

**A publication of the National  
Alliance for Direct Support Professionals**

# Frontline Initiative

Volume 8 • Number 2 • 2009

Spirituality  
Frontline Initiative

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## Spirituality, honoring the heart and the call of direct support

*By Reverend Bill Gaventa*

Direct Support Professionals (DSPs) work in a spiritual laboratory: A place where beliefs and understanding about the essence of life, and the meanings of humanity, community, love and care are tested every day. Who are you, and the people you support, as human beings? What is the purpose of everyone's life? These are not questions from a textbook but in the hands-on work that DSPs do every day. This is the place where faith, hope, and love have to walk the talk.

But spirituality is too often ignored or not talked about. It is almost like not

being able to see the air we breathe. It can be defined in many ways but they all come back to whatever we experience as holy and sacred at the heart of life. It is also about the ways in which we find meaning in the question of what it means to be human. Spirituality can also be seen as connection: connection with self, with others, with God (however God is defined), with nature, with place, with past, and with culture. Spirituality also has to do with choice, exercising free will and decision making, responding to the sense of call, vocation, and purpose we feel in our lives. It has to do with the spirit we bring to our work and the way that

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# Frontline notes

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Dear readers,

Welcome to the spirituality issue of *Frontline Initiative*. This is the first issue of *Frontline Initiative* in its new format. In this format, we hope to offer practical information that can be used in your day-to-day life supporting people with disabilities. This new emphasis on training is meant to assist DSPs in further developing professional skills and increasing confidence in supporting people with disabilities.

This issue approaches spirituality from multiple perspectives; it also provides training material and discusses spirituality within the framework of NADSP's Code of Ethics. We give special thanks to Reverend Bill Gaventa whose wisdom and insight helped develop this issue. We hope you find this

issue meaningful and practical as you do the complex work of supporting others to lead self-directed, fulfilling lives.

Please share your thoughts about this issue with us and feel free to contact us with topic suggestions for future issues. You can do this at [www.nadsp.org](http://www.nadsp.org).

We are also moving toward electronic dissemination, so please go to [www.nadsp.org](http://www.nadsp.org) to sign up for *Frontline Initiative* via email.

Thanks for reading this issue on spirituality and for your commitment to supporting people living with disabilities in the community.

The editors

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in peoples' lives



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

# NADSP update

It is a long-standing goal of the National Alliance for Direct Support Professionals (NADSP) to work in collaboration with other national agencies to promote the field of direct support and thereby enhance the lives of people with disabilities. Therefore NADSP was pleased to join efforts with the American Network of Community Options and Resources (ANCOR) National Advocacy Campaign (NAC). Mark Olson and Jenifer Adams were selected to represent NADSP on the NAC Steering Committee. The mission of ANCOR's National Advocacy Campaign is to enhance the lives of people with disabilities by obtaining the resources to recruit, train, and retain a sustainable direct support workforce.

NADSP was proud to support the NAC in promoting a resolution by the U.S. Senate (S. Res. 613) designating the week beginning September 8, 2008, as "National Direct Support Professionals Recognition Week." The National DSP Recognition Week resolution coincided with ANCOR's Governmental Activities Seminar and the Second Annual DSPs to DC event. DSPs from across the country gathered in Washington DC and rallied on Capitol Hill to demand better pay for the hard work DSPs do. Both U.S. Representatives Lois Capps (D-CA) and Lee Terry (R-NE) who introduced HR 1279 to Congress, spoke at the rally. They encouraged DSPs and expressed gratitude for the work of DSPs.

Andrea McMurray, DSP and award winner of the NAC DSP TV Online contest, spoke

about the challenge DSPs face. "When someone says they're a veterinarian or an accountant, it's fairly clear what they do. But tell someone you're a DSP and they don't have a clue," McMurray said. Recognition is one of the biggest challenges DSPs face. Giving a face to DSPs is part of the intent behind the DSPs to DC event. Most DSPs that attended the event also had the opportunity to visit the DC offices of their state representatives and/or senators. It was a great opportunity for DSPs to introduce themselves and tell the story of the work of DSPs.

NADSP and its allies promoted the National DSP Recognition Week locally by encouraging state and local chapters to recognize and commemorate the occasion. Many state and local chapters held picnics and recognition festivities to celebrate. DSPs also took the opportunity to contact and visit state policy makers.

