We heard it and we made

our own decision based on our plan for the day. It is ok if we make a choice that a DSP considers bad. We bear the consequences of our own decisions.

People receiving supports have a right to express their desires and make their own decisions just like anyone else. However, DSPs have their rights to comfort also. If you are uncomfortable performing a specific task requested by the person you are supporting, it is ok to say so. Sometimes the difference can be resolved by compromising. If not, the person being supported has the right to make adjustments as to who provides services to him or her.

In your work as a DSP, I encourage you to recognize that the people you support are the experts of their own lives. We are people just like you and want to control our own lives. If you go with the flow and provide information and support when needed, you have done your job well.

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*Zach Holler is a recent graduate of Wright State University, with a B.S. in Rehabilitation Services. He currently lives with his parents and younger sister in Clayton, Ohio, while working part-time for the Access Center for Independent Living, a local non-profit, independent living center. Zach is quadriplegic and partially Deaf-Blind. In his free time, Zach enjoys church and hopes to establish a new integrated Disability Ministry, one of these days. He also enjoys traveling, target shooting, horseback riding, swimming, and any other outdoor activities with his friends and family. Zach can be reached at zacharyholler88@gmail.com.*

# Signs and Symptoms Checklist

This form is for staff and health care provider (HCP) to communicate emerging signs and symptoms of health changes in clients and action plans.

CLIENT'S NAME: \_\_\_\_\_

DATE: \_\_\_\_\_

REPORTED BY: \_\_\_\_\_

REPORTED TO: \_\_\_\_\_

<b>ILLNESS</b>
Unable to perform normal daily activities
<b>BEHAVIORS</b>
Acting as if hearing or seeing things not there
Aggressive to self or others
Alcohol use increased
Attempting to escape home or program
Behaving differently
Destroying property
Doesn't know what day it is
Doesn't know where they are
Eating non-food items
Energy level increased or decreased
Inappropriate sexual activity
Increased interest in sexual activity
Increased number or different type of seizure
Less/no interest in activities
Looks weak, unsteady, dizzy or having trouble with balance
Losing skills like feeding and toileting
Mood changes
Not responding to name
Recent loss or stress
Repeating themselves over and over
Restless and unable to sit still
Rocking back and forth a lot
Seems confused or lost
Speech garbled or unclear
Tobacco use increased
Unusual movements
Wanting to be alone most of the time
<b>EATING/WEIGHT</b>
Burps a lot
Coughing or appearing to choke while eating
Difficulty swallowing or grimacing when swallowing
Holding food in mouth
Refusing to eat favorite foods
Texture of food they are eating is different
Trouble chewing
Wants to drink liquids all the time
Weight loss or gain
<b>PAIN</b>
Breathing fast or heavily

Complaining of chest, jaw, or left arm pain
Complaining of muscle or joint stiffness
Complaining of pain
Crying, holding or rocking any part of his/her body, head banging or jumping up and down
Difficulty standing, sitting or bending over
Facial expression is different
Facial expressions of pain or is holding a body part immobile
Joints are swollen or warm to touch
<b>SLEEP</b>
Difficulty falling asleep
Falling asleep during daytime activities
Sleep more disrupted than usual
Waking during the night
Waking earlier in the morning
<b>SKIN AND NAILS</b>
Fingernails or toenails look blue
Lice or bugs on skin
Lips look blue
Rashes, redness or open sores on skin
Scratching or complaining of itching
Seem to be too warm: sweating a lot, and warm to touch
Seems to be too cold: shivering, wearing many layers of clothing
Skin is dry
Unusual lumps or bumps on or under skin
Unusual moles or marks on skin
<b>EARS/EYES/NOSE</b>
Liquid draining from ear
Not wearing glasses
Not wearing hearing aide
Pulling at ear
Redness around ear(s)
Responding to sound differently
Rubbing eyes
Squinting
Swollen or bruised eyelids
Tears or pus-like material coming from eyes
Watery or bloody liquids draining from ear
Whites of eyes are red or yellow
Yellow or green mucous from nose

# Signs and Symptoms Checklist

<b>MOUTH</b>
Bad breath, not just morning breath
Bleeding or swollen gums
Drooling more
Dry cracked lips
Grinding teeth
Not wearing dentures
Sores on lips
White patches on tongue
<b>BREATHING</b>
Coughing or vomiting blood
Coughing or wheezing
Green or blood streaked sputum
Hoarse or no voice sounds
Holding chest
Short of breath
Whistling or gurgling watery sounds with breathing
<b>STOMACH AND BOWELS</b>
Black, sticky stools
Bright red blood in stools
Complains of heartburn
Diarrhea
Hard or dry stools that are difficult to pass
Large or watery stools
Light beige-colored stools
Nausea
No bowel movement for three days
Stools are pencil-thin
Very large stools
Vomiting

