

A Quarterly Newsletter of the National  
Alliance for Direct Support Professionals

# Frontline Initiative

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Ethics  
Frontline Initiative Newsletter

## Ethics on the Frontlines

One of the distinguishing criteria of a profession, as opposed to a “job”, is that professionals subscribe to a code of ethics. Direct Support Professionals (DSPs) have been around for generations, but only in the last few years has there been a formal national movement to acknowledge direct support as a “profession.” That’s not to say that DSPs have not conducted themselves in a professional or ethical manner; in fact, the best ethics are those formulated individually based on good judgment, responsibility, and commitment. DSPs have been making daily ethical decisions on their own for generations, and for the most part, making the right choices.

Codes of ethics are formal guidelines for professional action that are shared by persons within the profession and should be compatible with individual’s professional personal values. These “values” exist in two forms: “self-value” and “equal worth.” Self-value is one’s belief that one is of worth to others, while “equal worth” is the belief that other people are equal in worth to oneself.

The process of becoming a professional is complete only when the values of the profession are integrated into the values of the person. A professional can’t

hang up their “code of ethics” when they leave work at the end of the day. They must feel that their ethical conduct is part of the way they conduct every facet of their lives. Thus, “ethical” DSPs conduct themselves ethically at home, at school, in relationships, at other jobs, and in every activity in their

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Paula Wells and Shirley Towns are charter members of the Michigan Alliance of Direct Support Professionals. See the story on page 5.

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# Frontline Notes

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In this issue of *Frontline Initiative* we cover the important topic of ethics. We hope that you are challenged to think about the foundation of ethical behavior, standards for ethical professional behavior, and how you can practice ethical direct supports each and every day.

The National Alliance for Direct Support Professionals (NADSP) has completed its work on developing a Code of Ethics for Direct Support Professionals (DSPs). You will find the complete code in this issue of *FI*. We want the Code to become a point of discussion for you and your co-workers, supervisors, the people you support and their families.

Our next issue will talk about the changing roles of DSPs. As services become more and more individualized, the roles and expectations of DSPs are becoming more varied, more complex, and more isolated. The “changing roles” issue will, for example, feature DSPs who are employed directly by the people they support.

The late Fall issue will focus on public policy and legislative advocacy. We are looking for DSPs who have participated in some way in changing public policy through lobbying or testifying in hearings. If this describes you, contact us to share your experience.

Enjoy your summer!  
The Editors

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community they participate in.

The purposes of “ethics” are threefold. First, they serve to educate members of the profession about sound and appropriate behavior. Second, they provide a mechanism for sound professional accountability. Lastly, they serve as a catalyst for improving the practice of the profession overall.

Most codes of ethics have five underlying principles that govern the development of ethical standards. These underlying principles are —

1. Autonomy — the belief that all people have the right to self-determination.
2. Nonmaleficence — the belief that DSPs should strive to do no harm.
3. Beneficence — the belief that DSPs must promote something positive, namely the growth, development, and welfare of people receiving supports.
4. Justice — the belief that “fairness” must apply to everyone.
5. Fidelity — the belief that all promises made must be honest and attainable; we must honor our commitments to the people we serve and their families, supervisors, and colleagues.

While the above principles may seem like a gaggle of hard-to-remember words, if you concentrate on the beliefs they represent and apply them to any situation you encounter (for instance, in a group home setting, on a job site, in the

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# NADSP Member Organizations and State Contacts

**Frontline Initiative** is a product of the National Alliance for Direct Support Professionals. The NADSP is a collaboration of organizations who are committed to promoting the development of a highly competent human services workforce that supports individuals in achieving their life goals. The following are some of those organizations —

- Administration on Developmental Disabilities
- American Association on Mental Retardation
- American Association of University Affiliated Programs
- American Network of Community Options and Resources
- The Arc of the United States
- Association of Public Developmental Disabilities Administrators
- Association for Persons in Supported Employment
- CARF...The Rehabilitation Accreditation Commission
- Consortium for Citizens with Disabilities
- JFK Jr. Institute for Worker Education
- Council for Standards in Human Service Education
- Human Services Research Institute
- Institute on Community Integration (UAP), University of Minnesota
- International Association of Psychosocial Rehabilitation Services
- Irwin Siegel Agency, Inc.
- National Association of State Directors on Developmental Disabilities
- National Association of State Directors of Vocational Technical Education
- National Center on Educational Restructuring and Inclusion
- National Center for Paraprofessionals in Education
- National Organization of Child Care Workers Association
- National Organization for Human Service Educators
- National Resource Center for Paraprofessionals
- New Jersey Association of Community Providers
- President's Committee on Mental Retardation
- Program in Child Development and Child Care, University of Pittsburgh, School of Social Work
- Reaching Up
- Self-Advocates Becoming Empowered
- TASH
- United Cerebral Palsy Association

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# The Real Scoop

Welcome to *The Real Scoop*. Clifford is a self-advocate who has been politically active for years. He's here to give you his spin on how to deal with issues you face as you forge ahead in your role as a Direct Support Professional (DSP). Seth has been a DSP for many years, and he loves to give advice. He may ruffle your feathers, but hey, it's for your own good! Clifford and Seth tackle this one with a few suggestions.

