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Code of Ethics
Frontline Initiative

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NADSP Code of Ethics

Let's pledge to live by the Code

By Tom Harmon

2011 was a wakeup call for all in New York State's intellectual and developmental disabilities service community. It began with a front-page article in the *New York Times*, "At state-run homes, abuse and impunity" (March 12, 2011).

New York, however, was not alone. Here are some other recent headlines from around the country —

- "Starvation case shows abuse in state system" (*Dayton Daily News*, Ohio, January 8, 2012)
- "Streamwood health worker charged with abusing disabled boy" (*The Daily Herald*, Illinois, December 20, 2011)
- "Summit needed on vulnerable Iowans: Incidents raise questions about state officials' responses" (*The Gazette*, Iowa, September 22, 2011)



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Frontline notes

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Welcome to our *Frontline Initiative* on the Code of Ethics. Direct Support Professionals (DSPs) often experience ethically complicated situations, and they frequently find themselves under intense scrutiny from supervisors, family members and regulators. The public has recently read many accounts of DSPs behaving unethically in their profession and, most importantly and sadly, to people they support. The reality, however, is that most DSPs perform ethically as they grow and foster relationships with the people they support.

Since 2001, the NADSP Code of Ethics has been a living, breathing, and dynamic resource to help DSPs in their daily decision-making activities. DSP Lori Raymond and Program Coordinator Bethany Toledo (on behalf of DSP Belinda Sowers) offer inside perspectives of how the Code of Ethics has been a significant tool in their everyday work. Self-advocate Carrie Varner also shares her important perspective on what the Code of Ethics means to her.

Because being an ethical DSP requires effective decision-making skills, this issue includes several articles that can be used to facilitate discussion at a staff meeting or among coworkers. In an overview of the RIGHT Decision Method,

Annie Johnson Sirek discusses a useful framework for solving ethical dilemmas. Ruth Luckasson offers an important distinction between personal and professional ethics, and NYSACRA President Tom Harmon explores how the principles within the Code of Ethics can be used when DSPs find themselves in situations for which they may not feel well trained.

As an organization, NADSP has taken action in encouraging DSPs to do the right thing, all of the time, and Lisa Burck, president of NADSP, describes a new initiative to recognize excellence in DSP work. In addition, Richard Cohen, Executive Director of the Disabilities Rights Center of New Hampshire, shares some important history in regards to some of the policy initiatives as related to the Code of Ethics and the disability rights movement.

We hope you will enjoy this issue as you learn more about applying the NADSP Code of Ethics in your work as a DSP.

~ The editors

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Frontline Initiative is available in alternate formats upon request.

NADSP update

Carrying forward JFK Jr.'s vision

By Joseph M. Macbeth

As I was recently going through a box of historical information about the NADSP, one letter, dated May 22, 1996 really caught my attention. This letter was a call to action to launch a new initiative to establish a "National Alliance for Direct Service Workers". As far as I could tell, this may have been the first time these ideas were taking shape and put into action. The author went on to explain that a committed group of professionals wanted to "help develop a comprehensive agenda, informed public policies and effective strategies to strengthen and redefine the emerging role of the direct support workforce". The author of that letter was the late John F. Kennedy Jr. I am proud to say that we are carrying on John's vision and we hope that you continue with us as we "Make a World of Difference in People's Lives".

As I read and learned more about the beginnings of the NADSP, it became clear to me that we have already contributed a great deal to the field of intellectual and developmental disabilities and one of our earliest contributions is the Code of Ethics. In the late 1990s, Direct Support Professionals (DSPs) from around the country attended focus groups over a two year period to give their input on the values of the profession and they eventually identified nine broad areas. These areas were used to create the framework for the Code of Ethics. Subsequently, more DSPs and other disability advocates came together again to further develop and finalize



the Code of Ethics in 2001. Now widely disseminated, this body of work offers DSPs, individuals with disabilities, service organizations and family members a standard of conduct and professionalism. As you'll read in this issue of *Frontline Initiative*, the Code of Ethics is a powerful and dynamic body of work that contain the ideals of the profession. They are not something that one should be asked to simply read, sign and follow.

I have had the great privilege of travelling around the country with my colleague, John Raffaele, where we've provided thousands of DSPs an opportunity to be immersed into the Code of Ethics. During these sessions, participants are asked to navigate through a maze of ethical dilemmas that confront them on a regular basis. After these "ethical encounters," we provide the opportunity for them to share some of their own experiences with ethical dilemmas while working as a DSP. Sometimes these stories are heart wrenching and sometimes they are subtle - but all of them reflect the incredible responsibility of the

direct support role and how they are often asked to make critical decisions without notice. Often, the decisions that are made can be a matter of happiness, health, safety, life and death for the person who is receiving supports. As a facilitator, I can literally see the moment when a participant "gets it" – there's a nod of understanding that their work has a roadmap and once that map is consulted, the guess work of being an ethical practitioner is removed.

