By Robert Fletcher

A reality that all Direct Support Professionals (DSPs) face is that many individuals they support who have intellectual or developmental disabilities (I/DD) may also have psychiatric disabilities. This combination of disabilities is commonly referred to as a “dual diagnosis.” However, this is not always fully recognized and appreciated by support teams.

Appreciating the reality of dual diagnoses is critical. An individual’s behavior may be attributed to his or her I/DD and written off as such. Too often this happens when a person shows signs of an underlying mental health issue.

It is estimated that more than one million people in the United States have a dual diagnosis of I/DD and mental illness. According to NADD, the rate of mental...
Frontline Initiative is supported through a cooperative agreement between the National Institute on Disability and Rehabilitation Research, U.S. Department of Education (#H133B080005) and the Research and Training Center on Community Integration, University of Minnesota. The opinions expressed are those of the authors and do not necessarily reflect the views of the RTC, Institute, University of Minnesota, or their funding sources.

Frontline Initiative is available in alternate formats upon request.

Welcome to our Frontline Initiative issue on Dual Diagnosis. We are fortunate to have had the opportunity to collaborate with the national leading organization for dual diagnoses, the NADD (an association advocating on behalf of individuals with a dual diagnosis) for this issue. Together, we bring you a variety of perspectives related to providing effective supports for individuals with the challenging and complex needs inherent to dual diagnoses.

Dr. Robert Fletcher, Founder and CEO of NADD, served as an author and editor in contributing to this issue. In the cover story, he provides an overview of dual diagnoses and explains the most common types of mental health needs experienced by individuals with intellectual and developmental disabilities (I/DD) in our cover story. Dr. Fletcher also describes competency areas that are critical for DSPs supporting individuals with dual diagnoses.

DSPs play an important role in assuring that a person with I/DD and a mental health need receives appropriate assessment and treatment. In Partnering on Mental Health Needs: DSPs on the Frontline, Thomas Cheetham, MD, and Bruce Davis, PhD, identify important questions for DSPs to consider when sharing information related to changes in an individual’s behavior with a behavioral health professional. In her article, Providing Excellent Support to Individuals with a Dual Diagnosis: A Major League Approach, DSP Erin Paul describes how DSPs can provide effective supports to individuals with I/DD by creatively comparing the success of DSPs to that of a baseball team.

Elizabeth Dykens, PhD, explains how we can de-stress and increase positivity in our lives in Promoting Good Mental Health through Stress-Reduction and Self-Care. And Cheryl Felak, a mother of a son with a dual diagnosis, shares how DSPs have been critical in fostering her own mental health and positive well-being in her heartfelt story, How Do I Spell Relief? C-A-R-E-G-I-V-E-R.

In this issue, we are lucky to feature two self-advocates’ perspectives related to dual diagnosis. In It’s Hard to Explain… Defining my identity and finding success through self-advocacy, Daniel Ekman describes the complexity around labeling disabilities, and shares important experiences that have influenced his overall well-being and personal success. You may find self-advocate Laurel Rose Dean’s article, Active listening and respect: How to honor a person’s strengths and space, particularly relevant and helpful, as she shares concrete tips for DSPs supporting people with I/DD and mental health needs.

We hope you will enjoy this issue as you learn more about supporting individuals with dual diagnoses.

~ The editors
illness among people with I/DD is three-to-four times greater than the general population. Many professionals estimate that approximately one-third of people with I/DD have a psychiatric disability. The higher incidence rate of psychiatric disorders among individuals with I/DD — particularly anxiety and mood disorders, described below — is attributed to a variety of factors including biological and social. Individuals with I/DD may have coexisting central nervous dysfunction and medical problems, and they may take a variety of medications that influence the body’s basic chemistry. They are also subjected to increased stress and negative social conditions. They suffer abuse more frequently than other people. They often have inadequate social supports and, given societal attitudes, may experience low self-esteem.

The most common types of psychiatric disorders experienced by individuals with I/DD are:

- **Anxiety disorders** — a group of disorders characterized by excessive fears or nervousness or frequent physical complaints that have no medical basis (somatic complaints) and interfere with functioning. Panic attacks, obsessive-compulsive behavior, phobias (irrational fears) and post traumatic stress disorder (PTSD) are types of anxiety disorders.

- **Bipolar disorder** — a mood disorder, also known as manic-depressive illness, that causes extreme shifts in mood. A person with bipolar disorder may cycle between periods of mania (extreme levels of energy and overconfidence that may lead to reckless behavior) and depression, but also have normal moods. The length of a manic or depressed cycle may be days or months.

- **Major depression** — also a mood disorder that affects the mind, body and innermost feelings of an individual. Everyone feels down from time to time; it is a natural response to particular life events. But with major depression, however, the symptoms are severe or long lasting. Symptoms can include sad or irritable mood; loss of interest in activities once enjoyed; significant changes in appetite, sleeping patterns and activity level; feelings of emptiness or hopelessness; difficulty concentrating and thoughts of death.

