Voices
FROM THE FRONTLINES II:
OUR JOURNEY
January 2010
They are the frontline of a service system that night and day, year round, supports over 125,000 New Yorkers with developmental disabilities. They work in a myriad of programs from St. Lawrence County to Staten Island, from the shores of Lake Erie to Montauk Point.

It is rare that direct support professionals—upon whom so much and so many depend—have the occasion to gather together to reflect on their role, discuss and learn from each other, and recharge their batteries to carry on tomorrow, renewed.

Rarer yet is the opportunity for others—including the individuals being served and their families, program managers, policy makers, and the public-at-large—to hear the collective voice and wisdom of New York’s direct support professionals about matters critical to them and the people they support.

This paper presents such an opportunity. It offers a synopsis of information gleaned from direct support professionals as they discussed the leading tenet of the Direct Support Professional’s Code of Ethics, “My first allegiance is to the person I support, all other activities and functions I perform flow from this allegiance,” the relationships formed in carrying out this obligation, the obstacles they encounter, and the supports they need. These discussions occurred in open forums at six regional conferences for direct support professionals cosponsored by the New York State Association of Community and Residential Agencies (NYSACRA) and the Direct Support Professional Alliance of New York State (DSPANYS) in 2009.

A debt of gratitude is owed to individuals, too numerous to mention by name, from the following groups for making the 2009 Direct Support Professional Conferences and this paper possible: NYSACRA’s regional vice presidents and their conference committees which planned the conferences and worked out logistics; DSPANYS; and the Self-Advocacy Association of New York State (SANYS), which helped hone the open forum questions and facilitate the discussions. We are most thankful for the input of the more than 700 direct support professionals who were able to attend the regional conferences and share their views.

NYSACRA, DSPANYS and SANYS hope that the perspectives shared by these men and women will be listened to carefully, give rise for celebration and thanks, and prompt supportive action where needed.
Introduction

For the past decade, NYSACRA has sponsored regional conferences for direct support professionals in New York State. Designed to offer networking and educational opportunities for direct support professionals, in 2008 the tables were turned, allowing direct support professionals to connect with and educate a larger audience. At each of the six regional conferences, one session was dedicated to an open forum during which direct support professionals were invited to share their perspectives on a variety of issues. The results of those discussions were published in *Voices from the Frontlines* in 2009 and disseminated by NYSACRA to service provider agencies and policy makers in New York State. The National Alliance for Direct Support Professionals also posted *Voices from the Frontlines* on its website, thus allowing New York’s direct support professionals to speak to a national audience.

Subsequently, NYSACRA partnered with DSPANYS—the newly formed New York State Chapter of the National Alliance for Direct Support Professionals—in planning 2009’s six regional conferences and developing questions for open forums. The questions focused on the leading tenet of the Code of Ethics which guides direct support professionals: “My first allegiance is to the person I support; all other activities and functions I perform flow from this allegiance.”

At the heart of this tenet, and in fact the entire Code of Ethics, is the duty of direct support professionals to enter into a relationship with the individuals they support. The Code’s preamble describes their mission as following the individual path suggested by the unique gifts, preferences, and needs of the person being supported, and walking in partnership with the person toward a life of...
opportunity, well-being, freedom, and contribution. As such, during the forums, participants were invited to share their thoughts and experiences on these relationships. At times, participants became very emotional; their responses to some questions evoked tears, heartfelt stories of dedication and palpable frustration. These were the professionals who do the work, and this was an opportunity for them to openly share what they feel about the relationships that are developed while doing it. As the forums progressed, questions were added which explored how or why participants were drawn to the field of direct support.

As in 2008, the ground rules for the 2009 open forums were simple:
- there are no right or wrong answers, everyone’s perspectives, experiences, and opinions are valued;
- respect each other’s viewpoint and their opportunity to speak; and
- although notes would be taken for publication, no individual or agency would be identified.

Also like the 2008 forums, those conducted in 2009 were not designed as research tools yielding hard data. Rather, they were intended to give direct support professionals the opportunity to network across agency lines, discuss issues of mutual interest and concern, and share their perspectives with others, including individuals being served and their families, program managers, policy makers, and the public-at-large.

DIRECT SUPPORT PROFESSIONAL COMMENTS ON THE OPEN FORUMS

“It was nice to be heard. Sometimes it feels like we don’t count.”
“Insightful.”

“Intense…inspiring.”
“Best part: hearing others’ experiences.”

“Gave me inspiration to strive even more to be my best.”
“It reminded me to let the others I work with know how great they are.”

“I’m not alone… others spoke words that I feel.”
“I was reminded of how valuable the services I provide truly are.”

“I was reminded that I am important.”
“It made me think about how I interact with my consumers; gave me tools to improve my performance.”

“Sometimes it feels like you are out there alone.”
“Freshening to see so much positive energy.”

NYSACRA Regional Color Key:  • Capital  • Long Island  • Mid-Hudson  • New York  • Northern  • Western
Evaluations completed by conference participants and their written comments reflected the forums’ value. On a scale of 1 to 5—with a rating of 1 indicating “poor” and a rating of 5 indicating “excellent”—the open forums received an overall rating of 4.51, up from the prior year’s rating of 4.44. Nearly one-third (31%) of the participants (up from last year’s 25%) ranked the one-and-a-half hour open forum session as the “most useful” part of the six conferences’ full-day agendas.