Joseph Macbeth is the Executive Director of NADSP. He can be reached at jmacbeth@nadsp.org or 518-449-7551.

In the coming weeks and months, the NADSP will be joining our State Chapters in "Operation Ethics," where, in a variety of ways, we hope to reach as many DSPs with information about the Code of Ethics and provide them with our wallet cards and bracelets.

On our way to Circle K

Living the Code

By Bethany Toledo and Belinda Sowers

It was April, 2009 when Belinda and Teresa first met. Teresa was a forty-five year old woman with Rhett Syndrome who lived at home with her parents. This is a story of Belinda Sowers, a Direct Support Professional (DSP) in Zanesville, Ohio, whose commitment to living the Code of Ethics greatly impacted not only the person she supported, but an entire community.

When Belinda began working with Teresa, much of Teresa's day consisted of sitting in her wheelchair or on the couch. After participating in Teresa's routine several times, Belinda wondered what else Teresa could do. After watching Teresa carefully, Belinda noticed the changes in Teresa's facial expressions when her mother turned the pages of her magazines. Belinda wondered if maybe Teresa liked books, and started bringing interactive books to work with her. Teresa reacted with squeals of laughter!

Belinda began researching Rhett Syndrome and could not find anything saying that Teresa could not learn. Teresa already knew how to shake her head "no," but rolled her eyes for "yes." Belinda began teaching Teresa to nod her head "yes" instead. It worked! Belinda began asking Teresa yes/no questions as a way to start providing Teresa some choice in her daily schedule. For example, instead of leaving Teresa in the living room while she made dinner for her, Belinda would ask her if she wanted to

join her in the kitchen. Teresa nodded yes, and her mother agreed.

Belinda took time to build a relationship with Teresa's mother, and asked her questions to gain her trust. It was because of this built trust that Teresa's mom agreed to Belinda's request to take Teresa outside and sit on the porch. The next time, Belinda asked to go out back to the swing, then down the back alley, then all of the way into town. It wasn't long before they were spending two hours out, then three. They would visit the man that worked in the hardware store, the library, then to Circle K for a special treat, and sometimes they made it all of the way to the end of town to the IGA. Teresa's parents had never seen her so happy. Everyone noticed a huge difference in Teresa; she had fewer ear infections, slept better, she even started to get a tan. And her laugh, it was contagious!

One day, the manager from Circle K asked Belinda to bring Teresa on a certain day at a certain time. They had had a cement ramp poured and they wanted her to be the first to use it. Belinda has continued to ensure Teresa is included in her community around her. Together, they have traveled to the local high school for a musical concert, to the area pool to watch the kids swim, to the park for fireworks and outdoor movie nights, and there are many more plans in the making.

Belinda's actions illustrate several of the principles central to the Code of Ethics. In her commitment



to supporting Teresa, Belinda has prioritized person-centered planning, and has clearly promoted Teresa's personal and emotional well-being. With Belinda's support, Teresa has had opportunities to self-direct her life and build relationships with members of her community. Belinda's relationship with Teresa's family respectfully resembles that of a partnership. If you drive through New Concord on any decent spring, summer, or fall day, you are likely to see Belinda and Teresa continuing to make their rounds to visit their friends and neighbors.

Bethany Toledo is the MRI Program Coordinator and the Mideast PATHS Regional Coordinator in Zanesville, Ohio. She can be reached at pcbethany@prodigy.net.

Belinda Sowers is a DSP at Muskingum Residential, Inc. in Zanesville, OH. Belinda received the Ohio Provider Resource Association (OPRA) DSP Award this past fall. Belinda is also a Professional Advancement through Training and Education in Human Services; Certificate of Initial Proficiency (PATHS CIP) graduate.

From personal to professional ethics

A holistic approach

By Ruth Luckasson

The ethics we learn in our personal lives — to help others, be honest, be fair, be kind, be respectful, try to do good in the world — guide us in our actions with other people and make our communities better places. These *personal ethics* are usually not written down in one place, but are carried in our hearts. Parents and community leaders informally teach us *personal ethics* throughout our lives.

Strong personal ethics are necessary, and can be a basis for ethical actions in our work as Direct Support Professionals (DSPs). However, the professional work of providing direct support presents unique challenges and questions and requires the guidance of professional ethics.

Professional ethics are different from personal ethics in that professional ethics are —

- Written down in a “code” in order to become part of work, training, and employment contracts;
- Formally taught through professional development and courses so that every employee has the opportunity to learn and apply the ethical principles;
- Carefully designed to cover unique situations in the profession.