<b>LEGS/FEET/TOES/WALKING</b>
Blisters or calluses
Feet cold to touch
Fell
Redness or broken, dry, cracked or peeling skin in between toes or on bottom of feet
Redness or swelling around the toenails
Swollen ankles or legs
Thick, crumbly, uneven, discolored toenails
Trouble walking around house
Trouble walking on stairs
Walking differently
<b>GENITOURINARY</b>
Blood in urine
Blood or foul-smelling discharge in genital area or underwear
Bulges, lumps or swelling groin area
Burning, itching or pain with urination
Dark yellow or brown urine
Redness or sores in perineal area between legs
Trouble starting to urinate
Urine has foul odor
<b>MEN</b>
Blood or pus coming from penis
Redness or sores on scrotum (balls)
Trouble moving foreskin back if uncircumcised
<b>WOMEN</b>
Heavier or lighter menstrual flow
Large clots in menstrual flow
Menstrual period stopped
Menstrual periods are infrequent
Menstrual periods more than every four weeks
Periods lasting more than 7 days
Redness, white discharge, sores, or swelling at the opening of vagina
Spotting of blood between periods

	<b>Other</b> (please specify):
--	--------------------------------

**REPORTING HCP:** \_\_\_\_\_

**HCP RESPONSE** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

# Nine Components for Healthy Lives

Everyone is different. We all lead different lives. We make different choices about taking care of our health. Staying healthy throughout our lives is important! As we age, we change physically and our healthcare needs change too. In order to maintain good health, it is important to understand each of these nine components for healthy lives.

## 1. General Health Care Visits

General health visits are regularly scheduled appointments with a healthcare professional for basic preventative and routine health care. The healthcare professional conducts a physical to monitor a person's health.

*Common things that occur during a healthcare visit:*

- Review a patient's current health status and medications.
- Conduct routine health screenings or immunizations.
- Conduct an assessment of patient health and make suggestions as needed to maintain health.
- Identify potential problems and refer the person to a specialist if necessary.

## 2. Health Screenings

Health screenings are exams or tests used to assess your health and identify conditions or diseases before they become serious. This usually occurs during healthcare visits.

*Common health screenings include:*

- Auditory tests screen for problems in the ears such as hearing loss.
- Oral screenings check for disease such as oral cancer and gingivitis.
- Vision screenings test for conditions associated with sight, such as glaucoma.
- Cholesterol tests screen for high cholesterol levels which lead to hardening of the arteries and heart disease.

## 3. Immunizations

Immunizations are special vaccines designed to prevent diseases, illnesses, and viruses. Most immunizations are a good idea but sometimes not.

*Some reasons for getting immunizations:*

- To protect from getting diseases, viruses, and illness.
- To protect people around you who cannot get immunizations.
- Because the risks are low and side effects or reactions don't last for a long period of time.

*Some reasons against getting immunizations:*

- Some people have allergic reactions to certain components in a vaccine.
- Some religious beliefs disallow immunizations.
- Some immunizations cannot be given during pregnancy.

## 4. Vision Care

Most people think of eyeglasses when they think of vision care. Correcting vision so that a person can see better is one form of vision care; however, there are a lot of other things to be aware of.

*Common ways to take care of your eyes:*

- Make regular visits to the eye doctor to check for changes in vision and for abnormalities or diseases of the eye.
- Do not rub your eyes when you feel there is something in your eye. If there is a particle of dust, or fiber you could scratch the surface of the eye.
- Wear sunglasses with ultraviolet protection when outdoors so that the harmful sunrays do not damage your eyes.
- Make sure you have proper lighting when reading books or magazines.

## 5. Auditory Care

Hearing loss is one of the most commonly ignored health problems. If you can answer yes to one or more of the following questions, you may have hearing loss and should consult a healthcare professional or hearing specialist.

*Some important questions about your hearing:*

- Do you need to strain to hear people or sounds?
- Do the people around you seem to mumble or talk in a muffled manner?
- Do you regularly ask people to repeat themselves?
- Do you turn up the television or radio so loud that it bothers other people?
- Reduce fat in your diet.

*Continued on back*

## 6. Oral Health Care

Routine visits to the dentist twice a year are important to your oral healthcare. Here are some things to keep in mind when taking care of your oral health.

*Preventative oral care includes:*

- Brush and floss your teeth daily.
- Visit a dentist at least twice per year.
- Maintain regular fluoride levels in water and toothpaste.
- Maintain proper oral nutrition to build strong and healthy teeth and gums.