## Dating Dilemma

Dear Seth and Cliff,

I am a DSP supporting a 28-year-old woman. I have supported her for about one year and during the time that I have known her, she has talked about wanting to go on dates, but doesn't have opportunities to meet men she is interested in. Last month, she began talking about joining a dating service. I would like to support her with this since she currently makes most of her own decisions. However, her parents are her legal guardians and they oppose her dating. What are my responsibilities in keeping confidentiality, respecting her right to make decisions, and also respecting her parents in their role of legal guardians?

— In the Middle in Illinois

Dear In the Middle,

*Please be sensitive to the needs of the person you are working with, but you should also discuss with her parents that she wants to date. Plan a time to sit down and talk with the parents and the woman you support. Her parents may be afraid of what might happen if she dates. If you sit down and talk it through with them, you may be able to alleviate some of their fears. The person you support has a right to decide what she wants, but her parents have a right to make sure she's safe. Maybe they would feel more comfortable if they met the person she wanted to date.*

*Good luck.*

— Cliff

Dear In the Middle,

*Our goal is to advocate for and teach the people we support to lead responsible and happy lives. We all deserve a loving partner to share that life. People with disabilities now more than ever are a part of their community. They have real jobs and real issues. It might be a good time to look into recreational activities that the parents of the person you support can be a part of, to at least see that their daughter has the same wants as they do, and to help her fulfill these needs in a safe, positive environment.*

*It's obvious that you are walking a fine line, but you show respect for the person you support and her parents when you communicate openly with both. The more her parents trust you, the easier it will be to advocate and help them realize that they have to let go, sooner or later.*

— Seth

## Ask Clifford and Seth

Do you have a burning question about direct support, but don't know who to ask? Submit it to —

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Please include your name, day phone for verification, and alias, if desired.

# Michigan Direct Support Professionals Power Up!

Empowering people with disabilities by making their own commitment to self-determination is the pledge of many Direct Support Professionals (DSPs) in Michigan. However, most DSPs lack the opportunities that self-advocates, families, and professionals have to meet with colleagues and share ideas to advance their interests.

This changed on October 13, 2000 as the Developmental Disabilities Institute and 20 generous organizations co-sponsored the First Annual Michigan Alliance of Direct Support Professionals (MADSP) Forum. One hundred and eighty-five DSPs, supervisors, administrators, people with disabilities, and family members from 21 Michigan counties were hosted by Mott Community College in Flint, Michigan. The purpose of their gathering was to —

- Identify innovative ideas to increase DSP wages and benefits.
- Identify innovative ideas for DSP recruitment and retention.
- Meet each other, work in partnership, have some fun, and celebrate all that DSPs do for people with disabilities and their families.

The forum was a unique statewide event designed and implemented by and for DSPs. A lavish breakfast set the stage for inspirational speakers and 16 small work groups in which people recommended solutions, shared ideas, and established the relationships needed to support their own self-confidence, unity and path towards self-empowerment. MADSP members believe that taking control of their own future in partnership with

supervisors and people with disabilities will give them the tools they need to make positive contributions in their direct service profession. They also believe they can use these experiences to assist the people they serve to live self-determined lives.

The suggestions from forum participants could not have been offered by a more qualified assemblage of individuals. The DSPs attending the forum contradict the high turnover rates reported in the industry with an average 6.7 years with their current employer.



Marva Ways, advocate and motivational speaker.

The forum proceedings distributed following the event contained interesting and useful information such as the hourly rate DSPs believe to be a fair starting wage (\$12.58) and the percentage who believe their supervisor asks for (60%) and uses (58.3%) their ideas. The forum proceedings contained recommendations in these topical areas —

- Increasing DSP salaries.
- Increasing DSP benefits.
- Supporting a positive work environment.
- Designing a vibrant training initiative.
- Advertising job announcements.
- Developing energetic recruitment strategies.
- Implementing effective interviewing techniques.

Since 82% of forum participants were excited to use at least one idea upon their return to work, we believe that positive energy will be flowing throughout Michigan's DSP workforce in the new millennium.

The Developmental Disabilities Institute is a proud partner in enhancing the status of those individuals who provide the most direct, intimate, and consistent support to people with disabilities. We have numerous projects where we provide assistance to this important sector of disability professionals including the *Empowerment Education: Consumer-driven Training* for Michigan's DSPs initiative funded by the U.S. Department of Health and Human Services - Administration of Developmental Disabilities. Staff members Belinda Land, Janette Jennings, Elizabeth Janks, Angela Martin, Michael Wolf-Branigin, and Karen Wolf-Branigin are involved in these DSP self-empowerment projects through their work at the Institute. Elizabeth Janks can be reached at 313.577.2654 or at [ab3707@wayne.edu](mailto:ab3707@wayne.edu).

# “ Do as I say...”

My first recognizable brush with direct support ethics began when my agency asked me to work with a young man named Tony who had just been diagnosed with high cholesterol. This, plus a family history of heart trouble, made Tony a prime candidate for a heart attack. Explaining this to him did little good; not because of any disability, but because he had heard the words “eating less” and “exercising more” and didn’t want to listen any further. This whole “lowering my cholesterol” thing did not fit into Tony’s plans. He had said many times already that he would not cooperate with a new diet and exercise plan.