A professional code of ethics is critical to help individual workers make better decisions in their daily work. Professional ethics guide our actions to be more consistent with the values of the profession. Having a code of ethics marks the profession as a true profession in

the eyes of others and unites the profession around a high standard of actions. As a result, the profession is more likely to be respected for its contributions.

Direct support is a profession, and adhering to the NADSP Code of Ethics is essential for every member of the profession.

Writing a code of ethics and adopting it is a critical step in the development of a true profession. Direct support is a profession, and adhering to the NADSP Code of Ethics is essential for every member of the profession.

Given the critical nature of professional ethics, what should be done in order to highlight professional ethics in work with individuals with disabilities?

For DSPs themselves, it is essential to learn and follow the NADSP Code of Ethics.

For provider agencies, it is essential to include the NADSP Code of Ethics in all training and to incorporate it in all policies and procedures.

For state and federal funders, it is essential to respect and incorporate the NADSP Code of Ethics in funding and monitoring.

As a professional organization, NADSP must promote wide discussion of the principles of the NADSP Code of Ethics and continually update the Code so that it reflects best practices in the profession. It is also critical for NADSP to provide opportunities for all members to engage in continuous learning and practice of highest standards of professional ethics.

In conclusion, personal ethics are an essential foundation to professional ethics. But professional ethics go further. The NADSP Code of Ethics provides an ethical framework for workers, agencies, funders, organizations, and individuals receiving supports. Being a professional in this field means fulfilling professional responsibilities. This includes applying the NADSP Code of Ethics to all aspects of providing direct support.

Ruth Luckasson, J.D., is a Regents' Professor and Professor of Special Education at the University of New Mexico. She can be reached at ruth@unm.edu.

Storytelling, DSPs, and the Code of Ethics

A recipe for learning

By Direct Support Professional Alliance of New York State (DSPANYS)

Civilization would not be where it is today if not for storytelling. Long before written language and pens, paper, the printing press, and electronic media, simple storytelling imparted wisdom. The history, traditions and laws of most of today's societies had their origins in oral tradition, the sharing of stories.

Storytelling still has its place. From Aesop's fables and Jesus' parables to modern day courses in law, nursing, social work and other professions, stories or case studies play a key role in learning. They make abstract theories real; they put flesh and blood on bare bone principles! And so it should be with Direct Support Professionals (DSPs) and NADSP's Code of Ethics.

Every day, in many ways, DSPs live out the Code. That is good. But often, they don't realize it, and that is not so good. It's not so good because when DSPs run into difficult situations, need to make decisions but don't know the Code, they will have difficulty making the right decision. The Code is there to help DSPs to consciously or purposefully make the right decision, and not happen on it by luck or accident – or worse, make the wrong decision.

That's where storytelling comes in. Heather Daigneault, a DSP with the ARC of Rensselaer County and DSPANYS Regional Vice President, found a very simple way to spark such discussion. She took the nine principles of the Code, cut each one out and glued it to an

index card. She then distributed the index cards to a small group of DSPs she was meeting with at the ARC Day Program. She invited her colleagues to give an example of what they have done or seen which illustrated the principle on the card they were holding. It opened the door to an hour long conversation during which everyone gained a deeper understanding of the Code and how it can be applied in their everyday work. That deeper understanding happened because they shared their stories.

What DSP doesn't have a story to tell? What lessons are waiting to be learned? Not only can you help educate your fellow DSPs, but you can also inform the wider community. Storytelling is an essential strategy in advocating for our workforce and individuals who receive supports. Policymakers and leaders of organizations need to hear about your experiences on the frontlines. Your stories can inform their decisions to advance our field. As we tell stories, we shall always ensure and maintain confidentiality of individuals. This is an important principle in our Code. Confidentiality in practice and advocacy reinforces the foundation of our profession.

Read the stories below, shared by DSPs during NYSACRA's and DSPANYS's annual conferences, and think about how these DSPs applied the Code to their everyday work. (More stories can be found in the series of publications *Voices from the Frontlines* available online at: <http://www.directsupportprofessional.org>.)

Cancer scare

A woman had a significant family history of breast cancer. During an annual physical examination, the typical yearly mammogram was not ordered by the physician. The DSP who supported the woman noticed this and questioned why. The physician's office indicated that the mammogram was not ordered because the last three had come back negative. The doctor had wanted to hold off on the mammogram for three years, rather than continue to do it on a yearly basis. But the DSP insisted, citing the woman's familial history. She spoke with the nurse and then the physician, and prevailed. The mammogram was done; it revealed breast cancer, which is currently under treatment.