*Threats to your oral health include:*

- Poor dental hygiene
- Poor nutrition
- Smoking (e.g., cigarettes/cigars, "smokeless" or chewing tobacco)
- Obesity
- Oral Piercing

*Some oral related health problems include:*

- Oral cancer or lip cancer
- Bad breath
- Diabetes
- Drooling

## 7. Mental Health

Mental health is an important aspect of living a balanced and healthy life. People who enjoy good mental health generally have positive feelings about themselves and others.

*Common ways to maintain good mental health include:*

- Think before you act or speak on your thoughts or emotions.
- Learn to express your emotions and feelings in appropriate ways.
- Work to achieve balance in your life.
- Learn to deal with stress.

## 8. Nutrition

Good food, proper nutrition, and hydration are needed in order to maintain good health. Because food is the way that the body gets energy, it is important to select the right foods in the right amount for your age and level of activity.

*Some basic information about eating healthy includes:*

- Make sure you have a great variety of foods in your diet.
  - » Eat fruits and vegetables.
  - » Eat whole grain cereals and breads.
- Reduce fat in your diet.
  - » Eat lean meats like poultry and fish.
  - » Eat low fat or no-fat dairy products.
  - » Include beans and lentils in your diet for protein.
- Make sure you drink enough water to keep hydrated.
- Reduce salts and sugars in your diet.
- Moderate how much alcohol you drink.

## 9. Exercise

Exercise allows you to keep your body healthy through activity.

*Some common household activities that exercise your body:*

- Putting away laundry
- Yard work
- Light house cleaning
- Walking to the mail box
- Gardening
- Grocery shopping
- Vacuuming
- Using objects in the house (e.g., telephone book, plastic grocery bag with cans, etc.) to strengthen your muscles.



**DirectCourse**  
ONLINE CURRICULA FOR LIFE IN COMMUNITY

# College of Direct Support

## Reference

*Supporting Healthy Lives from the College of Direct Support*

Course Authors:

Nancy McCulloh, Institute on Community Integration, University of Minnesota, Minneapolis, Minnesota

Traci Laliberte, Institute on Community Integration, University of Minnesota, Minneapolis, Minnesota

## Dental care

# A necessary part of a healthy life

By David H. J. Pavasko, DMD

“My son wears that helmet because in the past several months he has begun banging his head on walls,” a mother explained. She must have seen my startled look as they entered the office. This was my first appointment with this young man. From his intake form, I knew he had developmental disabilities and was non-verbal, but there was no mention of a helmet. In the few seconds it took to form that first impression, several possible reasons for the helmet had crossed my mind, but the identified behavior was not one of them. The mother continued, “His doctors have not been able to identify a cause for this change in behavior, but wearing the helmet will at least provide some protection for him.” We continued with the examination, and found lots of work to do. He had not been seen by a dentist for a very long time, and treatment would require several visits. At the last appointment, all was finally looking good. We scheduled his next visit for a check-up and cleaning.

Thinking I wouldn’t hear from the family again until I saw them at the next appointment, I was surprised when, after a week or so, my receptionist asked me to take a call. It was the mother. She had some exciting news to share about her son. “A few days after his last appointment with you my son stopped banging his head! Dr. Pavasko, do you think that the dental problems you fixed for him could have had anything to do with his behavior?” I replied that while I couldn’t say for certain,

there was a good chance that his dental condition would have caused intermittent, if not constant pain. Banging his head could have been his only way of communicating the seriousness of his condition.

The mother was so thankful that so much had changed for the better for her son. Every time I see these folks at an appointment, I can’t help but recall our first meeting. I will remember it forever.

**Studies have shown a direct link between a person’s dental health and their overall physical condition.**

Studies have shown a direct link between a person’s dental health and their overall physical condition. We now know that chronic dental problems, left untreated, can lead to serious physical complications. Just like the mom who had a loving and close relationship with her son, Direct Support Professionals (DSPs) have that same close relationship with the individuals they support. That relationship allows them to identify even



the most subtle changes in an individual’s condition and behavior. DSPs bring great value to the healthcare community through observation of, and interaction with, the individuals entrusted to their care. That’s great news because, just like the young man I was able to help because his mom identified the dental problems and brought him to me for treatment, DSPs have the same opportunity to make a difference in the lives they touch every day.