I eagerly accepted the challenge to work with Tony in addressing his cholesterol problem. I had been working as a Direct Support Professional (DSP) for a little over a year and had been working with Tony for that entire time. I figured that, with enough time together, we could turn the diet and exercise into habits that Tony would keep for a lifetime.

The major flaw in my plan was that, minus the high cholesterol, I was exactly like Tony. If someone had come to me and said, “Don, we have a great plan of diet and exercise that’s going to help you lose weight!” I would tell them what they could do with those plans.

Completely unaware of the irony of the situation, I took Tony to the grocery store for his first low-fat shopping trip. In the past, I had barely looked at Tony’s shopping list. If he had the money, he could get what he wanted. On this day we went over everything with an eye for detail that would make a drill sergeant proud. All of the foods that

Tony enjoyed; pizza, hamburger, hot dogs, were out, replaced by low-fat substitutes that to him (and me) tasted like an old shoe. The hardest cut was peanut butter, a staple in Tony’s life, now taken out entirely because he refused to eat low-fat peanut butter. A trip to the store that used to take us twenty minutes now took an hour.

Our next shopping excursions weren’t much better. It was a battle to get through the store every week. After a few months of arguments in the grocery aisle, Tony stopped

He talked softer; he laughed less; he didn’t look me in the eyes as much as he used to. He was a defeated man and I was the one that had defeated him.

fighting. I had won. We only got the things I deemed appropriate for a person with high cholesterol.

Exercise was pretty much the same. We would go to walk at a local track and Tony would threaten not to go in. I would threaten to go walk by myself. I knew he didn’t like being alone, but I got the results I was looking for; Tony went in and he exercised.

Three months later, Tony and I went to the doctor to find out the results of his blood test. I expected dramatic improvement. Tony was

eating right and exercising more. Everything was going according to plan. Tony’s cholesterol level was still dangerously high — slightly higher than it had been the first time, in fact.

A quick trip to Tony’s house revealed the truth. Tony was ordering pizzas and hiding the boxes in his dresser drawers. Tony was buying cheeseburgers at the convenience store up the street and hiding the wrappers behind his TV. Tony now had high cholesterol and a bug problem in his house.

So, I started cracking down on that, too. Tony and I began “weekly cleanings” at his house. This was where I came in under the guise of helping Tony get things spic and span, when really I was looking for fast food containers. Once found, I would put them on the kitchen table and Tony and I would talk about it until Tony told me how wrong he was. He promised he wouldn’t do it again.

Eventually, through medication and the constant struggles between the two of us, Tony’s cholesterol started to come down. Around that same time I started to notice that he wasn’t as happy as he once had been. He talked softer; he laughed less; he didn’t look me in the eyes as much as he used to. He was a defeated man and I was the one that had defeated him.

It was here that I was reminded that I don’t work for the doctor — I work for Tony. Goals set in Tony’s life should be a mixture of things — Tony needs and things Tony wants.

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# State of the Art Definition

## Quality Assurance

Quality assurance is a catch phrase that most of us have been hearing for awhile. But what exactly does it mean, especially for Direct Support Professionals (DSPs)? At a very basic level, it means that the quality of services we provide extends beyond the minimal level mandated by government or that which is required to stay in business.

The idea of Total Quality Management (TQM) is often associated with quality assurance. TQM means that the organization's culture is defined by and supports the constant attainment of customer satisfaction through an integrated system of tools, techniques, and training. Many of the concepts of TQM are easily adapted for use in the Human Service Industry.

The main elements of TQM include —

- **Customer-driven quality**

The people who receive supports drive our pursuit of quality of services. Feedback is sought from self-advocates and family members as to the quality of services. Goals and strategies are designed in response to this feedback.

- **Strong quality leadership**

For TQM to be effective, quality service must be a central value of the organization, with top management having a deep long-term commitment to infusing the goal of quality in the organization's mission, vision, and values.

- **Continuous improvement**

This is often referred to as Continuous Quality Improvement (CQI), and can be defined as the activity of continually improving the process and systems that un-

derlie the services we provide. The quality of services needs to be a continuous discussion, with new goals and strategies for continuous improvement evolving as the discussion progresses.

The more effort that we put into quality assurance, the more we will see our efforts reflected in the quality of life experienced by the people who receive the valuable services provided by DSPs.

- **Action based on facts, data, and analysis**

In TQM, the short-term fixes are converted into consideration of the long term. Instead of applying band-aids, the time is taken to gather information about how problems have been fixed successfully in the past. All problem-solving approaches are considered so that the best possible solution can be reached to achieve quality of service in the long term.

- **Employee involvement**

Frontline employees are of central importance in the TQM process. Employees play crucial roles in the quality of service provided, with management serving these employees with support and training.

Through techniques of quality assurance such as TQM and CQI, all of the people within a system, especially the customers, are highly valued. In an effort to improve the product, data are collected, employees are empowered, and their opinions and those of the customers are sought and re-sought. In human services, the product is the supports that DSPs provide. The more effort that we put into quality assurance, the more we will see our efforts reflected in the quality of life experienced by the people who receive the valuable services provided by DSPs.