Individuals with I/DD may also have psychotic disorders, such as schizophrenia. The major symptom of these disorders is psychosis, or delusions and hallucinations. Delusions are false beliefs that impair a person’s functioning. One example of a delusion is a person believing that someone is trying to hurt him or her when there is no tangible evidence of this. Another example is a person believing that he or she is somebody else, such as the President. Hallucinations are false perceptions. They can be visual (seeing things that aren’t there), auditory (hearing), olfactory (smelling), tactile (feeling sensations on your skin that aren’t really there, such as a person feeling bugs crawling on him or her), or taste. Unlike anxiety and mood disorders, the incidence of psychotic disorders among people with I/DD is believed to be the same as that for the general population.

Individuals with I/DD may also have personality disorders. These are patterns of dysfunctional behavior that present as personality traits. They may also have adjustment disorders. These are described as an inability to cope with or adjust to a particular source of stress.

The issue of dual diagnoses is not new. It has just become more visible as people with I/DD have emerged from the shadows of institutions. Taking their rightful place in the community with their fellow citizens, they and their advocates, families, clinicians and direct support professionals have demanded that attention be paid to needs that they share with people who do not have I/DD, including mental health needs. And like individuals who do not have I/DD, their mental health needs can be addressed through appropriate professional interventions. These may include psychopharmacology (medications), psychotherapy, behavior management, social skills training, residential supports and crisis intervention services.

An excellent resource on this matter is *The Dual Diagnosis Primer: A Training Manual for Family Members, Case Managers, Advocates, Guardians and Direct Support Professionals*, published by NADD. For more information, visit [http://thenadd.org/](http://thenadd.org/).

Robert Fletcher, DSW is the Founder and CEO of NADD and can be contacted at rfletcher@thenadd.org.
Partnerships & professional engagement

By Joseph Macbeth

This edition of *Frontline Initiative* is particularly important because it gives Direct Support Professionals (DSPs) an idea about the prevalence of dual diagnoses and provides strategies for supporting people who experience developmental disabilities and mental illness. The NADSP is proud of our partnership with NADD; our joint efforts provide DSPs with the necessary knowledge and skills in supporting the complex lives of people experiencing dual diagnosis. We encourage you to learn more about NADD’s competency-based certificate program for those of you who support people with intellectual disabilities and mental illness. We’re also proud NADD has adopted the NADSP Code of Ethics as its values base for practitioners.

Partnerships like NADSP and NADD are critical to the success of supporting people in our communities. We believe that it is important for DSPs to expand their own professional partnerships beyond the colleagues with whom they work every day. It’s what professionals do! But the reality is that the work world of DSPs is extremely focused on the individuals we support. It is critical to focus on their immediate needs and interests. Therefore the DSP worldview is often, and necessarily so, framed by what’s going on in the “frontlines.”

It can be hard for DSPs to get a broader, systemic view of issues impacting the profession. But we can challenge ourselves, our colleagues, and the people we support to learn more about the systems. When we explore this bigger picture together, we can understand how services are shifting. There are emerging state and federal policies that will reshape service delivery, budgetary issues, and organizational changes at agencies. It is important for us to play a role in impacting positive changes. Taking a broader view can spark and continue movements toward more opportunities in our profession and for the people we support. Reading this issue is a great way to start learning about issues that impact our profession. Then take some time to reach out, connect, and share insights about what you learn from your view and from your experiences on the frontline. DSPs are encouraged to use the NADSP as a resource for you to connect with your vast network of colleagues.

Every summer, the NADSP conducts our annual membership drive. This year we want to engage DSPs, agency administrators, people with disabilities and their families about the value of being connected to a professional community. We hope that you’ll help us spread the word. You can join our membership online by going to www.nadsp.org or filling out the membership form inside this edition of *Frontline Initiative* and sending it back to us.

Finally, National Direct Support Professional Recognition Week will be September 8th – 14th. During September, the NADSP works hard to bring positive attention to our dedicated workforce and we help other organizations to do the same. Look for special announcements on our credentialing opportunities. We will be offering discounts on our first level of certification, DSP-R, which is intended to recognize people who have entered the profession and desire to have careers in the field of community human services. We’ll be sharing a lot more information about these special offers through our eFlash communications and on Facebook (https://www.facebook.com/groups/57675171735/#!/groups/nadsp/).

I hope you’ll consider joining our membership. When you do, you will experience what all professionals experience - a rich discussion of the issues at hand and critical information on best practices of the profession.