*David H. J. Pavasko, DMD, was the recipient of the 2011 AAIDD Service Award for his commitment to providing specialized quality dental care for individuals with disabilities. Dr. Pavasko is a dentist in private practice in Murrysville, Pennsylvania since 1980. He is the Dental Director for Accessible Dental Services, Inc., a unique, non-profit organization in the Pittsburgh, Pennsylvania area that provides specialized, quality dental care to individuals with disabilities. The alleviation of pain, improved dental care, and comfort that he has brought to individuals living with developmental disabilities is both noteworthy and remarkable.*

### From hospice to fishing: Families, DSPs, and healthcare providers working together

continued from page 1

many different specialists, some not familiar with people with intellectual and developmental disabilities (I/DD). We saw a pulmonologist at our local hospital, and his team was convinced that it was not pneumonia again. Daniel's chest x-rays were very hard to read and his labs were inconclusive.

Daniel's health kept deteriorating to the point where we took him to Gillette Specialty Healthcare, a hospital that has expertise serving people with I/DD. His neurologist and neurosurgeon said that Daniel's brain stem was aging rapidly and it was "just his time." Daniel was then referred to the palliative care team and put on hospice care at home. We started a Caring Bridge webpage to keep family and friends informed of any updates. But something kept bothering me and my husband. Why did this come on so suddenly?

After a very difficult week Daniel was given his last rites. He was sleeping 20 hours a day. Because of his erratic breathing, there were two or three times we thought that this would be the last night we would have him with us. Then after a couple weeks of this I thought, "I am not buying this," because he would wake up and be perky and happy for a while and then he would drift off again into a deep sleep. It didn't make sense. So we brought him back to specialty healthcare to see a doctor in pulmonology. After examining Daniel and learning what had been going on, he said, "I'm not buying this either! We're not doing any more tests. We are going

to treat him as if he had pneumonia. We have nothing to lose."

He put Daniel on two different nebulizer treatments three times a day, antibiotics and continuous oxygen. Almost immediately after the first nebulizing treatment, Daniel started to improve. I remember during that time I went out for a short time and called my husband to check on Daniel. I asked, "What is that noise in the background?" Unbelievably, Daniel was laughing! This was the end of November and he slowly started to improve. So he obviously did have pneumonia, even though his tests were negative. We needed that person who was going to say, "Ok, let's just try something. If it doesn't work, it doesn't work. But you just have to keep trying."

On February 6th, Daniel was able to leave hospice care. His hospice team didn't even know which papers to fill out! That was a wonderful day. He turned 31-years-old the next day and we had a big celebration! Daniel then started gradually returning to Lifeworks.

### What kinds of support did you receive during this time?

**Joan:** We had a lot of support from friends and family. Lifeworks was unbelievable. Kelly and Kayla, Support Specialists, were wonderful. They were calling and coming over all the time. They were at the house the night we thought Daniel was dying and they have been involved ever since. It was so reassuring that so many people cared about Daniel. We set up Skype video calls so Daniel could hear his friends. It was nice to know that so many people cared about him outside of our family.

**Kelly Stowell:** I was so used to seeing Daniel every day. His friends were always asking about him while he was out. I just did whatever I could to keep communication between his home and our program. There wasn't a whole lot we could do, but we wanted to let the family know that we were thinking about them. We visited when we could. We made sure to keep it so we weren't intruding on the family. But we cared so much about Daniel and his family. We wanted to make sure they knew that we were still here for them, and that all his friends still cared about him. There was one day we Skyped...

**Joan (laughing):** ...Kelly was including people from all over the program and the office on that Skype call, including the bus driver. There were friends I didn't even know about who were talking to him.

### What was it like to receive this support?

**Joan:** We never felt isolated because I knew the Lifeworks staff were always there for us. The support that came from Lifeworks was overwhelming and it just felt so reassuring. Kelly and Kayla kept coming over. To keep that connection alive is incredible because five months is a long time to be out of a program. I kept asking the program staff, "Are you sure that he won't lose his space?" They said, "We will always have a place for Daniel." It was the same with transportation. They told us that they would always have a place for him on the bus. They took us beyond the moment. It helped us look into the future and say, "Daniel, they're waiting for you! Get well so you can go back!" I

# Lifeworks

A nonprofit serving  
people with disabilities

## From hospice to fishing: Families, DSPs, and healthcare providers working together

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never thought we'd be here today having this conversation. Having Daniel here is just amazing to me.

**Kelly:** He is amazing. Since he's been back, he's been out fishing and even caught the biggest fish of the day. It is so nice to see him back enjoying activities and his friends. He will always show us that he is happy and give us a big smile.