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# Institute on Community Integration Turns Fifteen

The Institute on Community Integration is celebrating its 15<sup>th</sup> year of working to improve the capacity of communities to support the full inclusion of persons with developmental disabilities. Beginning in 1985 with fewer than 20 staff, the Institute is now home to more than 150 staff and students. In collaboration with a variety of organizations, the Institute seeks to improve the services and supports that enable persons with disabilities to live as valued members of local schools, workplaces, neighborhoods, and community organizations.

The Institute, originally known as the Minnesota University Affiliated Program on Developmental Disabilities (MUAP), based its earliest work on the previous research activities of the University's Center for Residential and Community Services, which focused on collecting and analyzing data on the institutional and community settings. Those efforts quickly expanded to focus on the needs of individuals with disabilities and their families across the life span and in all types of community settings.

Renamed the Institute on Community Integration in 1988, its mission has remained the same while its scope of activities has grown dramatically. Major activities of its projects include the following —

- Pre-service training for University students and continuing education for professionals aimed at ensuring the availability of quality services for persons with disabilities. Among the training opportunities is the newly approved graduate-level Certificate in Disability

Policy and Services, a joint effort of the Institute and the Department of Educational Policy and Administration.

The Institute has held a constant course in its commitment to building the capacity of communities to offer the services and supports that enable persons with developmental disabilities to live full lives as valued members of society.

- Applied research that leads to improved policies and services affecting persons with disabilities across the lifespan. Current projects include: the outcomes for students with disabilities of K-12 educational practices, measures of early child development, strategies for improving the quality and continuity of in-home supports for adults with disabilities, and the health status of older adults with mental retardation.
- Technical assistance and program evaluation services that enhance the work of agencies and programs providing services to persons with disabilities, including K-12 schools, social service agencies and programs, community organiza-

tions, higher education institutes, and a wide range of professions.

- Publishing activities that share practical, leading-edge information through curricula, resource guides, training manuals, newsletters, research reports, web sites, and multimedia products.

Of special interest to DSPs is the Institute's Research and Training Center on Community Living (RTC). This program is currently developing a national multi-media and Web-based curriculum for DSPs. In addition to developing and reviewing training modules for DSPs, there is also a focus on investigating the relationship between the challenges faced by DSPs and the impact on the individuals that they serve as well as developing best practices based on programs that advance the goals of the NADSP. These are only a sample of the many projects underway at ICI that directly impact the important work of DSPs.

In reflecting on the past 15 years and where the Institute stands today, Director David R. Johnson observes, "The Institute has held a constant course in its commitment to building the capacity of communities to offer the services and supports that enable persons with developmental disabilities to live full lives as valued members of society. And while there have been, over the past 15 years, significant improvements in community attitudes, professional practices, and legal protections regarding persons with developmental disabilities, we have yet to experience inclusion as the norm rather than the exception, so we still have much work to do."



# Ethical Challenges in Support Agencies

OHI was founded out of Maine's desire to "do the right thing" on behalf of citizens with the dual diagnoses of mental retardation and mental illness. Our mission continues to be helping people with disabilities to be freed from years of institutionalization in a variety of healthcare settings. Twenty-two years later, our agency continues to struggle with the day-to-day challenge of always doing the right thing. The "right thing" for us has never been premised on legal or regulatory descriptors. Ethics at OHI find their fundamental basis in morality — what we believe to be the deepest societal values.

Doing the right thing has become increasingly complex! More and more frequently, we find ourselves asking, "Is this the right thing to do?" in at least three areas: Professional Ethics, Organizational Ethics, and Biomedical Ethics. Space does not permit an in-depth description of each of these areas, but, perhaps, a few examples will capture their essence —

## • Professional Ethics

We promote frontline staff as professionals. We call them Direct Support Professionals (DSPs). We tell the Legislature that they deserve more money and benefits because they are professionals. We promote a career ladder so that they will call what they do a profession. Do we hold professional expectations? Yes! To get to that point, it took a year-long effort to identify the marks of a professional a process which resulted in a "Role of a Professional" job description. A professional ethical question that confronts our field in this

time of drastic workforce shortages is whether it is ethical to actively recruit employees from other social service agencies. The answer for us is a resounding "no." Simply put, it is not the right thing to do.

It is our belief that the essential character of services for a person with disabilities — particularly, residential supports — can be profoundly altered by the nature of a single decision about how to support that person.

## • Organizational Ethics

As flat funding continues, year after year, while we want to give deserving DSPs an annual raise, is it right to pad new individual budgets that are being submitted to the state so that we can spread excesses to valued employees? The answer is "no." We must find another way.

## • Biomedical Ethics

Not long ago, a parent of a young adult with autism informed us that she wanted our staff to take her son to the hospital over the course of several weeks to undergo a series of injections of secretin. She had heard that secretin ameliorates the affects of autism. Based on research, we knew that the only

possible positive effects that were evident were in children and, even then, the research was questionable. There was no evidence of success with adults. Furthermore, her son has a phobia of needles. After much discussion, bringing the mother's mandate to one of our Human Rights Committees, and doing further research, we made the decision that we simply could not participate in this treatment. This treatment was simply not the right thing to do! The treatment went forward with the mother and family members supporting the young man, but was not successful.

In the early years, without thinking about it, we developed our mission, values, and philosophy around "right thing" statements. As the years have passed, we have tried to instill ethics into our organizational fiber and throughout the culture of our corporate life.