Coming up roses

A young man regularly attended a day habilitation program where one of his activities was packaging sponges. He was productive, but extremely bored and unhappy. A DSP working at the day program knew the young man and knew that he loved gardening at his home on weekends. The DSP suggested, and the young man agreed, that they look for a job in the gardening business. Together they went to greenhouses in the area and eventually the young man landed a job watering and fertilizing plants several days a week. He loves his new job. Not only is it more fun than packaging sponges, it pays \$7.25 an hour.

DSPANYS is the New York State Chapter of NADSP. More information can be found at www.dspanys.org.

More than just a paycheck

How the Code has impacted my personal, professional, and community life

By Lori Raymond

When I first read the Code of Ethics from the National Alliance for Direct Support Professionals (NADSP), I had a warm physical reaction and a smile grew from the inside out. The Code of Ethics describes what being a Direct Support Professional (DSP) truly means — they get it! The Code encompasses all the responsibilities and values of the work we do.

I have had the privilege to work as a DSP for over twenty years. This has been important work for me and has inspired and taught me to be a more accepting and forgiving person. I have become more aware of bias and judgments from witnessing judgments people have made about me, the work I do, and the people I have supported. Every day I have an opportunity to learn how to be a better advocate and educate others about people with disabilities. For example, I apply the Code of Ethics to the interactions I have with the people I support. I make sure I speak to people and not at people. I am purposeful about the day being about their goals, needs, and desires, and not my own. I apply the principles simply by remembering to treat the person I am supporting with respect and dignity in every situation and encourage his or her growth and happiness.

It can be difficult to come out of the caretaking role and remember we are helping the people we support live self-directed lives. It is important that we advocate for their needs and wants and en-



courage them to build their own relationships. It is not about us as DSPs; it is about them and how they want to be engaged with their lives, the community around them and the relationships they choose to build and develop. It has become my desire and passion to help others see the people I am supporting as whole people, not just their disabilities.

I have learned the importance of being connected with one's own community. For example, one of the people I have supported, Ray, wanted to volunteer with the elderly. As Ray and I connected with the elders in the community, Ray learned how to advocate for himself, build new friendships, and develop valuable social skills. Supporting Ray and helping him connect with elders in the community was a rich experience for me. I most enjoyed experiencing community members seeing Ray for himself and not his disability.

As a DSP committed to the Code of Ethics, I receive much more than my weekly paycheck. I am engaged in work that is enriching, rewarding, and life-changing. Living by the Code of Ethics has positively impacted how I interact with others in my personal, professional and community life. How cool is that?

Lori Raymond has had over twenty years experience working as a Direct Support Professional with children, adults and the elderly. She is currently working on her degree in Human Services, and is working to build a NH chapter for NADSP. She is currently raising five teenagers and is an activist for human rights. Lori can be reached at fitchick38@comcast.net.

A vital tool:

Self-advocacy leader Carrie Varner shares insights on the Code of Ethics

Frontline Initiative interviewed Carrie Varner to learn about her insights into the National Alliance for Direct Support Professionals (NADSP) Code of Ethics. Carrie is an empowering leader in the Self-Advocacy Movement. She serves as a Board Member of The Arc Minnesota, in addition to her work with Advocating Change Together (ACT) and the Self Advocates Minnesota (SAM) Network.

How did you learn about the NADSP Code of Ethics?

Carrie: I heard about the NADSP Code of Ethics at a convention that myself and three other self-advocates hosted for various agencies in Southern Minnesota. The convention focused on how to implement self-advocacy into their curriculums and philosophies.

Why do you think the Code of Ethics is important?

Carrie: The Code is important because Direct Support Professionals (DSPs) are here to help and assist people with disabilities to their fullest potential. If the Code wasn't in place, people with disabilities, as well as DSPs, could be subjected to widespread fraud, abuse, and neglect. The Code cannot be left unchecked.

Why is it important to speak out about the Code of Ethics?

Carrie: Speaking out about the Code is huge. Like many things in the world, new ideas and attitudes are constantly happening in the disability field. We need to speak

out about how the Code can be implemented to best accommodate DSPs and individuals who receive supports. At the same time, we need to make certain that loopholes and bottlenecks don't become the norm. These can create problems and obstacles in applying the Code.

How do you teach DSPs and self-advocates about the Code of Ethics?

Carrie: I assist DSPs and self-advocates to learn about the Code by telling them my story. My story includes what happens when the Code is exploited or not applied at all. This makes me want to book the next flight to Washington DC to advocate for our community and the Code. I know that when the Code is used as it's intended, DSPs and self-advocates alike are much more successful. It promotes a better quality of life for everyone involved.

How do you know when a DSP is living by the Code of Ethics?