### What advice would you give DSPs about promoting individuals' health and wellbeing?

**Kelly:** Communication is so important. Sometimes there are no words that can describe how you feel. But checking in, offering support, and just being there to hold a person's hand are all helpful. I would call Joan and ask, "How can we help?" I would visit and make sure Daniel was comfortable. I would check updates on his health status through the Caring Bridge webpage. I suggested we use Skype, which worked great.

Communication with healthcare practitioners is key. It's about getting someone to listen to you. You may have to emphasize when something is still wrong and not being treated effectively. You may have to send a message that "I'm not going away!" Or if the person is not getting better, you can work to find another practitioner.

I also think it's important to respect boundaries and privacy. It is hard to know where the boundaries are, so I took direction from the family. I would call and say, "Are you still up for a visitor?" I would call right before I would head over because his condition could change. Sometimes he needed rest and didn't need to be interrupted by people moving through his house. I let the family set the pace.

### How important is having an advocate during these times?

**Joan:** I cannot emphasize enough that when a person with a disability cannot communicate effectively, the person needs an advocate for health issues and healthcare. When I was working in a nursing home, I always had this dream that this whole new profession of healthcare advocacy would start up for people unable to help themselves—a personal advocate who can step in and make sure that medical needs are being met. People would tell me how they were miserable because their dentures didn't fit, or their hearing aid didn't work, or they needed new glasses. The same kinds of things happen to people with I/DD.

### Would you share some insights about effective healthcare for people with I/DD?

**Joan:** I think the most important thing is to find medical practitioners who are familiar with people with disabilities. And even if they are not, you need to find someone who will listen to you and who will think outside the box, because every single patient is different.

What's typical for one patient is atypical for another. For example, at one clinic, I heard, "Well, we did some tests, and everything looks fine. There's nothing more we can do." It wasn't cruel, but they were relying only on one set of lab results. Really I think it takes a great practitioner to be able to say, "I am going to send you to someone else who is more familiar with the unique needs of Daniel." It was really nice to know that I/DD specialty healthcare services are out there... especially a team that has caring and involved staff.

### What have you learned from this experience?

**Kelly:** I am in awe of the strength and courage of the family. (To Joan) With your spirit you kept pushing forward. You knew not to just accept the first diagnosis. You had that instinct that it just didn't seem right. There were weeks and weeks where you were going from specialist to specialist. I'm sure it was just exhausting. Some days you had four to five appointments. You kept going and going. This was amazing, and I learned how amazing this family is.

---

*Joan and Daniel Gacki live in Saint Paul, Minnesota and can be reached at joanmg27@gmail.com.*

*Kelly Stowell is a Service Facilitator at Lifeworks Services. She thanks Kayla Jetter and her colleagues for their support and contributions to this story.*

# Preventing health problems

## Observing and reporting early signs and symptoms

By Beth Marks and Jasmina Sisirak

People with intellectual and developmental disabilities (I/DD) have earlier age-related health conditions compared to the general population. They also tend to have poorer overall health. This may be a result of inappropriate health-care services. In general, observing and reporting early signs and symptoms of health changes among people with I/DD is often not done. They often receive less preventive care and more emergency care. This may result in more severe health problems.

In many community-based organizations, a nurse conducts annual healthcare visits with each person receiving services. But many people with I/DD have not been taught how to observe or communicate early signs and symptoms of health conditions. Thus, Direct Support Professionals (DSPs) share in the responsibility for regular monitoring of healthcare. Not only do DSPs assist nurses, they are critical in following up to make sure that people receive ongoing healthcare.

Research suggests that many people with I/DD have health issues that are not diagnosed or managed correctly. Some of these conditions include pain, dental hygiene problems, epilepsy, and difficulty seeing or hearing. People also have problems with constipation, malnutrition, and obesity. Depression, osteoporosis, and thyroid problems are common as well. As people with I/DD experience these conditions along with disability related issues, emerging

health conditions can be further compromised. This is often due to under-diagnoses and misdiagnoses. Or there may be lack of prompt treatment.

DSPs are in key positions to observe and report early signs and symptoms of health conditions. DSPs may provide daily hands-on support, such as assisting with personal hygiene, feeding, and dressing. DSPs also provide more in-depth healthcare. This includes passing medications, caring for wounds, and offering emotional support. The responsibilities of DSPs have a vast and diverse range. These depend on individual circumstances.

Because DSPs provide direct support, they are often the most familiar with the general health status of people supported. They know how individuals tend to work and act. DSPs also have an understanding of their communication styles. As such, DSPs have a vital role in observing subtle changes in health status among people they support.