Joseph Macbeth is the Executive Director of NADSP. He can be reached at jmacbeth@nadsp.org or 518-449-7551.
Providing excellent support to people with a dual diagnosis: A Major League approach

By Erin Paul

Does a major league pitcher win by throwing the same pitch to every batter every time? Does a singer advance his or her career by singing the same song every time he or she sings? Does a leader become great by reciting the same speech over and over? The answer, of course, is no. Just as doing the same thing as always doesn’t work for athletes, artists, and leaders, nor does it work when working with folks who have a dual diagnosis. A Direct Support Professional (DSP) can’t use the same methods with each person supported and expect positive results. Every person is unique and requires a unique, individualized approach to intervention. Let’s discuss a couple of ways this can be done.

1. Work with a team

You’ve heard the saying — two heads are better than one. Several minds and levels of experience can be very valuable when supporting individuals with particularly challenging behaviors. Other people’s ideas might help uncover what the person’s core therapeutic issues really are and how you might best support him or her. Let’s go back to the baseball player. If a baseball player wants to win games and lead his team to victory, then he needs the help of his teammates. Teammates can help him increase his abilities, practice new and better plays, and become stronger at what he does. It is the same with supporting people with dual diagnoses. As a DSP, I rely on the help of my team.

I began my career working with adults and transitioned to working with youth. The first youth I worked with was challenging for me. He had Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD). He also had a number of other diagnoses. I worked very intensely with him as he had behaviors that put his participation in school at risk. After weeks of trying the same way to work with him and realizing that wasn’t working, I sat down with several of my team members and discussed other possible strategies. We talked about why he might have the behaviors he was having and what he may be getting out of it. We also discussed how to help him get the same result without having the inappropriate behaviors that put him at risk of classroom removal. Based on those conversations, I changed the environment in which I worked with him and added another person to the support team. I also addressed his behaviors in a different way that was more concrete for him. After some time, he was able to stop his own inappropriate behaviors with only a few reminders. Then he went on to successfully graduate. This was not thought to be a possibility when I started working with him. I believe the support and collaboration of my team were critical in allowing me to provide effective supports during the short amount of time I worked with him.

2. Seek training

Search out and request training in areas that you may be less knowledgeable about. Trainings can be very beneficial in opening up your mind to new possibilities and other methods. I have attended some trainings that I found very useful and insightful. One of the most beneficial lectures I attended was given by someone living with the diagnosis that I was there to learn about. She talked about how she worked through her difficulties and what support strategies were most helpful. Not only was it inspiring, but it was the most informative lecture I had ever heard. I learned how someone with a disability can succeed when she develops self-advocacy skills and participates in the community.

There are lots of things a DSP can do to increase his or her knowledge and skills for supporting people with dual diagnoses. The recommendations I have provided are a couple of important key actions that DSPs can take to promote effective supports. Working within a team and seeking out specific trainings have both shown to be positive strategies when supporting people with dual diagnoses. How might you utilize a team approach? What trainings or professional development opportunities might be available?

Erin Paul, BS, OBHP, NADD-DSP, is a Team Leader at Meridian Health Services. She can be reached at erin.paul@meridianhs.org.

Adapted with permission from the DSP Interests and Concerns column in the NADD Bulletin (November/December 2012, Vol. 15, No. 6.).
Promoting good mental health through stress reduction and self-care

By Elisabeth Dykens

Negative emotions drain our energy, like a car guzzling gas. Chronic negative emotions can affect our health. Feeling positive about one’s self and one’s life can be learned and practiced. How we feel affects those we interact with daily. Direct Support Professionals (DSPs) can feel less stressed and help individuals they support to feel less stressed and more positive.

We can learn and practice ways to take better care of ourselves by living more attentively and finding things for which we can be grateful. We can focus on the joys and pleasures around us, which we often miss when we focus on our troubles.

Think of the nervous system as having an accelerator - the stress response, and a brake - the relaxation response. It is helpful to take our foot off the accelerator some of the time. Just 3 minutes of deep belly breathing turns on the relaxation response and turns off the stress response. Conscious breathing is our most important stress reduction tool. We can practice it anywhere, anytime. Our breath is our “go-to tool” because we always have it with us.

We can reduce stress by learning to be open to whatever life brings without judging it as good or bad. This does not mean we have to like what happens, but we can manage even painful or difficult experiences one moment and one breath at a time.

The tips here can help you learn to live moment to moment. Do not try to do everything at once.

Practice Tip 1 for Week 1. In Week 2, add Tip 2, and so forth. Practice these tips yourself and with the individuals you support, adapting for their abilities. If it is difficult, be kind to yourself. There is no right or wrong way to practice these tips. Experiment and find what works for you.

Tip 1: Practice relaxation twice a day

Schedule a time twice daily for a 3- to 5-minute breathing space. Lie or sit comfortably. Breathe slowly and deeply. Count silently or softly aloud on the inhale matching the same count on the exhale. Gradually extend the count to deepen the breath. Or use words like “breathing in, healing” on inhale, and “breathing out, release” on exhale. Choose words that work for you.