Carrie: A DSP is living by the Code when she or he is respectful. Also when a DSP goes above and beyond what is asked or expected. And importantly, a DSP lives by the Code when she or he promotes, teaches, and encourages self-advocacy.



What would you tell a new DSP about the Code of Ethics?

Carrie: I would tell a new DSP that the Code is a vital tool for DSPs and clients alike. However, if it's utilized improperly or not at all, it will lead to widespread abuse and neglect of the system. This could lead to potentially devastating consequences. By working together to make the Code stronger, more effective, and better efficient, everyone will benefit in the long run. The community will benefit as well.

Carrie is passionate about helping individuals with disabilities attain their human and civil rights on a local, state, national, and international level. She currently lives in Marshall, Minnesota and is looking at moving to the Twin Cities Metropolitan Area to be closer to the action. Carrie can be reached at carriemv2001@yahoo.com.

Continuing the tradition of bridging gaps

Why the Code applies to everyone in policy and services

By Richard Cohen, Esq.

The National Alliance for Direct Support Professionals (NADSP) Code of Ethics captures the modern values of the disability rights movement. The standards in the Code represent best practices. Many have been widely accepted in the field for at least 40 years. Below are some excerpts from the Code. With these are examples of important movements that the Code has been built upon.

Direct Support Professionals (DSPs) commit to person-centered supports... focusing first on the person. DSPs understand that the role requires flexibility and creativity. These related principles came about in the 1980s. They have formed the essence of person-centered planning.

DSPs encourage growth and recognize the autonomy of individuals... while being attentive and energetic to reducing their risk of harm by, among other actions, reporting alleged abuse or neglect. These principles represent the legal obligation to help protect individuals from harm. They also balance individuals' "dignity of risk." These principles date back to the early 1970s. They have formed the basis of landmark cases such as Willowbrook and *Romeo v. Youngberg*.

DSPs consistently address challenging behaviors proactively, respectfully and by avoiding... aversive or deprivation... techniques. In 1981, TASH adopted a resolution calling for the removal of aversive and deprivation practices. The resolution advocated for positive ap-

proaches to challenging behaviors. More clinical and scientific work was conducted in this field. This showed the effectiveness of positive approaches. Now it is standard to use functional behavioral assessment.

The implementation of the Code of Ethics principles and their historical counterparts have moved mountains.

DSPs advocate with the people they support... including finding additional advocacy services when needed. The initial 1977 Pennhurst case is a prime example of the importance of advocacy. This case ordered the replacement of a 1200-person institution with community services. It was required that each Pennhurst resident be assigned a "friend-advocate". This raised awareness that advocacy helps meet individuals' needs in the community.

The implementation of the Code of Ethics principles and their historical counterparts have moved mountains. Hundreds of institutions have closed. Individuals with challenging behaviors or health conditions are living in the communities. The lives of many people have improved.

Despite these standards, inadequate services remain. There continues to be a gap between what is written in regulations and the Code, and what happens

in reality. One reason for this is funding. For example, in New Hampshire per person funding has steeply declined from \$75,000 annually in 1994 to \$29,000 in 2010 (taking into account inflation). The impact has been significant for DSPs. Workforce training has been significantly cut, and wages have remained low.

There is another reason for the gap between what should ideally happen in direct support and reality. That is a lack of full organizational commitment to the Code of Ethics principles. This can create a dilemma for the well-intended and committed DSP. The efforts of DSPs are consistent with the Code in many situations. However, the other parts of the system may not follow through in an ethical manner. For example, there was one case where a DSP tried to address poor housing conditions. The DSP filed a number of incident reports. The DSP ultimately made a report of neglect to the state adult protective service agency. Unfortunately, the recipients of those reports failed in their responsibility. The result was a tragic fire in which a person receiving supports died.

This heartbreaking example further emphasizes that it is essential for everyone to live by the Code of Ethics. This includes both DSPs and all those who provide supports and services. The lives and well-being of our fellow citizens depend on it.

Richard Cohen, Esq. is the Executive Director of the Disabilities Rights Center of New Hampshire. He can be reached at RichardC@drcnh.org.

The RIGHT Decision Method

An approach for solving ethical dilemmas

Developed By Marianne Taylor, Julie Silver, Amy Hewitt, and Derek Nord

Adapted By Annie Johnson Sirek

What is an ethical dilemma?

An ethical dilemma requires a person to define right from wrong. But, as Direct Support Professionals (DSPs), we know that this is not so simple. We face difficult decisions in our daily practice. There are often many different rules, principles, and opinions at play. We are called to respond in allegiance to the individuals we support. The National Alliance for Direct Support Professionals (NADSP) Code of Ethics provides a roadmap to assist in resolving ethical dilemmas.

How do I resolve ethical dilemmas?