However, due to limited training opportunities, DSPs may not know how to observe and report signs and symptoms. They may not recognize serious health conditions experienced by people receiving support. Because DSPs work on the frontlines, having training to know the early signs and symptoms of emerging health conditions is critical. Effective training may also promote communication with health professionals. With this, healthcare among people with disabilities can

be better managed. Additionally, the onset of serious health conditions can be prevented.

One training program was developed to support DSPs to learn about signs and symptoms of health problems. This training curriculum and workshop is called *Continuity of Care: Early Recognition of Signs and Symptoms of Emerging Health Issues*. The curriculum includes a *Head-to-Toe Observation Checklist*. DSPs can use this to record and monitor emerging health issues of people they support. The Checklist is provided on the center pullout of this issue of *FI*. It can also be used to facilitate communication among individuals supported and healthcare providers. Following this training, DSPs reported improved knowledge of signs and symptoms. DSPs also gained skill in health advocacy and were more confident in reporting observations.

An active partnership between individuals, DSPs and healthcare providers can be achieved. This is promoted by effective training. DSPs can routinely look for signs and symptom of potential health problems as they provide daily support. They can communicate their concerns to healthcare providers. Or they can assist individuals to communicate concerns. DSPs become empowered by effective training. As a result, people with disabilities will be able to participate in their communities when they are not constrained by

# Frontline resources

**Preventing health problems: Observing and reporting early signs and symptoms**  
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poor health. This is an important mission that we can all share and strive for.

As our Code of Ethics states, we are “responsible for supporting the emotional, physical, and personal well-being of the individuals receiving support” ([NADSP.org/Library/Code-of-Ethics](http://NADSP.org/Library/Code-of-Ethics)). We can advocate for our purpose by speaking with policy makers and organization leaders. The information in this article may provide helpful talking points. We can influence the system to fulfill effective healthcare training for all DSPs.

Information about the Continuity of Care: Early Recognition of Signs and Symptoms of Emerging Health Issues training program can be found at: <http://www.health-mattersprogram.org/recognition.html>

*Beth Marks, RN, PhD, is a Research Associate Professor in the Department of Disability and Human Development at the University of Illinois – Chicago. She can be reached at [bmarks1@uic.edu](mailto:bmarks1@uic.edu).*

*Jasmina Sisirak, MPH, PhD, is an Associate Project Director in the Rehabilitation Research and Training Center on Aging with Developmental Disabilities in the Department of Disability and Human Development at the University of Illinois – Chicago. She can be reached at [jsisirak@uic.edu](mailto:jsisirak@uic.edu).*

## **American Academy of Developmental Medicine and Dentistry**

<http://aadmd.org/>

This website offers several webinars that may be of interest to DSPs, self-advocates, health professionals, and organizations and agencies that support people with Intellectual and Developmental disabilities. The webinars are offered free of cost, and registration is required.

Three webinars that are specific to the topic of emergency healthcare include —

- Emergency Healthcare in Adults with IDD; An Introduction to the Issues and Challenges  
<http://aadmd.org/articles/webinar-emergency-healthcare-adults-idd-introduction-issues-and-challenges>
- Emergency Healthcare in Adults with IDD; Part 2 Hospital Care  
<http://aadmd.org/articles/webinar-emergency-healthcare-adults-idd-part-2-hospital-care>
- Emergency Healthcare in Adults with IDD; Communication of Health Care Needs  
<http://aadmd.org/articles/webinar-emergency-healthcare-adults-idd-communication-health-care-needs>

## **Supporting Healthy Lives: College of Direct Support**

*By Nancy McCulloh and Traci Laliberte, University of Minnesota*

[collegeofdirectsupport.com](http://collegeofdirectsupport.com)

## **Rehabilitation Research and Training Center (RRTC) on Aging with Developmental Disabilities: Lifespan Health and Function**

[http://rrtcadd.org/research/health\\_promotion/related\\_projects/staff\\_education/index.html](http://rrtcadd.org/research/health_promotion/related_projects/staff_education/index.html)

This two hour training helps DSPs learn how to observe early signs and symptoms of new or changing health concerns among the people they support. DSPs will also learn how to accurately communicate these observations to healthcare providers. The curriculum aims to establish continuity of health care services so that healthcare providers and administrators can see DSPs as health advocates and develop better communication strategies in organizations that support “the voice” of DSPs. The RRTC will provide ongoing technical assistance.

## **Substance Abuse and Mental Health Services Administration (SAMHSA)**

<http://promoteacceptance.samhsa.gov/10by10>

SAMHSA created a Wellness initiative that provides information, training, and tools for people with mental and substance use disorder. Teleconference recordings are included in the Wellness Training Archive, and include a number of free trainings that may be of interest to DSPs, such as *Joining Together for Wellness & Recovery*, *The Impact of Trauma on Wellness*, and *Prevention and Holistic Approaches to Wellness*.