A serious focus on ethics really began in 1997 when our Board granted a request for our Assistant Executive Director and I to attend a week long intensive bioethics course at the Kennedy Institute of Ethics at Georgetown University. Daily concerns were rising and as an agency we were also looking ahead to troubling times that were calling on us to make very difficult decisions — decisions that could ultimately make the difference between life and death; decisions that could influence the "system" to fund us or deny us funding; decisions that involved overlooking the lack of professionalism of an

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# Gerry White and the Code of Ethics

This is a one act play in three scenes that depicts the struggles of a consumer, his mother, and Direct Support Professionals (DSPs) in their search for answers to some perplexing issues. They find some help in a new and developing set of standards called the Code of Ethics for Direct Support Professionals. You'll have some fun and learn a lot through this theatrical adventure.

## The Characters: (In order of appearance)

Gerry White .....	Person, 19 years of age, his own legal guardian
Terry White .....	Gerry's Mother
Donna Dooitall .....	Gerry's favorite DSP
Curtis Candu .....	Donna's "usual" co-worker
Veri Stressed .....	Donna's Immediate Supervisor

## The Setting

Gerry's home, one evening in May, when spring is in the air and also in the step of every young heart in the world. This large house has been converted into a duplex. Each unit consists of two bedrooms, a living room, a kitchen, the dining room, and private baths for each resident. Both units share a porch and basement /laundry room. The small sitting room, just off of the front entrance, has been converted into a small office for support staff to use while providing service in the home.

Each scene takes place in one or more of the areas in the duplex.

## Act 1 Scene 1

*The front entry, Gerry and his mother Terry have just returned home from the mall and as they enter the entry area they are in the middle of a discussion. Donna is working in the adjacent office.*

**Gerry:** *(Pleading)* But, Mom, you don't understand! Shana and I have been seeing each other for 9 months now and we both feel we are ready

to have sex. We have developed our relationship over time, we have discussed becoming sexual and want to do it together. Heck! we've even taken the classes that teach us how to have safe sex. Mom, we're ready! *(They move towards Gerry's room just off of the dining room and sit, mother on a chair, Gerry on the bed.)*

**Terry (Gerry's mother):** *(In a matter of fact tone of voice)* Gerry, you know what I think of that: If you two want to have sex it's o.k. with me....I just worry that safe sex classes won't be enough. Let's make an appointment with Dr. Smith and talk about a vasectomy....I would feel much more comfortable with you being sexually active if you weren't able to have children.

**Gerry:** *(Somewhat exasperated)* We've talked about that before and you know I don't want to do that. I may want to have children some day and I should get to make my own choice. Besides, Shana and I like kids.

**Terry:** *(Frustrated now)* Liking children and raising children are two different things. You and Shana couldn't possibly handle that much responsibility; you can't even balance your checkbooks.

**Gerry:** *(Agitated and antsy)* I have to get ready for my softball game now so why don't you go home. I don't want to talk about this anymore. *(Gerry goes to his walk in closet to get changed for his gam.. Terry walks out to the office area and stops to talk to Donna.)*

**Terry:** *(Walks in without knocking)* Donna, I'm going to leave now even though Gerry's upset with me. Did you hear any of our discussion?

**Donna:** *(Turns from paperwork)* I overheard something about Gerry becoming sexually active but I didn't listen in on all the details.

**Terry:** *(Calmed down a little)* Well...we were discussing setting up an appointment for Gerry to get a vasectomy because I don't feel the classes that teach safe sex are enough. *(Walking slowly towards Donna; in a low, calm tone)* You're his favorite staff person, Donna, he trusts and listens to you. I want you to use your influence to convince him to see things my way. *(She turns around quickly and leaves before Donna has a chance to respond).*

**Narrator:** This one act play is an outgrowth and expansion of an activity that occurs at the end of a presentation (*Direct Support Professionalism: Ethics, Education, and Respect*) that the writers recently conducted at a direct support conference. The activity involved small groups (5-7 people each) of

DSPs discussing a scenario about some typical ethical dilemmas they face quite frequently as they provide supports to people with developmental or other disabilities.

Each of the groups was assigned one of the nine different areas of the Code of Ethics (developed through the National Alliance of Direct Support Professionals, NADSP). Participants were instructed to use the ethical standard and several interpretive statements described for

their area to guide their discussion and to develop a plan to address the ethical dilemma. In addition, the groups were asked to talk about and share with the entire group how the code was helpful to their discussions and in what ways was it not helpful.

The purpose of the overall presentation was intended to provide participants with new knowledge and understanding and initial skill development around their roles in direct support. It is

about how their work is professional, requires education and training, can be validated through a credentialing process, will be strengthened through local and national professional associations, and can be guided with a code of ethics.

Now, let's look and listen in on Gerry, Terry, Donna, and the others to see how this ethical dilemma is progressing.

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## Applying the NADSP Code of Ethics to Your Ethical Dilemmas

### Step 1: Identifying Stakeholders

Think about the situation at hand. Who are all of the people who are potentially involved in the situation and who may be affected by any decision you make? There may be primary relationships — those people directly involved in the situation and there may be secondary relationships — people who may have an interest in the outcome, but are not directly involved.