Another activity of the National Advocacy Campaign was an online video contest titled "DSP TV Online." The entries varied from interviews and comedy skits, to music videos. Six very creative DSPs were chosen as winners. Each winner received a \$500 cash prize. The grand prizewinner received \$1,000, plus hotel and travel expenses paid to the DSP to DC event held in September 2008. All winners were recognized at the DSP to DC event. For further information about the National Advocacy Campaign, visit <http://www.youneedtoknowme.org> on the Web.

Through partnerships and supporting one another, DSPs can make a difference in the lives of other DSPs and ultimately, in the lives of the people they support.

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*Jenifer Adams, NADSP secretary, works at OHI in Hermon, Maine. She is also president of MEDSP a state chapter of NADSP. She can be reached at MEDSP@yahoo.com.*

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What's new at **nadsp.org?**

**NADSP blog**

**Interactive calendar**

**DSP registry**

**Online membership registration**

# The ethics of supporting spirituality

By Mark Olson

As DSPs, is it important to include the spirituality of the people we support in our professional practice? If so, how do we do it in an ethical manner? Can we draw from our own beliefs and spiritual walk in providing that support? Answers to these questions and others are in NADSP's Code of Ethics. This document is a great starting point for plotting a course of ethical spiritual support to those you serve.

The first question is whether we should support the spirituality of others at all. NADSP's Code of Ethics, or what I like to think of as a compass for DSPs, speaks clearly to this. The preamble reads, "A primary purpose of DSPs is to assist people who need support to lead self-directed lives and to participate fully in our communities and nation." When an individual seeks a spiritual connection, whether it is religious, cultural, natural or self-defined, it is the role of DSPs to support the person's self-direction and connection to the community.

## Person-centered supports

*As a DSP, my first allegiance is to the person I support; all other activities and functions I perform flow from this allegiance.*

- » Sometimes we may question the individual's choice, we may believe our own spiritual path is correct, or we may be tempted to "suggest" our own beliefs and values on those we support. This leaves DSPs unsure of how

to reconcile these questions with the person-centered focus. At these times, it can help to revisit the ethical standards by which we practice. Person-centered supports is an overarching premise of our practice.

## Promoting physical and emotional well-being

*As a DSP, I am responsible for supporting the emotional, physical, and personal well-being of the individuals receiving support. I will encourage growth and recognize the autonomy of the individuals receiving support while being attentive and energetic in reducing their risk of harm.*

- » For DSPs, this means knowing and respecting the values of the people being supported and facilitating their expression of choices related to those values.
- » As a part of promoting physical and emotional well-being we are expected to know and respect the values of the people we support and help them to express their choices related to these values. And spirituality may be one of those values.

## Integrity and responsibility

*As a DSP, I will support the mission and vitality of my profession to assist people in leading self-directed lives and to foster a spirit of partnership with the people I support, other professionals, and the community.*

- » For DSPs, this means being aware of their own values and

how those values influence their professional decisions.

- » In acting with integrity and responsibility, we look inward and think about our own values and how they influence our decisions. Often our values will share enough in common with the person we support to make concerns about ethical support of spirituality moot. In my experience, there are more commonalities across spiritual, religious, and cultural paths than differences. Support often starts with dialogue and relationship building. Both are key parts of providing ethical support. When we share values it can often lead to an easier path to spiritual support and it is important to note the similarities. When there are differences it may be more difficult to offer spiritual support. But it still remains our responsibility.

## Respect

*As a DSP, I will respect the human dignity and uniqueness of the people I support. I will recognize each person I support as valuable and help others understand their value.*

Continued on page 11

A NADSP Code of Ethics pocket card is included with NADSP membership. Pocket cards and posters may also be purchased, visit [www.nadsp.org/library](http://www.nadsp.org/library)

# What does spirituality mean to you?



By Noel Querrie-Minor

Spirituality means different things to different people. Spirituality can even serve a different purpose or be used differently by each person you support. Yet, no matter how different each person's definition of spirituality, we all share the right to hold our own beliefs. With that common understanding, DSPs are called upon to provide support to people of many faiths and spiritual beliefs. How will you ethically provide these supports? Here are some other thoughts on these issues from DSPs, parents, and self-advocates.