Continued on back cover

# NADSP supporting & affiliate organizations, state chapters and contacts

We would like to acknowledge NADSP Supporting Organization members for their generosity and ongoing dedication to the goals and mission of NADSP.

## Sponsoring organizations: \$2000 level

- American Network of Community Options and Resources (ANCOR)
- Crystal Run Village, Inc.
- Koinonia Homes, Inc.
- NYSARC, Inc.
- NYSACRA
- Rise, Inc.
- Research & Training Center on Community Living, University of Minnesota
- Welcome House, Inc.

## Supporting organizations: \$500 level

- The Adirondack Arc
- The Arc Otsego
- The Arc of Schuyler County
- Apple Patch Community, Inc.
- Beyond Abilities, LLC
- Bost, Inc.
- Butler Co. Board of Developmental Disabilities
- Cardinal Services, Inc.
- Catholic Charities Disabilities Services
- The Center for Family Support
- Cerebral Palsy Association of New York State
- COARC
- Creative Foundations, Inc.
- GMR Exceptional Care, Inc.
- Grace Community Services
- Embracing Autism, Inc.
- Hawaii Waiver Providers Association

- Heartshare Human Services of New York
- Heinzlering Foundation, Inc.
- Jefferson Rehabilitation Center
- John Raffaele Educational Support for DSPs
- Mercy Home
- New Hope Community
- New Horizons Resources, Inc.
- NYSARC, Inc.—Orange County Chapter (OCAHRC)
- OHI (Maine)
- Opportunity Enterprises, Inc.
- Pathfinder Services, Inc.
- The Resource Center
- Renaissance House, Inc.
- RHC—The The Resident Home
- SCO Family of Services
- SECOH
- Special People in Northeast, Inc. (SPIN, Inc.)
- Stone Belt ARC, Inc.

## Affiliate organizations: \$200 level

- ACLD
- Advocating Change Together, Inc.
- ARC Broward
- The Arc of California
- The Arc of Somerset County
- The Arc of Southside, VA
- The Arc of Steuben
- Block Institute
- Bona Vista Programs, Inc.
- Cardinal McCloskey Services
- Community Residences, Inc.
- Community Support Services, Inc.

- Connections of Moorhead
- The Council on Quality and Leadership (CQL)
- CUNY School of Professional Studies
- Delta Projects, Inc.
- Developmental Disabilities Institute
- Diane McComb
- Eggleston Services, Inc.
- The Emmaus Community of Pittsburgh
- The Epilepsy Foundation of Long Island, Inc.
- Heritage Christian Services
- Hopewell Center, Inc.
- Irwin Siegel Agency, Inc.
- Job Path, Inc.
- Laura Baker Services Association
- Life's WORC
- Mat-Su Services for Children and Adults
- Miami Cerebral Palsy Residential Service Inc.
- Opportunities Unlimited, Inc.
- Outcomes, Inc.
- Parent to Parent of NYS
- Passages, Inc.
- Presbyterian Homes and Family Services
- Rainbow of Challenges, Inc.
- RTC Media
- Rural Living Environments, Inc.
- St. Amant Community Residential Program
- Self-Advocacy Association of New York State
- Seven Counties Services
- Spaulding Support Services
- SPEAK, Inc.
- Western New York Training Consortium
- WestSide Support Services, LLC.

## State chapters and contacts

As a membership organization, NADSP requires the involvement of its members to share information on DSP issues, achievements and directions. Chapters and contacts do this important work in concert with NADSP. We encourage the involvement and participation of DSPs in leadership roles at both the local and national levels.

### Arizona

DSPs of Arizona  
Michelle Noe  
dsp@dsparizona.com  
www.dsparizona.org

### Arkansas

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### California,

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### Connecticut

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### Florida

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### Georgia

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### Illinois

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### Kansas

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KLStiffler@rsskansas.org

### Kentucky

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Cheryl Prusinski  
cprusinski@sevencounties.org

### Louisiana

Nancy Robertson  
504.942.8289

### Maryland

Gina McDonald  
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### Michigan

Michigan Alliance of DSPs (MADSP)  
Michael Bray  
mikebray@wayne.edu  
www.ddi.wayne.edu/michigan\_alliance.php

### Minnesota

DSP Association of Minnesota (DSPAM)  
Donald Krutsinger, President  
minnesotaDSPAM@yahoo.com

### Mississippi

Support Professionals  
Advocating for Real Quality  
of Life for Everyone (SPARQLE)  
Lisa Burck  
lburck@nadsp.org