### Step 2: Identifying Ethical Principals

What ethical standards from the NADSP Code of Ethics come into play in the situation? Is there more than one standard to be considered? Are there any ethical principles that may come into conflict with each other? Which two or three of the ethical standards are the most important for this situation? Do other principles come into play?

### Step 3: Brainstorming Possible Actions

What are all of the possible actions you could take in this situation? Don't immediately discount any idea – be open to any potential solution, no matter how silly it may seem at first. But do consider the ethical standards and potential stakeholders when suggesting a course of action.

### Step 4: Choosing a Course of Action

Consider the possible benefits and potential negative outcomes or costs for each action. Select an action or combination of actions that you can do to resolve the situation. Then go ahead and act on your decision.

### Step 5: Evaluating Your Decision

What were the outcomes of your actions? Did the situation resolve itself the way you had hoped? What did you learn from this that can be applied to future dilemmas?

### Act 1 Scene 2

*(On the front porch) Donna's co-worker, Curtis, has returned from providing training to Gerry's housemate on how to ride the bus. Gerry's housemate will not need Curtis' support for about an hour. Gerry has left for his softball game and won't return for at least an hour and fifteen minutes.*

**Donna:** *(Looking somewhat puzzled)* Curtis, I've been struggling with something Gerry's mother said to me on her way out the door. Do you have a few minutes to discuss it with me?

**Curtis:** *(Looking up while writing in the log book)* Sure, I don't have to leave to help George for half an hour or so.

**Donna:** Here's how it played out. I was working in the office earlier when Gerry and his mom returned from their shopping trip. They were discussing Gerry and Shana becoming sexually active. It seemed like they were having a good discussion when passing by me so I just kept working and stayed out of it.

**Curtis:** *(Goes back to writing in the log book)* That was probably smart. If Gerry or his mother needed your input they would have asked.

Continued on page 12

**Donna:** That's the thing, Mrs. White did come to me for support on the way out the door and I'm not too comfortable with what she asked me to do.

**Curtis:** (*Looks up slightly*) Why? What did she ask you to do?

**Donna:** She asked me to use my influence as Gerry's "favorite staff" to encourage him to get a vasectomy if he's going to become sexually active.

**Curtis:** (*Stands straight up at full attention*) Wow! That's a tough spot for her to put you in. Did you say anything to her about how uncomfortable that request made you?

**Donna:** (*Looks down slightly*) No, she didn't give me time. She was out the door so fast it would make your head spin. Since I didn't agree to anything, though, it gives me the opportunity to work out what the best response would be.

**Curtis:** Yeah, I suppose a little time to process this dilemma is a good thing, but we'll have to come up with something before she starts asking if you had a talk with Gerry yet.

**Donna:** Do you think I should talk with Veri after our staff meeting tomorrow?

**Curtis:** I think this is important enough that you should and I would also be willing to sit in since we work as a team.

**Donna:** Cool. Maybe the three of us sitting down can come up with a solution. I'm still concerned about Gerry, though — he didn't say much before he went to softball.

**Curtis:** Sounds like a good idea....Gotta go help George with the bus, I think he has the routes down well enough now so he can

choose to go it alone next time if he wants. See Ya later.

**Donna:** Ciao.

**Narrator:** The plot begins to thicken.

Does this seem familiar? This type of scenario about sexuality has gotten special attention at all of our workshops. While the topic can be a "sticky wicket," if you review the entire code (the preamble and each of the nine ethical standards with their interpretative statements), you will have the basis of many positive and challenging dialogues with each other, your supervisors, consumers, and other stakeholders.

Let's see what's going to happen next.

### Act 1 Scene 3

*The next day after the staff meeting in the little office off of the entryway.*

**Donna:** Veri, do you have some time to talk about an issue that came up yesterday afternoon when Mrs. White dropped Gerry off after their shopping trip?

**Veri:** (*Flustered*) What is Mrs. White's issue NOW?

**Donna:** It's not that she has any issue with our services. She has asked me to do something I'm not comfortable with.

**Veri:** What's that? (*Her pager goes off and she looks at it as if she'd like to toss it against the wall*) Let me look at this and see how urgent it is. (*She looks at pager text*). It can wait so shoot.

**Donna:** Mrs. White asked me to encourage Gerry to get a vasectomy. You know Gerry and Shana have become close and have taken sexuality classes that teach them about safe sex.

**Veri:** And?

**Donna:** And Gerry says he doesn't want to go through that surgery, he thinks that he and Shana can be responsible adults and practice safe sex.

**Veri:** What do you think?

**Donna:** I think it should be Gerry's choice since it is his body....And he has gone above what most people do by taking those classes, too.

**Veri:** But what about the possibility of Gerry and Shana having children?

**Donna:** I don't know. My gut tells me that should be their choice... but the challenges they face will make it difficult if it were to happen. I know we will have to talk to Gerry more alone and with Shana. Probably Mrs. White too.

### Epilogue

The final scene of this play, The Epilogue (How the team dealt with this ethical dilemma and what sources within the Code they used), will be printed in the next edition of the *Frontline Initiative*.

We encourage you and your team to spend time reviewing the Code of Ethics for Direct Support Professionals, to engage in dialogue around all the issues in this play scenario, and to develop a specific and realistic plan that deals with this ethical conundrum.

To assist you in this assignment, you might want to review and use the checklist for considering ethical dilemmas.