Tip 2: Be in the present moment

When we are fully in the present moment, we are not revisiting the past or worrying about the future. You can train your mind to be in the present moment. For example, try walking to where you are going while being fully aware. Practice noticing the moment your foot hits the ground, or pay attention to sounds you hear while walking. Choose one routine in daily life and try to bring moment-to-moment awareness to that activity each time you do it. With practice, you will be present in the moment more often and for longer times. If you get lost in your thoughts, begin again.

Tip 3: Take hold of your mind

Our thoughts and feelings are like the weather. They come and they go like clouds. We can’t control the weather, but we can choose how to meet it. Getting stuck in negative thoughts adds to stress. When you notice you are stuck in negativity, name how you feel. Then try using your breath to move your attention from your thoughts to your breath. For example, breathing in: “Frustrated.” Breathing out: “Kindness.” Shifting your focus from your thoughts to your breath gives your mind a break. Like our bodies, our minds need rest.

Tip 4: Cultivate lovingkindness

Lovingkindness is our capacity to feel friendliness to ourselves and others without conditions. Sit comfortably. Bring attention to your breath and allow tension to flow out of your body. “Breathing in, may I feel peaceful. Breathing out, may I be in a space of well-being.” Picture persons who have cared for you. Imagine them around you. Say to yourself, “May I be filled with lovingkindness. May I be peaceful.” Repeat these wishes for others.

Tip 5: Practice gratitude

At the end of each day, name one to three things for which you are grateful.

Elisabeth Dykens, Ph.D., Professor of Psychology and Psychiatry, Vanderbilt University, conducts research on stress intervention in families.
It’s hard to explain...

Defining my identify and finding success through self-advocacy

By Daniel Ekman

My name is Daniel Ekman and I am 27 years old. I could introduce myself by saying that I am an individual with autism spectrum disorder (ASD) and an individual who is diagnosed with depression and social anxiety. But I’m not sure that would explain everything. I was discussing with a friend how I am affected by each of these diagnoses; I found that it was harder to explain than I had thought. When I was younger, my parents were the ones who advocated for me to get services to help me manage my autism. When I was a teenager, I initiated seeking therapy for depression, so I thought far more about having depression than having autism. I also didn’t know how to interact with others or even call people on the telephone, so I thought that social anxiety was more of an issue than autism. Now, as a former graduate student in special education and a self-advocate who works for the New Mexico Developmental Disabilities Planning Council, I think more about my autism. But I still go to therapy for clinical depression, which runs in my family.

In short, it’s hard to think about what to call myself. It is more useful to think about the why and what I can do about any problems coming up from either having ASD or depression and social anxiety. For instance, when I feel depressed, feeling a lack of dignity or respect often comes up. I have seen this with other self-advocates as well. Instead of labeling something depression and simply seeing it as inevitable, maybe it is more useful to ask a question. Does the person have the dignity of making as many of his or her own decisions as possible? Is the person living as independently as possible? After all, a lack of control in one’s life would make anyone depressed. I am fortunate to be able to choose what types of therapy I get. This helps me feel in control of my own life. Choice and self-determination shouldn’t simply be a matter of good fortune. It should be a right.

Sure, therapies at a young age helped. But being in an international student community during my undergraduate degree was an even more important moment of growth. I could learn through living in a caring community of people. I could push my comfort zone and try new things. I made mistakes and certainly had some suffering, but those were the moments where I truly learned and grew up. It is critical for people to have opportunities to learn through experiences and make mistakes. Each person, including individuals with dual diagnoses, deserves to experience the triumphs that come through working towards success in that kind of environment. Direct Support Professionals (DSPs) can support individuals through those growth moments rather than taking them away. Let individuals you support try new things, make mistakes, and perhaps even fail. After all, a life without those moments seems depressing, and, well, antisocial.

Daniel Ekman is a former program assistant and current interim program manager for the New Mexico Center for Self Advocacy. He is a member of various self-advocacy groups and coalitions. Daniel lives in New Mexico and can be reached by phone (1-505-341-0036) or email daniel.ekman@state.nm.us.

College of Recovery and Community Inclusion

CRCI is an integrated, web-based curriculum designed for community mental health practitioners. Self-directed courses focus on helping this critical workforce respond to the unique needs of people with mental health conditions. This curriculum is in the final stages of development and will launch in August 2013. Go to the website http://directcourseonline.com/recoveryandcommunityinclusion/ to sign up for updates and to be notified when the curriculum launches.
Active listening and respect
How to honor a person’s strengths and space

By Laurel Rose Deans

The first thing someone notices about me is my beautiful smile. It lights up the room. The next thing people notice about me is my self-determination. I have led an interesting life! I have visited other countries. I have taken college classes in sign language and massage therapy. I completed a 45 credit hour certificate in childcare. I dance in a local company, Keshet. I own a car that I use to drive to work, appointments and fun activities. I even own a unique pet, an African Grey parrot that talks and keeps me company. I also work part-time for the local ARC. I still find time to enjoy the beautiful outdoors of New Mexico with family and friends.