### Missouri

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Don Carrick  
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### Nebraska

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Mary Lawson  
Nebraskadsp@gmail.com

### New Hampshire

Robin Carlson  
carlet@metrocast.net

### New Jersey

Colleen McLaughlin  
Colleen.mclaughlin@umdj.edu

### New Mexico

www.nmdirectsupport.org

### New York

DSP Alliance of New York State (DSPANYS)  
Michael Tuggey  
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### Ohio

Ohio Alliance of DSPs (OADSP)  
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### Oklahoma

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prost@epmi.org  
Diane Potts  
dpotts@tulsacc.edu

### Pennsylvania

Pennsylvania Alliance for DSPs (PADSP)  
Ernest Gibson  
padsp@gmail.com

### Texas

Richard E. Garnett  
The Intellectual & Developmental Disabilities Needs Council of Tarrant County  
817.877.1474

### Virginia

Amanda Panuline  
panuline.amanda@egglestonservices.org



program is a partner that participants hang out with on a day-to-day basis. For many participants, their partners are Direct Support Professionals (DSPs).

Mark's DSP, Pam, played an integral part in Mark's weight loss success. Mark and Pam attend and participate in *Project HEALTH* as a team. As Mark wipes off beads of sweat from his forehead, Pam does too. If Pam feels exhausted and wants to take a break, Mark motivates her to keep going. To watch this partnership in action is truly inspiring.

The vision of *Project HEALTH* is to see more successes like Mark and Pam. What if every DSP encouraged healthier activities like Pam does? What if every agency supporting people with disabilities had ongoing opportunities for adaptive fitness classes? What if people with disabilities were no longer classified as "having higher rates of obesity?" What if EVERYONE had greater opportunities to live a healthy lifestyle? This vision IS possible. Everyone has abilities. Now let's see to it that they have opportunities!

*Megan Graf, BA, ACSM, CPT is the Coordinator for Project HEALTH. For additional information on Project HEALTH, contact Lori Cutler-Turner, lori@s4af.org, 615-354-6454.*

# NADSP membership form

## DSP level \$10/year

DSP

## Other individual level \$20/year

If your state has a NADSP chapter, you will receive dual membership in the state chapter and NADSP.

Frontline supervisor  Self-advocate  Family member

Other professional (please specify) \_\_\_\_\_

## Affiliate level \$200/year

For individuals, agencies, providers, associations, and NADSP state chapters who wish to demonstrate a commitment to support the efforts of DSPs.

Individual  Organization

## Supporting organization level \$500/year

For individuals and organizations dedicated to advancing the interests of DSPs and the people they support at a national level.

Individual  Organization

## Sponsoring organization level \$2000

For individuals and organizations dedicated to advancing direct support as an accepted profession at the national level and participation on the NADSP Advisory Committee.

Individual  Organization

**Total enclosed**

Make checks payable to NADSP. To pay by credit card, visit [www.nadsp.org/membership](http://www.nadsp.org/membership) (Discounts are not available with online payment)

### Mail membership form and payment to:

NADSP, 240 Washington Ave. Ext., Suite 501, Albany, NY 12203-0305

Name \_\_\_\_\_

Organization \_\_\_\_\_

Address \_\_\_\_\_

City State Zip \_\_\_\_\_

Phone \_\_\_\_\_

Email \_\_\_\_\_

**Frontline resources**  
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## Wellness curricula for adults with disabilities

Title	Target population	Developer
Continuing to Live Well with a Disability: A companion course to Living Well with a Disability	Adults with disabilities	Center for Disabilities and Development, University of Iowa
Healthy Lifestyles for People with Disabilities	Adults with disabilities	Center on Community Accessibility, Oregon Health & Science University
Steps to your Health	IDD	South Carolina Department of Disabilities and Special Needs
Health Advocacy Program	IDD	NY State Institute for Basic Research in DD
MENU-AIDDS: Materials for supporting nutrition and education with adults with intellectual or developmental disabilities	IDD	Rural Institute, University of Montana
Women Be Healthy, A Curriculum for Women with Mental Retardation and Other Developmental Disabilities	Women with disabilities	North Carolina Office on Disability and Health, Frank Porter Graham Child Development Institute
Exercise and Nutrition Health Education Curriculum for Adults with Developmental Disabilities	IDD	RTC on Aging with DD, University of IL, Chicago
Health Matters: The exercise and nutrition health education curriculum for people with developmental disabilities	IDD	RTC on Aging with DD, University of IL, Chicago Published by Brookes Publishing
Living Well with a Disability	Adults with disabilities	Rural Institute, University of Montana