Mark Olson is an Advocate at Hennepin-Carver Arc, and can be reached at 952.920.0855. John Sauer is a Project Coordinator at the Institute on Community Integration, and can be reached at 612.626.0535.

# Frontline Resources

## **The Network on Ethics and Intellectual Disabilities Web Site**

[www.georgetown.edu/research/kie/intdisnews.htm](http://www.georgetown.edu/research/kie/intdisnews.htm)

Supports the efforts of those engaged in or committed to ethical issues concerning health care and people with intellectual disabilities. It is associated with the International Association of Bioethics but does not commit to any particular state of thought.

## **The Newsletter of The Network on Ethics and Intellectual Disabilities**

A free newsletter from The Network on Ethics and Intellectual Disabilities that includes articles, book reviews, case studies, and announcements of meetings concerning ethical, social, and legal developments affecting people with mental disabilities.

*Contact: Robert M. Veatch, Professor of Medical Ethics, Joseph and Rose Kennedy Institute of Ethics, Georgetown University, Box 571212, Washington, DC 20057-1212 USA, [veatchr@gunet.georgetown.edu](mailto:veatchr@gunet.georgetown.edu)*

## **Family Village Web Site**

[www.familyvillage.wisc.edu/hospital/ethics.htm](http://www.familyvillage.wisc.edu/hospital/ethics.htm)

This Web site provides a variety of disability-related information in a user-friendly format. Areas highlighted are specific diagnoses, communication connections, adaptive products and technology, adaptive recreational activities, education, worship, health issues, and disability-related media and

literature. Click on the hospital icon to check out the information on Ethics!

## **National Organization for Human Service Education Web Site**

[www.nohse.com](http://www.nohse.com)

The National Association for Human Service Education was established in 1975 as a way to unite educators, students, practitioners, and consumers of services to promote the effective preparation of human service workers. Their Web site has information about ethics, working in human services, and student scholarships for those thinking of furthering their education.

## **The Quality Mall**

[www.qualitymall.org](http://www.qualitymall.org)

This Web site uses the theme of a shopping mall to help connect visitors to the best products and resources that promote quality of life for persons with developmental disabilities. Not in the shopping mood? View video clips, slide shows, and interactive presentations at the Quality Cinema, participate in a live chat at the Coffee Shop, or find out the late breaking news at the News Stand.

## **What Would You Do? An Ethical Case Workbook for Human Service Professionals**

*Patricia Kenyon (1999)*

*See review, page 14.*

This workbook is designed as a starting point for ethical discussions on a variety of topics. Examples

gathered from actual human service professionals are used to provide real life exercises that are relevant to the situations and issues faced every day.

*Available from Brooks/Cole — Wadsworth Helping Professions at [humanservices.wadsworth.com](http://humanservices.wadsworth.com).*

## **Designing Ethical Practices for Quality Services: Employment and Community Services**

*Michael Wirth-Davis (2001)*

This manual provides basic steps on how organizations can begin to develop a code of ethics that is useful for making the tough decisions that DSPs face. It provides definitions for ethics and values, explains different decision-making approaches, and finally takes a step-by-step approach to guide an organization through creating a set of ethical practices of its own.

*Available from CARF Employment and Community Services, The Commission on Accreditation of Rehabilitation Facilities, 4891 East Grant Road, Tucson, Arizona 85712, Voice/TDD (520) 325-1044, Fax (520) 318-1129, [www.carf.org](http://www.carf.org)*

It is not enough to do good; one must do it in the right way.

— John Morley  
(1838–1923)

# Resource Review

A good resource for developing ethical competence is *What Would You Do? An Ethical Case Workbook for Human Service Professionals*. See page 13 for ordering information.

As a human services educator, I had found — as many of you have probably also discovered — that little was written about ethics for Direct Support Professionals (DSPs). Those who support vulnerable people daily in such roles as caregiver, case manager, behavior changer, and advocate often confront situations with major ethical components, often with little support. So, I set out to create a workbook that would help students and professionals prepare themselves to recognize and handle such situations with an appropriate ethical awareness.

Central to *What Would You Do?* is the use of real experiences reported by human service students and entry-level professionals from across the United States. Collected in a national survey and at regional conferences, these experiences have been developed into anecdotes that provide the focus for exercises promoting individual reflection and group discussion. The anecdotes are arranged topically, starting with issues that are familiar to people new to the field and progressing to issues that are more familiar to those with experience in human services.

This workbook is used as a resource in courses and in workshops for professionals. Many exercises provide starting points for in-depth consideration of ethical issues related to particular popula-

tions, such as the aged or those with HIV or disabilities.

DSPs need to make informed ethical decisions in the course of their work. If DSPs learn to make those decisions ahead of time, before facing ethical dilemmas, rather than on their own in the workplace, they minimize the potential harm that could occur to themselves and others. They also increase their comfort with the process. As people learn, they think through their own beliefs and values, explore the possible consequences of action, decide what action to take and defend their decisions to others. They also learn to change their minds when challenged with preferable ethical thinking, instead of sticking to decisions based on their emotional reactions.

I have written this workbook to challenge DSPs. I hope you find it valuable in addressing some of the everyday problems we all face in this nation that often discounts human services consumers and providers.