I have a strong and supportive family that helps me achieve and maintain a satisfying life. I recently moved into my first apartment after living in a group home for some time. I also have some formal support from direct support professionals (DSPs) of a local agency. They help me keep track of my medications and my apartment. Importantly, they support my participation in the community.

Given my wide range of life experiences, I have learned what helps me be successful and what doesn’t. The most important thing a DSP can do when providing support for someone with a developmental disability and another diagnosis is to listen. Listen first and act second. It is important for a DSP to first ask each individual about his or her goals; then spend time getting to know him or her before doing anything else. This will get the relationship off to a good start. It will help make sure the support provided is focused on the needs of the individual.

It is important to keep listening even after a DSP begins working with a person with dual diagnosis. The individual being supported may be feeling more anxious on some days than others. When that happens, the DSP needs to be willing to change plans. This means adjusting the assistance provided to meet what the person is experiencing. On some days, I just don’t feel like going out and doing things. It is important for the DSP to honor that and be flexible. The DSP should also watch to see if suggestions or directions are overwhelming the person being supported. It is important for the DSP to slow down and let the person being supported have time to think and process.

Another tip I have for DSPs working with people with dual diagnoses is to respect peoples’ personal space. This includes things like hugging someone (ask first, please!) or touching and rearranging peoples’ personal things without permission. This is especially important to me since having personal space is one reason I wanted to move out of the group home. Understanding how important this issue is and respecting a person’s space can reduce anxiety and make things go more smoothly.

Active listening and showing respect for a person’s personal space are essential components for a positive relationship between a DSP and an individual receiving supports. Honoring his or her unique talents and interests will serve to strengthen that relationship, making it a good support experience for everyone.

Laurel Rose Deans is a self-advocate for the New Mexico Center for Self-Advocacy.

Laurel (third from right) performing with Keshet Dance Company in Albuquerque, New Mexico. www.keshetdance.org
Caregivers* are the life support and backbone to families, especially to families such as mine. My husband and I have four children, one of whom has a developmental disability that is exacerbated by episodes of mania and psychosis.

We have had several caregivers over the 19 years of Thomas’ life but there are two who stand out. These two are the ones who knew Thomas, understood him and really cared about him as a person. These two even volunteered to hang out with Thomas prior to being compensated as a caregiver. They still keep in touch with him and take him out when they are in town. They get him. I couldn’t feel luckier knowing that these two people and their respective spouses love my son and enjoy spending time with him. Thomas loves and adores his friends and his enthusiasm over outings is infectious.

As a mom of four and a part-time nurse, my life and health depended on caregivers to help so that I could work, go to the doctor, attend another child’s special event, or exercise or take a walk with my husband. My first and foremost thought for every moment of the day would be who would be there to take care of Thomas. All events were planned around his care.

Our son’s caregivers gave me life. At the same time, they provided my son a safe environment by entertaining him, taking him various places and building lifelong relationships with him. They took him places that he loved but I just didn’t have the energy to do. I often wonder if they know how instrumental they were to our family. Or how desperately I waited for them to arrive so I could have a break to just sit and think or take a nap.

I also remember having caretakers who were not reliable. They would “forget” to come, maybe thinking that it wasn’t really a job but just “babysitting.” I remember bursting into tears at times when I had been so looking forward to a break but the caregiver didn’t show up. I don’t think they realized how much I relied on the couple of hours of their time to survive. What really hurt me though was that my son so looked forward to someone coming to do something with him. His sadness from not being able to do what he planned broke my heart. How could I explain this to him when he didn’t understand?

Now that my son lives in a supportive community with appropriate supports, I work hard to advocate for our caregivers. I think about all the other families who are struggling but do not have the strength to even ask for help. Even if they could ask for help, would there be anyone to help them?

Our caregivers need to make a living wage. This is hard work. It is not babysitting. It takes so much to safely care for a person with a developmental disability who also happens to have a mental health issue. Many parents are finding that the caregivers disappear as their children grow into teens and adults. Families struggle and become isolated in their homes. Yet no one is aware because they are hidden away behind closed doors.

Caregivers are the key to people with dual diagnoses participating in our community. Not only do they provide respite and relief for families but also build relationships and provide new and interesting experiences for the person they care for.

Thank you to Gretchen and Alex for reaching out to Thomas. He loves you!