## How do you define the word spirituality?

"I guess it's more of a state of mind for me — a matter of ethics and morals rather than

that of religion. Especially regarding those we support, viewing them as spiritual beings, and nothing less."

– Sara, DSP

"Spirituality is what you believe in. It does not mean you have a certain religion or that you believe in the supernatural."

– Kathryn, DSP

"Spirituality means believing in God and having faith that God will pull you through the rough times in your life. Spirituality helps you grow closer to God if you pray and have faith in him. You believe that he really exists."

– Joaquin, self-advocate

## How do you define spirituality in your own life?

"To be the most ethical and spiritual person I can be. I mean, I talk to God daily and ask His help in this: for Him to help me to be the best person I can be at my job, and in supporting Robert, as well as other individuals I work with each day."

– Sara, DSP

"It has helped me get through rough times. It has helped me get happy when I am down. It helps me cope with life because I have trouble coping with life. Without God, I'd be nothing."

– Joaquin, self-advocate

## Do you believe it is ethical to impose your spiritual values on others?

"No, you should not impose spiritual values and beliefs on anyone. They should be able to find it themselves. They will have a need to find it themselves. People should be given an opportunity to be exposed to it if they choose and pursue in the direction they wish."

– Parent

"No, because that's like forcing someone to believe what you believe. I do not believe that is a good thing to do. I love my religion but there are some things I don't agree with. We all believe what we believe and have differences in opinions — especially when it has to do with spirituality."

– Joaquin, self-advocate

"I do not believe it is ethical to impose anything on anyone, especially your beliefs. You can certainly support someone, be a mentor, as well as lead by example. But to impose your beliefs onto someone else, in my mind, is definitely unethical."

– Sara, DSP

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*Noel Querrie-Minor is a DSP working for ARCA in Albuquerque, New Mexico. She can be reached at Mykidzmom71@hotmail.com.*

# Spirituality and spiritual connections

## Assess it, train it, and practice it

By Reverend Bill Gaventa

In the last two decades, health and human services have worked hard to determine appropriate ways to discover and support individuals' spirituality and how it can improve their healthcare and/or quality of life. Assessing spiritual needs and interests is not the same as asking how religious you are or what/whether you believe.

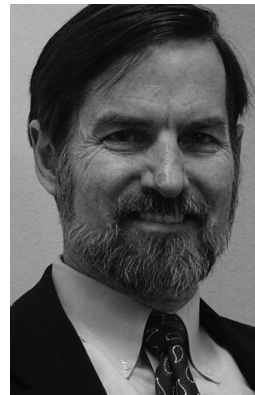
There are many forms of spiritual assessments. (See Erik Carter's book, *Including People with Disabilities in Faith Communities: A Guide for Service Providers, Families, and Congregations*, from Brookes Publishing). Each agency needs to decide how to use or design a spiritual assessment that fits into their person-centered and/or IHP planning. One format that is easy to adapt and remember is called FICA. There are four areas of questions to be answered by the person receiving support (see box below).

It may help to involve family members or friends in this discussion. Just don't stop with the question, "Do you go to church or synagogue?" People with intellectual disabilities often have not had the opportunity, or they did so as a child but not as an adult. And if your agency does not have a chaplain or professional who works in spiritual supports, think about inviting an interfaith group to help you plan how to do this.

Assessment is the first step. Next is training. Develop an in-service to help staff become comfortable with asking these questions; they can practice with each other. The training should allow time to talk about how our attitudes are impacted by our experiences and traditions, the appropriate staff roles (guiding, facilitating, supporting, but not proselytizing), the policies and supports needed to carry this out, and the skills needed to connect

with clergy and congregations.

Finally, consider inviting people from congregations who welcome people with intellectual disabilities to explain how DSPs can work with them to honor and respect individuals' choices and dreams. The biggest complaints I hear from people with disabilities and congregations are about lack of staffing on weekends or staff who don't see this as their jobs. But it is everyone's responsibility: the person receiving support, DSPs, and faith communities. DSPs can help make it happen, transforming individuals and congregations in the process. It does not mean DSPs have to believe or practice the way someone else does. Rather, it is an opportunity for DSPs to demonstrate the best of their professional role and commitment: helping the people they support to connect meaningfully with people in the community. In fact, like a good job coach, DSPs can work themselves out of the "faith connector" part of their jobs. And when they do, everyone wins.