Ethical dilemmas can be resolved through effective decision-making. Since we are so often called upon to make independent judgments, it is important to incorporate the NADSP Code of Ethics within our daily practice. Many ethical dilemmas can be resolved easily with consultation and reflection. However, some issues cannot. Therefore, to help make it easier to solve difficult ethical dilemmas, consider a framework from which to work. The College of Direct Support has provided an approach to ethical decision-making with the NADSP Code of Ethics. This is called the RIGHT Decision Method.

RIGHT Decision Method

- R** Recognize the ethical dilemma.
- I** Identify points of view.
- G** Gather resources and assistance.
- H** Have a plan.
- T** Take action based on ethical standards.

What is the RIGHT Decision Method?

Sometimes there really is a “right” way to make decisions under difficult conditions. The RIGHT Decision Method gives us tools to make sound ethical decisions and resolve ethical dilemmas. RIGHT is an acronym that stands for each step of the decision-making process:

R: Recognize the ethical dilemma.

The first step is recognizing the conflicting obligations and clearly stating the dilemma. It is important to recognize and use the NADSP Code of Ethics as you begin with this step. You may consider —

- In what ways is the Code of Ethics applicable to this issue?

I: Identify points of view.

The second step is identifying points of view in the situation. This means considering the viewpoint of the person receiving services, your colleagues, other parties involved, and the NADSP Code of Ethics. Restating the problem clearly to someone else can also help you check out whether you have interpreted the situation accurately. It is important to understand how the person receiving supports feels. Consider —

- What does the person receiving support expect?
- Then think about others who are involved in the situation and how they feel.
- What do these individuals want or need?

G: Gather resources and assistance.

The third step is gathering resources and assistance that might help you figure out what to do. Now that you have an accurate understanding for the problem and various perspectives, this step encourages you to consider other people who may be able to assist you. You may also need to find important information. For example —

- Are there agency policies that could be considered? What do these documents say? Are there any laws or regulations in the state that may influence your decision-making?
- Is this a situation where legal advice is needed? Does the person have a legal representative who must be involved?
- Are there community resources that might help resolve the problem?

H: Have a plan.

The fourth step means that you are ready to make your decision. Formulating a plan will help you decide the best way to put your ideas into action. Once you have considered the following issues, write a plan down and identify step-by-step actions that you plan to take —

- Whom must you speak to first? What will you say? What preparations will you make?
- What steps can you take to ensure the best possible outcome for your decision?
- How might people react?

T: Take action based on ethical standards.

The fifth and final step is implementing the plan you developed in the manner you decided. Then, it is important to monitor its success using the success indicators you identified in the planning

process to help you reflect on your decision —

- What worked well and why?
- What did not work well and why?
- What would you do differently after you have evaluated your outcomes?

Reference

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Annie Johnson Sirek, MSW, is a Project Coordinator at the Institute on Community Integration at the University of Minnesota. She thanks Marianne and Julie of the Human Services Research Institute, and Amy and Derek of the University of Minnesota, for developing this method to use in daily practice and training. She can be reached at joh02055@umn.edu.



College of Direct Support

Course II: Direct Support Professionalism

Lesson 3: Applying Ethics in Everyday Work



First things first

Current NADSP initiatives



Last spring a contingent from the National Alliance for Direct Support Professionals (NADSP) went to Washington D.C. to speak with the Administration on Developmental Disabilities (ADD) regarding the future of the field of direct support. They came armed with information and materials about the next great things for Direct Support Professionals (DSPs); college degrees, national credentialing; recognition and awards; apprenticeship programs and the like. Turns out, what ADD wanted to discuss was not next things, but first things.

The question posed was, "How can we celebrate the advancement of direct support when you can't even keep our loved ones safe?"

There has been an outbreak of mistreatment, neglect, and exploitation, or, unprecedented

attention to a longstanding problem; you decide. Eleven years ago, NADSP developed a Code of Ethics. Over the years, individuals, organizations, policy makers, and fields of study have adopted the Code. As is stated in the Preamble, "There is no other position today in which ethical practice and standards are more important than direct support." DSPs hold lives in their hands.

NADSP's challenge to DSPs is to **do the right thing even when no one is looking**. To help promote this challenge, NADSP now offers Code of Ethics bracelets. DSPs can use them to declare their character, to make a statement about their values, and take a stand against mistreatment, neglect, and exploitation. Organizations have numerous ways they can use the Code of Ethics bracelets to recognize excellence in the most important members of their

organization —

- Catch someone doing the right thing, and reward him or her with the matching Code of Ethics bracelet.
- Employees of the month, quarter, year.
- Let family members and persons being supported award bracelets.
- Set up benchmarks for your DSPs to earn bracelets.
- Create value in striving to earn all nine bracelets.