*Editor’s Note: In this article, caregiver is a general term used to define people who provide support. A caregiver could be a family member, DSP, or other source of support.
Partnering on mental health needs  
DSPs on the frontline

By Thomas Cheetham and Bruce Davis

Direct Support Professionals (DSPs) know the individuals they support well. They are likely the first to notice changes in behavior patterns. DSPs can advocate for mental health evaluation by being alert to early signs of changes in both physical health and mental health. These types of issues can overlap significantly. Acting early can help prevent a crisis.

People with intellectual and developmental disabilities (I/DD) are at much higher risk for mental health problems than people without disabilities. Risk factors vary widely across people. Many behavioral health problems first occur during late adolescence and early adulthood. Behavior change may be the only way that a person with I/DD can show that something is wrong. These changes can signal that treatment or more specialized supports are needed.

DSPs play a vital role in recognizing behavior changes. DSPs can take action in three important steps —

**Step 1**

Describe and keep detailed records. Note how often, how intensely and how long behaviors occur. Note the circumstances in which they happen. *(Use questions I-V to the right.)*

**Step 2**

Consult the person’s primary care physician.

**Step 3**

Refer to a behavioral health care provider if medical problems are ruled out as a cause. A behavioral health care provider may be a mental health professional, psychiatrist, psychologist, or therapist.

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*How to advocate for quality healthcare:*

When making a referral to a behavioral healthcare provider, it is important to be able to provide as much information as possible. This information can assist a behavioral health care provider with identifying the cause of the change in a person’s behavior. This can also assist in identifying appropriate treatment plans. DSPs are encouraged to think through the following questions when gathering information to share with a behavioral healthcare provider.

**I. Describe the behavioral problem**

- When did the behavioral problem start?
- When was the person last at his or her best or usual self before the issue?

**II. Describe the current difficult behavior**

- What specific behaviors or symptoms are occurring?
- What in the past helped or did not help with it (including medications)?
- What is being done to help the person manage the behavior? How is it working?
- Is there risk to self, to others, at home or in the community?
- Is there aggression to self or others; and is it mild, moderate, or severe?
- How frequent is the behavior?
- Subtle changes in the person’s daily routine also may show a problem starting. Has there been a recent change in mood, bowel/bladder habits, appetite, sleep, social involvement, communication, interest in leisure activities or work, self-care, independence, thinking or memory, or movement?
- Has there been a recent need for change in support or supervision? When did these changes start?

**III. Consider possible physical health problem or pain**

- Are you aware of any physical health or medical problem that may be contributing to behavior problem?
- Could pain, injury or discomfort be contributing to behavior change?
• How would you know if the person was in pain?
• Are there concerns about medications or side effects?

IV. Consider changes in environment
• Were there changes in or stress with caregivers before the concerning behavior began?
• In care provision? In living situation or daily routine?

V. Consider support issues
• Is the person receiving needed supports?
• If there are sensory triggers, what is in place to help?
• Are there opportunities for suitable physical activity?
• Are there supports or programs not in place that you think might help?

VI. Consider relational and emotional issues
• Has there been a recent change in relationships?
• Additions, losses, separations, deaths?
• Teasing or bullying?
• Anxiety about completing tasks?
• Disappointments?
• Growing insight into disability and its impact?
  Life transitions? Traumatic experiences?

By being alert to important changes in behavior, DSPs can be effective partners with behavioral health providers. By collaborating with the person and his or her support team, DSPs play a central role in preventing crises and addressing behavioral needs.

Thomas Cheetham, MD, is Director of Health Services, and Bruce Davis, PhD, is Director of Behavioral and Psychological Services, both in the Tennessee Department of Intellectual and Developmental Disabilities.

Peer mentoring

Peer mentoring has been shown to decrease anxiety and depression in people with mental health issues. Peer mentoring may also be an effective approach to supporting people with a dual diagnosis. A peer mentor is someone who has experienced something and is willing to share their experiences with others who are in a similar situation. Peer mentors with a dual diagnosis can encourage and support other individuals with I/DD and mental health issues to lead a healthy, productive, and fulfilling lifestyle. Talking with peers and learning about others’ challenges and successes can help people with a dual diagnosis develop important relationships and build a community with other people who may have faced similar adversity and have persevered.
Individuals with dual diagnoses and the critical role of competent DSPs

By Robert Fletcher

What’s the first thing that we need to know about supporting individuals with a dual diagnosis? It’s what we don’t know. Then it’s important to learn how to find out more.

It’s also important for us to understand the significance of the role of a Direct Support Professional (DSP) in a person’s life. A DSP can play a key role in assuring that a person with an intellectual or developmental disability and mental illness (IDD/MI) receives appropriate assessment and treatment. Individuals who have IDD/MI have complex needs. They may have difficulties with their behavior, communicating with others or maintaining relationships. They may be at risk of being over-medicated, having their rights restricted or being abused or neglected. Of all the professionals who enter the life of a person with IDD/MI, it is the DSP who spends the most time supporting the individual in his or her pursuit of a fulfilling life.