Reverend Bill Gaventa

### FICA

#### spiritual assessment tool

**Faith:** What is your preference, choice, tradition, or identity?

**Influence and importance:** How important is it? How does it influence your life?

**Communal expression:** Is there a group or organization in which it is expressed? For example, a congregation or organization? Are you part of one? Would you like to be? In what ways?

**Assistance:** How can I/we help you with this?

Reverend Bill Gaventa is the director of Community and Congregational Supports at the Elizabeth M. Boggs Center on Developmental Disabilities, Robert Wood Johnson Medical School/UMDNJ. He can be contacted at 732.235.9304.

# Training natural supports in your faith community

By Lisa Burcke

Quality of life is in the details. We are made to concentrate on the bread and butter of fee-based services for people with disabilities and never seem to get to the bread and wine of life. Recently, members of the congregation from the Chapel of the Cross Episcopal Church in Madison, Mississippi contacted the Arc of Mississippi with an interesting question: What could we teach a group of volunteers from their church that would qualify them to support their pastor's family with regard to their son with disabilities?

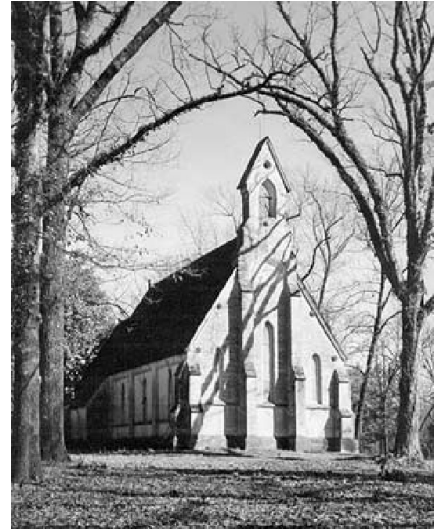
Easy answer: use the College of Direct Support. There are so many courses and lessons that speak directly to natural supports. A curriculum of 29 lessons was put together which included portions of You've Got a Friend, Safety, Intro to Developmental Disabilities, Positive Behavior Supports, Supporting Healthy Lives, Maltreatment of Vulnerable Adults, Teaching People with Developmental Disabilities, and Community Inclusion. Every lesson selected addressed specific needs expressed by the volunteers.

"The lessons were of immense benefit to me because I had no experience around people with disabilities," said Barbara, a church volunteer. "I had great fears that I would do something inappropriate or not be vigilant enough which could cause injury to the child. The lessons gave me the confidence and enthusiasm to spend time with our pastor's son with-

out fear. The lessons were crucial in that they instructed me to do the things the child wanted to do as opposed to what I thought he should do. For example, at the Natural Science Museum he only wanted to watch the alligators. Normally, I would have wanted him to view everything in the museum but I came to understand that watching the alligators was the most meaningful to him. The lessons also helped me communicate with him and know how to help him understand and utilize proper behavior. I highly recommend these lessons for people who have no experience with persons with disabilities not only will they help specific situations, but they changed my total outlook on all who have disabilities. I am no longer afraid to look people with disabilities in the eye and greet them cheerfully."

The College of Direct Support is managed not according to the number of DSPs employed but by the number of people being served and supported. This design purposefully allows the curriculum to be used by all of the people who interact with a person with disabilities. Pastors, Sunday school teachers, peers involved in youth and adult groups, nursery workers, and others would benefit from such an opportunity but none more than the person they support.

Quality of life is often measured by the number of unpaid (natural) supports in a person's life. If Medicaid doesn't pay for the support, does that mean the support



Chapel of the Cross, Madison, MS

is not valid or needed? Consider the spiritual lives of the men, women, and children you support. The College of Direct Support can facilitate the strengthening of relationships with other members of their congregation. The essence of who and what we are is contained within the relationships we have with others as well as our Creator. Help others be accessible to people they care about and you will have made a difference.