Patricia Kenyon is a Professor of Human Services at Arizona Western College, Yuma, AZ 85366-0929. She can be reached at 520.726.1347.

*Ethical Challenges in Support Agencies*, continued from page 9

employee or, on the other hand, not tolerate that behavior; and decisions that could ultimately deny the persons we support their basic freedom, rights, and choices.

Since 1997, we have woven ethical decision-making, behavior, language, policy, and culture throughout OHI. All new staff receive an Ethics course during orientation that also includes exposure to our Ethics Policy, our Professionalism Statement, and the role of the OHI Ethics Committee (a committee comprised of a diverse group of individuals, including an ethicist). All DSPs within our agency were also asked to give feedback to the National Alliance for DSPs on its Draft Ethics Statement for DSPs and did so with great hope. The NADSP Ethics Statement has also become part of new employee orientation.

It is our belief that the essential character of services for a person with disabilities — particularly, residential supports — can be profoundly altered by the nature of a single decision about how to support that person. Michael Kendrick, a disability advocate, has written that each person has a “human identity that both precedes and transcends the identity ascribed to them by services and their processes.” We are mindful of this statement every day at OHI and try to be ever vigilant about doing the right thing.

Bonnie-Jean Brooks is the Executive Director of OHI. She can be reached at 207.848.7978 or [OHIfamily@aol.com](mailto:OHIfamily@aol.com).

# Alliance Update

"Do as I Say...", continued from page 6

The need for Tony's cholesterol to go down had to be weighed against the need for Tony to live his own life. Although this revelation hit me like a thunderbolt, rebuilding the trust between Tony and me took longer. The rebuilding continues everyday, every time I work with him.

I don't think I'm a stupid person. With a little bit of training in this area, I don't think things would have gotten as bad as they did. A Code of Ethics for DSPs would have kept me from damaging my relationship with Tony. This is why I feel a Code of Ethics is important for DSPs and why I will continue to work towards the goal of a fully accepted and implemented national code of ethics for all direct support staff.

Don Carrick works for Nodaway County Services in Maryville, Missouri and is a member of the State Core Group for DSPs of Missouri. He can be reached at 660.582.7114 or [dcarrick@asde.net](mailto:dcarrick@asde.net).

The National Alliance for Direct Support Professionals (NADSP) is pleased to present the Code of Ethics for Direct Support Professionals. This Code is the result of much hard work from many dedicated people over the past two years. This development process began with many state and local workshops with DSPs from all over the country helping to identify and define the ethical dilemmas they face in the course of their day-to-day work with people who receive support services in the community. Once common experiences were identified and categorized, a national workshop was held which brought together DSPs, self-advocates, managers, administrators, and educators to draft the Code of Ethics. This draft was then validated through a survey process.

We believe that the resulting Code of Ethics will serve as a valuable tool and resource for DSPs as they work to support people in their communities. As DSPs across

the country have interacted with and used the Code through workshops and training sessions, they have expressed that the Code does provide valuable assistance in helping them to problem-solve when faced with ethical questions.

We encourage DSPs to embrace this Code and to use it as a guiding principle in the course of their everyday work. We further encourage consumers of support services and agencies to adopt the Code as an expectation of quality for the DSPs with whom they work.

A warm hearted thank-you to the many people who supported the development of this Code either through participation in a workshop, drafting the words, or completing the validation survey. This valuable tool would not have been possible without your assistance and support.

Amy Hewitt is the managing editor of *FI*. She may be reached at 612.625.1098 or [hewit005@umn.edu](mailto:hewit005@umn.edu)

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community or on a recreational outing) you will soon see that they are simple and readily applicable.

A draft Code of Ethics was created by the National Alliance of Direct Support Professionals (NADSP) and was presented to DSPs across the country last year. DSPs had the opportunity to offer feedback and suggestions for modification to the code. The process to create the code was lengthy and complex involving professionals from many disciplines, DSPs, self-advocates, families, and policymakers from a variety of settings across the country. The National Code of Ethics for Direct Support Professionals was finalized and approved at a recent meeting of NADSP. (Editor's note: The code is included as a pullout of this newsletter.)

The true test of the effectiveness of a code of ethics is the tried and true "reality check." In order for

ethics to have merit and relevance (and ultimately adoption), they must be able to be translated into everyday life...at home, in classrooms, on the job. The Code of Ethics can help fulfill the need of DSPs to conduct themselves in appropriate, legitimate and honorable ways — meeting the five above mentioned underlying principles of ethical behavior (autonomy, non-maleficence, beneficence, justice, fidelity).

Your next step is to look over the Code of Ethics, familiarize yourself with it and then take it for a road test....Take it to work with you tomorrow.

Rick Rader, MD is the director of the Morton J. Kent Habilitation Center and the Orange Grove Center in Chattanooga, Tennessee. He can be reached at 423.493.2936. This article was originally published in *The Credentialing Chronicle* and was revised for this issue of *Frontline Initiative*.

For an act to be moral the intention must be based on compassion, not duty. We do something because we want to do it, because we feel we have to do it, not because we ought to do it. And even if our efforts fail — or we never even get to implement them — we are still moral because our motivation was based on compassion.

— Arthur Schopenhauer  
(1788-1860)

Visit the DSP Web site at <http://rtc.umn.edu/dsp>

## Frontline Initiative Newsletter

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