NADSP also offers Code of Ethics posters and handouts, and technical assistance to embed the Code in your organization. Go to nadsp.org/library/code-of-ethics.html for more information. Let's take care of first things first!

Lisa Burck, MPA, MEd, is President of NADSP. She can be reached at lisaburck@bellsouth.net.

Doing the right thing when no one is looking

A one day exploration into the Code of Ethics

NADSP has developed an intensive, one-day training program and will visit your organization to inspire, energize and educate your employees while making the Code of Ethics understandable and fun. While the day's discussions will center on direct support practice, all levels of your organization would benefit from understanding the ethical responsibilities in supporting people with disabilities.

Your organization will experience —

- The five elements of any profession—including direct support.
- A Code of Ethics encounter— An engaging interactive role play that requires the audience to think quickly and ethically.
- A facilitated discussion that explores the ethical encounters that your DSPs have experienced during their careers.
- Small group sessions to deconstruct the Code of Ethics and connect its tenets to personal experiences and competency areas.
- A recorded, large group exercise that connects the "relevance" and application of the Code of Ethics to day-to-day activities.
- A commitment ceremony — Attestation to the NADSP Code of Ethics and wrap-up.

Please visit our homepage at www.nadsp.org to learn more.

Joe Macbeth is Executive Director of NADSP, he can be reached at jmacbeth@nadsp.org.

John Raffaele, LMSW, is a DSP educator and trainer, he can be reached through <http://johndraffaele.org/>.

Frontline resources

Book: Make a Difference: A Guidebook for Person-Centered Direct Support

By John O'Brien & Beth Mount

This user-friendly book guides DSPs in relationship building, planning with people in a person-centered way, supporting choice, & building community inclusion. This book also promotes the discovery of meaning in the work of offering direct support and encourages reflection on day-to-day practice to guide self-improvement.

Voices from the Frontlines III: Advancing the Profession of Direct Support

Contact: New York State Association of Community and Residential Agencies: nysacra@nysacra.org; (518) 449-7551 (phone)

This booklet presents thirteen vignettes illustrating dilemmas that have been encountered by DSPs. Following each vignette are discussion points designed to guide participants in applying ideas from the Professional Competency Standards and Code of Ethics that have been developed by the National Association of Direct Support Professionals to advance the stature of the work done by DSPs. This booklet is set up as a training tool for DSPs, and can be downloaded at no cost from the publisher's website.

College of Direct Support

Course 11: Direct Support Professionalism (Revision 2); Lesson 3: Applying Ethics in Everyday Work

<http://www.collegeofdirectsupport.com>

Taylor, M., Silver, H., Hewitt, A., Nord, D., O'Neill, S. & Sauer, J. (2006). Minneapolis, MN: University of Minnesota, Institute on Community Integration, Research and Training Center on Community Living.

Frontline Initiative archives

<https://nadsp.org/communication/frontline-initiative/9-communications/100-frontline-initiative-archives.html>

- 2001 - Volume 4, Number 4, Issue on Ethics
- 1999 - Volume 3, Number 4, Tribute to John F. Kennedy, Jr.

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 (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 _____

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.
- NYSARC, Inc.
- NYSACRA
- Rise, Inc.
- The Research & Training Center at the 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

- Heinzerling Foundation, Inc.
- Jefferson Rehabilitation Center
- John Raffaele Educational Support for DSPs
- Koinonia Homes, Inc.
- 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 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.

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Amanda Panuline
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Cover story