*Lisa Burcke is project director of Direct Support Professional Opportunity at the Arc of Mississippi. She can be reached at 866.497.1035.*

For more information  
about the College of Direct  
Support, visit  
**collegeofdirectsupport.com**  
or call toll free  
**1.877.353.2767**

# Frontline resources

## **Dimensions of faith and congregational ministries with persons with developmental disabilities and their families: A bibliography and address listing of resources for clergy, layperson, families, and service providers.**

*W. Gaventa (Ed.)*

A 180-page resource guide divided into areas of congregational ministry and outreach, e.g., worship, outreach, pastoral care, religious education, awareness videos, with sections on respite care, community building, person centered planning, coping with grief, and more. (2005).

*Price: \$15. To order, call 732.235.9300. Also available as PDF in the products section of the Boggs Center Web site at <http://rwjms.umdj.edu/boggscenter>*

## **Brain injury: When the call comes. A congregational resource**

*W. Gaventa & W. Berk (Eds.)*

A 28-page booklet developed in collaboration with the Brain Injury Association of New Jersey. (2001).

*Price: \$5. To order, call 732.235.9300. Also available in PDF format in the Products section of the Boggs Center Web site at <http://rwjms.umdj.edu/boggscenter>*

## **Autism and faith: A journey into community**

A 52-page booklet with stories, strategies, and resources for congregations and families. (2008).

*\$5 per copy, shipping included, for orders outside of New Jersey. First copy is free to people and organizations in New Jersey. To order, call 732.235.9300.*

## **Impact: Feature issue on faith communities and persons with developmental disabilities, 14(1)**

*Institute on Community Integration, University of Minnesota*

This entire 36-page issue of the newsletter is about faith communities and people with developmental disabilities. It is broad snapshot of trends, resources, and ideas in this country.

*Price: First copy is free; additional copies are \$4 each. To order, call 612.624.4512 or go to: <http://ici.umn.edu/products>*

## **Believing, belonging, becoming (11 min)**

*Wisconsin DD Council*

This video features four vignettes of congregations including individuals with developmental disabilities.

*Price: \$10. To order, make check payable to "Religion Division, AAIDD," c/o Bill Gaventa, The Boggs Center, P.O. Box 2688, New Brunswick, NJ 08903.*

## **Bridges to faith (10 min, VHS)**

This video is about a program in Massachusetts that utilizes "faith companions" to assist adults with developmental disabilities to participate in faith communities.

*Price: \$10. To order, call 508.999.5007, e-mail [colleen.perkins@dmr.state.ma.us](mailto:colleen.perkins@dmr.state.ma.us), or write to: Bridges to Faith/DMR, 750 County Street, New Bedford, MA 02740.*

## **Planning for life (30 min)**

*Elizabeth M. Boggs Center on Developmental Disabilities*

This documentary is about DSPs assisting people to accomplish their dreams through person-centered supports with five vignettes, one of which is about assisting a man to be part of his church. (2004).

*Price: \$89.95 for DVD; \$44.98 for VHS. To order, visit Program Development Associates at [www.DisabilityTraining.com](http://www.DisabilityTraining.com)*

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# National Alliance for Direct Support Professionals

## About NADSP

NADSP is a professional association for DSPs that is committed to supporting professionals who choose careers in supporting people with disabilities to achieve their life dreams. We recognize that people needing support are more likely to fulfill their life dreams if they have well-trained, experienced, and motivated people at their side in long-term, stable, compatible support relationships. NADSP, a 501(c)(6) non-profit organization, has developed a national agenda to address these workforce issues and to develop strategies to —

- Enhance the status of DSPs.
- Provide better access to high-quality educational experiences for DSPs.
- Strengthen working relationships and partnerships among consumers, family members, and DSPs.
- Promote system reform, including incentives for education, increased compensation, and access to career pathways.
- Support a national voluntary credentialing process.

## Become a member today!

- Join a growing national movement to elevate the status of DSPs.
- Learn about national and international successful practices, such as certificate programs, apprenticeships, credit-bearing coursework, and ways to improve agency culture.
- Help educate policymakers and legislators about the importance of high quality human services.
- Learn about and gain access to public forums and conferences on DSP issues.
- Learn how to develop and enhance DSP regional affiliations.
- Develop leadership skills in the field of direct support.

## Membership form

### Individual memberships\* \$20

Includes *Frontline Initiative*, Code of Ethics card, NADSP membership card. *\*If your state has an NADSP chapter, you will receive dual membership in the state chapter and NADSP.*

**DSP**

DSP  Frontline supervisor

**Associate**

Self-advocate  Family member

**Other professionals**

For professionals working in community human services, such as social workers, administrators, and healthcare professionals.