Therefore, in partnership with individuals and their support team members, it is important that DSPs develop competency in critical areas. These competency areas enhance DSP skills and abilities to provide individualized support for people with dual diagnosis —

Assessment and observation
A DSP often has opportunities to observe an individual in a variety of daily living situations and how the person functions. Often other professionals on the person’s support team don’t get to see this full picture. It’s important that DSPs appreciate the significance of signs and patterns they notice, and how to document and communicate the observations. See the article, Partnering on Mental Health Needs: DSPs on the Frontline, on page 10-11 in this issue for questions to think through when gathering information for a health care provider.

Behavior support
DSPs are often the first to note behaviors or changes that are challenging. DSPs can understand the function that behavioral changes may play in a person’s life. They can discover the best ways to support the person, rather than trying to control the behavior.

Crisis prevention and intervention
At times individuals with IDD/MI may experience a crisis when their behavior leads to risk of immediate and serious harm. Therefore, it is important that DSPs know how to identify the potential for a crisis and how to act to prevent it.

Health and wellness
Good health is a state of overall physical, mental and social wellbeing. It’s not just the absence of disease or illness. Promoting good health and wellness is an active process that requires daily effort. People with IDD/MI are at risk for more health and wellness problems than people without; therefore DSPs are called to play a role in mitigating these risks.

Community collaboration and teamwork
People with IDD/MI require assistance from many systems and professionals. Supporting their quest for a fulfilling life requires a team effort; DSPs can’t do it alone. Highly competent DSPs know how to communicate across the various systems and foster positive relationships.

Robert Fletcher, DSW is the Founder and CEO of NADD and can be contacted at rlfletcher@thenadd.org.

The College of Direct Support (CDS) offers courses that touch upon some of the above topics (e.g., Supporting Healthy Lives, Positive Behavior Supports, Functional Assessment, and Documentation). CDS is developing more course offerings specifically geared toward supporting individuals with dual diagnoses. To learn more about CDS, visit the website: http://directcourseonline.com/directsupport/.

NADD, which has been collaborating with NADSP and has adopted NADSP’s Code of Ethics, also offers a credential for those direct support professionals who demonstrate proficiency in the above five competency areas. To learn more about offerings of the organization, visit the website: http://thenadd.org/.
Working with People with Challenging Behaviors: A Guide for Maintaining Positive Relations *
By Nathan Ory
This book introduces general practices and specific solutions to behavior problems that will work with people who display difficult and challenging behaviors regardless of who they are. The methods also apply to the person with emotional or psychiatric disturbances, or another serious mental health problem.

Quandaries: Understanding Mental Illness in Persons with Developmental Disabilities *
By Sue Gabriel
This book is for all who have puzzled over, questioned about, or wrestled with the dilemma of understanding the differences between mental health and mental illness, specifically in persons with developmental disabilities. Using many examples, this book provides a humorous, yet empathic guide to those who need it.

The Dual Diagnosis Primer: A Training Manual for Family Members, Case Managers, Advocates, Guardians, and Direct Support Professionals *
By Edward Hughes
This book provides a historical overview of the field of dual diagnosis, as well as overviews of related support and treatment strategies. Each chapter begins with learning objectives, and closes with review questions that assist readers in evaluating their understanding of the information.

Book review: Intellectual Disability and Mental Health: A Training Manual in Dual Diagnosis
By Sharon McGilvery and Darlene Sweetland
People living with both intellectual and developmental disabilities and mental illness (IDD/MI) face multiple challenges to receiving adequate care and support. People with these conditions may struggle with challenging behavior as a result of this poor response to their needs. They are the most likely to live in very restrictive settings, have few positive relationships and suffer from a poor quality of life. Outcomes could be greatly improved with proper treatment and support.

This book is 250 pages of incredibly helpful information for understanding the unique needs of individuals living with both IDD/MI. The authors describe practical tools and methods for improving services and supports. This book offers a comprehensive review of the many aspects that influence outcomes for people with dual diagnoses. It starts with a review of systems issues and likely outcomes for people if their needs are not met. The authors share insightful information on the effects of cognitive limitations as well as common psychiatric disorders and how they might be expressed. Drs. McGilvery and Sweetland provide a solid overview of behavior analysis, data collection and positive interventions. Specific tools and forms to utilize in actual direct support settings are included as appendices.

In the introduction, this book is described as applying to “…direct care providers, such as social workers, counselors, and direct care staff…”. It is important to note that the methods described in the book would be difficult to sufficiently implement without organizational support. Portions of the content may be better utilized by clinicians and program managers. However, for the ambitious DSP or the support team ready to really apply best practices, this is an extremely valuable resource that provides the key information to make a better approach a reality.