continued from page 1

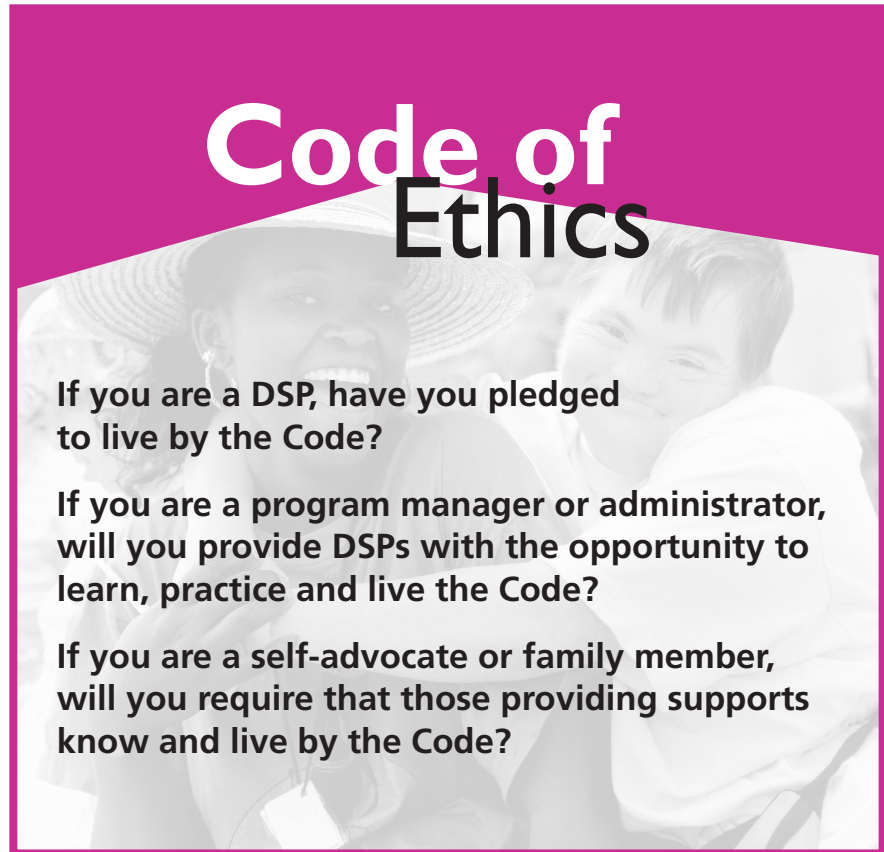
- “Is D.C. neglecting neglect?” (*Washington City Paper*, Washington, DC, May 27, 2011)
- “Disability workers rarely prosecuted for violence” (*Texas Tribune*, Texas, January 20, 2010)
- “Funding for group homes pulled after abuse” (*The Daytona Beach News Journal*, Florida, April 15, 2011)

In New York State, and undoubtedly elsewhere, these articles have led to calls for reform. Reform that includes better reporting of abuse; better investigation of reports; increased involvement of law enforcement authorities; and swifter administrative and criminal action against those responsible for abuse.

In the history of human services, be they institutionally or community based, abuse is not new. Improving efforts to identify abuse, investigate it, and weed out perpetrators through improved administrative and criminal action is good. But it is also like closing the barn door after the horse has bolted.

A new remedy that prevents or reduces the likelihood of abuse from occurring in the first place is what’s needed. Universal adherence to NADSP’s Code of Ethics offers just that.

Abuse comes in many forms. For most, the term brings up images of brutal acts. But abuse also happens under less sinister situations. Abuse can happen when DSPs are put in situations for which they are not well trained, when they are asked to do more than is humanly possible, or when in stressful situations without any assistance. Unfortunately there are many situations that can too easily turn into one of neglect or



Code of Ethics

If you are a DSP, have you pledged to live by the Code?

If you are a program manager or administrator, will you provide DSPs with the opportunity to learn, practice and live the Code?

If you are a self-advocate or family member, will you require that those providing supports know and live by the Code?

abuse. This is a problem that is larger than just the DSP, and must be addressed as a shared responsibility.

Nonetheless, DSPs are the direct link to the individual. For a moment, consider just several of the tenets of NADSP’s Code of Ethics (refer to page 16 for a brief overview of the Code; the full text of the NADSP’s Code of Ethics can be found on the NADSP website: <https://www.nadsp.org/library/code-of-ethics/10-library/72-code-of-ethics-full-text.html>)

Consider what a DSP who subscribes to this Code would do if he or she witnesses a fellow staff endangering an individual. How about a DSP who is in a situation for which she or he was not properly trained, or asked to do something that is not possible? What would the Code demand that she or he do?

Recent news has created the opportunity for DSPs to change the course of human service history. This change will happen by embracing and living the Code of Ethics.

If you are a DSP, have you pledged to live by the Code?

If you are a program manager or administrator, will you provide DSPs with the opportunity to learn, practice and live the Code?

If you are a self-advocate or family member, will you require that those providing supports know and live by the Code?

By embracing a person-centered Code of Ethics we can seize the opportunity to end abuse.

Tom Harmon is a consultant at the New York State Association of Community and Residential Agencies (NYSACRA), and can be reached at tomh@nysacra.org.

National Alliance for Direct Support Professionals

Code of Ethics

Person centered planning

My first allegiance is to the person I support; all other duties and functions I perform flow from this allegiance.

Promoting physical and emotional well-being

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

Integrity and responsibility

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.

Confidentiality

I will safeguard and respect the confidentiality and privacy of the people I support.

Justice, fairness, & equity

I will promote and practice justice, fairness, and equity for the people I support and the community as a whole. I will affirm the human rights, civil rights and responsibilities of the people I support.

Respect

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.

Relationships

I will assist the people I support to develop and maintain relationships.

Self-determination

I will assist the people I support to direct the course of their own lives.

Advocacy

I will advocate with the people I support for justice, inclusion, and full community participation.