**What is your profession?** \_\_\_\_\_

### Other memberships

**Affiliate membership \$200**

For individuals, agencies, providers, associations, and NADSP state chapters who wish to demonstrate a commitment to support the efforts of DSPs. Includes certificate of membership and two subscriptions to *Frontline Initiative*

**Supporting organization membership \$500**

For agencies and organizations dedicated to advancing the interests of DSPs and the people they support at a national level. Includes certificate of membership, four subscriptions to *Frontline Initiative*, and listing as a NADSP supporting organization in *Frontline Initiative*.

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, P.O. Box 13447, Minneapolis, MN 55414

\_\_\_\_\_  
Name

\_\_\_\_\_  
Organization

\_\_\_\_\_  
Address

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

( \_\_\_\_\_ ) \_\_\_\_\_ - \_\_\_\_\_  
Phone

\_\_\_\_\_  
E-mail

**Total enclosed \$** \_\_\_\_\_

# NADSP member organizations and state contacts

## NADSP supporting organizations

We would like to acknowledge the following NADSP Supporting Organizations for their generosity and ongoing dedication to the goals and mission of NADSP —

- Alexandria Community Services Board
- Bost, Inc.
- College of Direct Support
- Community Advantage
- Crystal Run Village, Inc.
- Innovative Learning, LLC
- Koinonia Homes, Inc.
- Laura Baker Services Association
- NHS Human Services
- OHI
- People Enhancing People
- SECOH
- Special People In Northeast, Inc.
- The PLUS Company, Inc.
- Woodfords Family Services

## Start a NADSP state affiliate in your area now!

For more information, contact Don Carrick, NADSP State Affiliate Coordinator, at 660.582.7113 or [dcarrick@nadsp.org](mailto:dcarrick@nadsp.org) or visit [www.nadsp.org](http://www.nadsp.org).

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**Spirituality, honoring the heart and the call of direct support**  
continued from page 1

work touches our own spirituality.

One reason that spirituality is ignored is that it is too often defined only as religion. Many people discover and express their spirituality through a faith tradition and faith community. Faith communities can be one way of helping people with their spirituality. It is not the only way. As DSPs we know we are not supposed to proselytize or force anyone to participate or believe. That does not mean we cannot help the people we support express their spirituality and find the community in which to express their spirituality. This demonstrates the heart of respect and professional care.

DSPs bring their spirit to the people they support. It shines through, whether they know it or not, yet DSPs are not the only spiritual figures in the lives of people they support. In fact, the role of DSPs is to recognize and honor the spirituality of the people being supported, help

them find ways to express it, and find communities or practices in which they can learn, grow, and give. That means listening, introducing, guiding, and facilitating. It is not just about taking someone "to church," especially if that task feels uncomfortable. DSPs spiritual roles are teacher, advocate, and guide. DSPs connect the people they support with congregations and spiritual communities.

When DSPs help people live out what is most important to them, these professionals create opportunities for care and connection. When DSPs find ways to talk about what motivates them as caregivers, what they learn, and what sustains them in their vocation of support, they honor the heart and call of what it means to be professional. The blessings can go in many directions!

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*Reverend Bill Gaventa is the director of Community and Congregational Supports at the Elizabeth M. Boggs Center on Developmental Disabilities, Robert Wood Johnson Medical School/UMDNJ. He can be contacted at 732.235.9304.*

**The ethics of supporting spirituality,**  
continued from page 4

- » For DSPs, this means honoring the choices and preferences of the people they support.
- » Lastly, DSPs can reflect upon the ethical statement of respect. Respect is often easiest when someone has similar values and preferences to us. But what about when their choices and beliefs are vastly different? This is when we are really called upon to be a professional and honor the code.

When we support a person in living the life they choose, the Code of Ethics guides us to include what they value in charting the journey of support. Spirituality is often one of the values that a person deems important to them. It may be a person's defining value. In reflecting upon your role as a DSP, review the Code of Ethics, try it out, and learn from your experiences. Ethics can guide us but it is still up to us to examine them, apply them, and learn from them.

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*Mark Olson is president of NADSP. He can be reached at molson@nadsp.org.*

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