Published by NADD. Available through the NADD Store (online) and Amazon.com.
Review contributed by Susan O’Neill. Institute on Community Integration, University of Minnesota.
We would like to acknowledge NADSP Supporting Organization members for their generosity and ongoing dedication to the goals and mission of NADSP.

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- American Network of Community Options and Resources (ANCOR)
- Crystal Run Village, Inc.
- Homeplace Support Services
- Koinonia Homes, Inc.
- NYSACRA
- NYSARC, Inc.
- Provider Search, LLC
- Research & Training Center at the University of Minnesota
- Welcome House, Inc.

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- West Side Support Services
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**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 participation and partnership 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**
Vanessa Smith
SmithVanessa@uams.edu

**California**, Tony Anderson
The Arc of California
tony@thearc.ca.org

**Connecticut**
Kristine E. Foss
kfoss@abilitybeyonddisability.org

**Florida**
Florida Alliance for DSPs
cwilley@floradaaf.org

**Georgia**
Georgia Alliance of DSPs
Joy Eason Hopkins
joyeasonhopkins@gmail.com
www.gadsp.com

**Hawaii**
Hawaii Alliance for Direct Support Professionals
Nancy Atmospera-Walch
walchnancy@yahoo.com

**Illinois**
Illinois DSPs
Dawn Kellogg
idsprotim@idspros.org
www.idspros.org

**Indiana**
DSPIN
Elizabeth Patel, INARF elizabeth@inarf.org

**Kansas**
Kathy Stiffler
KLStiffler@rsskansas.org

**Kentucky**
SPEAK
Cheryl Prusinski
cprusinski@sevencounties.org

**Louisiana**
Nancy Robertson
504.942.8289

**Michigan**
Michigan Alliance of DSPs (MADSP)
Michael Bray
mikebray@wayne.edu
www.ddi.wayne.edu/michigan_alliance.php

**Minnesota**
DSP Association of Minnesota (DSPAM)
Bridget Siljander, President
bridgetsiljander@yahoo.com

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

**Missouri**
DSPs of Missouri
Don Carrick
dcarrick@nasdd.org

**Nebraska**
NDSP
Mary Lawson
Nebraskadsp@gmail.com

**New Hampshire**
Robin Carlson
carlet@metrocast.net

**New Jersey**
Colleen McLaughlin
Colleen.mclaughlin@umdnj.edu

**New Mexico**
www.nmddirectsupport.org

**New York**
DSP Alliance of New York State (DSPANYS)
Michael Tuggey
tuggeyadk@yahoo.com
directsupportprofessional.org

**Ohio**
Ohio Alliance of DSPs (OADSP)
Bethany Toledo
pcbethany@prodigy.net
www.oadsp.org

**Oklahoma**
DSPs of Oklahoma (DSP-OK)
Patricia Rost
prost@epmi.org
Diane Potts
dpotts@tulsacc.edu

**Pennsylvania**
Pennsylvania Alliance for DSPs (PAPBDSP)
Ernest Gibson
papdps@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
### 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:

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**Frontline resources**

**continued from page 13**

**DVD - Management of Anxiety and Stress in Persons with Developmental Disabilities**

This DVD includes a general discussion of setting/predisposing factors for stress, anxiety disorder and related symptoms, and criteria for related disorders. Treatment modalities are discussed, as well as the part everyone in the individual’s life can play in successful treatment programs.

**DVD - Dual Diagnosis: Present and Future Directions**

This DVD includes an overview of the field of dual diagnosis. Current practices are presented, and a vision for future services for persons who have intellectual and developmental disabilities co-existent with mental illness are provided.

**The Little Book of Practical Solutions: A Common Sense Guide to Understanding and Preventing Problem Behavior**

*By Edward Hughes*

This book provides a concise yet comprehensive review of the issues related to problem behavior by individuals with developmental disabilities and/or mental health needs. The book is designed to be a resource for family members, case managers, advocates, direct support professionals, and clinicians without advanced training in psychology or behavior analysis.

**Self-Directed Instructional Courses - (NADD website)**

- Introduction to Dual Diagnosis, Depression in Persons with Mental Retardation, Personality Disorders in Persons with Mental Retardation, General Principles of Psychotic Disorders in Persons with Mental Retardation

These staff training materials are designed to provide basic information on a variety of issues. Each course is self-contained, has pertinent educational objectives, and includes a pre-/post-test. While the materials were designed for direct support staff, they also can be utilized for professional staff, parents, and self-advocates.

*Editor’s notes: Resource descriptions have been adapted from either the NADD website or Amazon.com; *available on the NADD website: [https://netforum.avectra.com/eweb/DynamicPage.aspx?Site=nadd&WebCode=naddCatalog](https://netforum.avectra.com/eweb/DynamicPage.aspx?Site=nadd&WebCode=naddCatalog)
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