But the forums’ larger value will lie in the degree to which direct support professionals’ voices are heard and they are recognized for, and supported in, the mission they’ve undertaken.
As children, most of us have dreams of what we’d like to be when we grow up: a ballerina, a fireman, a doctor, a teacher, and so on. During several forums, participants were asked to raise their hands if they dreamed of becoming a direct support professional when they were young. No one raised their hand and, after an awkward silence, stories began emerging on how they embarked on the path of supporting individuals with developmental disabilities.

A few had family members with disabilities and felt compelled to work in the field in some capacity. Others wanted to do something meaningful and make a difference in someone’s life. But most participants indicated that they “fell into” the job, some quite blindly by attending a job fair or answering a help wanted ad, and others by a stroke of good luck, such as a number of participants who were working other jobs and were invited by family members, friends, and even program managers “to come and check out” working as a direct support professional.

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“Two roads diverged in a wood, and I, I took the one less traveled by, and that has made all the difference.”

Robert Frost’s The Road Not Taken
**WALKING IN PARTNERSHIP: FIRST STEPS ON THE JOURNEY**

1. “I have a sister who has a disability. That is what interested me in the field. I chose this field to stay close to her.”
2. “My child was born with a disability and my wife and I were told she was not going to progress in her life. I became motivated by my child. That is the reason why I chose this field.”
3. “I worked in the Financial District. I needed to do something that made a difference in people’s lives.”
4. “I have a brother with disabilities, and yet this work never struck my interest. One of my friends who was a maintenance worker at an agency introduced me to the field. I have been doing this now for 15 years.”
5. “I was working at a McDonald’s. A residential program manager came in and asked me if I wanted a new job. He said that he was impressed with how I interacted with the individuals from his program who visited McDonald’s and thought I’d be perfect. I’ve been with the program now for 10 years.”
6. “I was a factory worker and applied for a job with the agency. I had no expectations. On the first day, I was given a hug and knew I belonged.”
7. “I was a home maker and went to a job fair. At first, I thought I wouldn’t last. That was 13 years ago.”
8. “I worked as a diesel mechanic and got my job as a direct support professional through a job fair.”
9. “I was working as a bartender and visited my niece who was working in a group home. I thought I’d give it a try. It changed my life.”
Participants discussed the expectations, both generally and particularly with regard to the relationships they would form with the persons they support, that they had when they first became direct support professionals. They also offered insights into how those expectations had changed.

Without exception, at each forum there were several participants who indicated that, from the onset, their expectations were crystal clear: to enter into supportive relationships with the individuals. One participant’s written comment best illustrates the perspective they shared: “I expected to be there to help and support the individuals as well as to become their friend and gain their respect.”

Most forum participants, however, did not share similar expectations when they became direct support professionals. Some spoke candidly of their fear of working with people with disabilities. Others indicated that they had no initial expectations, “It was just a job; if it didn’t work out, I’d move on.” And still others had fairly minimal expectations, “I thought I’d be babysitting.” But as the discussions progressed, the forum participants talked about how their initial expectations changed and the relationships that they formed.
### A TRANSFORMATIONAL JOURNEY

“I was afraid…I walked into a house with eight wheelchairs.”

“I was scared to death.”

“I expected the worst. There have been a lot of negative portrayals of people with disabilities in the media.”

“I had no expectations. It was just a job.”

“I thought it would just be a job: punch in, punch out.”

“I thought I was going to be a glorified baby sitter.”

“I needed a job. I thought I was going to be a maid, do showers, clean, etc. I thought I was only going to be there until my personal situation got better. I went for a job, and stayed for a career.”

“I thought I was going to just help people with activities of daily living. It has become so much more.”

“I thought it would be strictly business. I didn’t foresee the caring.”

“I didn’t have many expectations and thought I’d leave if it didn’t work out. But it became a mentoring relationship.”

“I felt my role was just to work with the individuals and monitor them. But I developed relationships. I know they say you are not supposed to call it friendship, but it is.”

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**NYSACRA Regional Color Key:**
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- Mid-Hudson
- New York
- Northern
- Western
By a show of hands, the majority of participants at the forums indicated that the nature of the relationships they developed with the individuals surpassed what they had expected upon entering the field of direct support. Time and time again, participants spoke of the family-like relationships they had developed with the people they were supporting. They also spoke of how those relationships were transformative: not only were they assisting individuals in life’s journey of growing, learning, and being part of the community, they themselves were being supported, growing, and learning through the relationships and traveling on the path the individuals led.

### A TRANSFORMATIONAL JOURNEY

- “I knew I’d be giving personal care. But I didn’t expect to build relationships like I have.”
- “I thought I’d lose my time with my family. Now I have a new family.”
- “I thought I’d be just a caregiver…caring for needs. Now, it’s so much more—life long relationships.”
- “I felt it would be a learning experience: how would I benefit people. I didn’t know what to expect. It went beyond any expectations I could have.”
- “My self esteem has grown. You grow with the people you support.”
- “They become such a part of your life.”
- “The individuals become your family and friends. They teach you as much as you teach them.”
- “I need them as much as they need me.”
- “The relationships are challenging and rewarding.”
- “I learn with the individuals…it is mutual learning, mutual rewards, mutual respect.”
- “The individuals are supportive of you while you’re supporting them.”
- “The individuals are like family now.”
- “I didn’t expect to have relationships. I get just as much from the individuals I support as I give them.”
- “I feel like they are teaching me/helping me more than the other way around.”

*NYSACRA Regional Color Key: Capital Long Island Mid-Hudson New York Northern Western*
Walking in partnership with individuals on their journey toward a life of opportunity, well-being, freedom, and contribution is a source of many rewards for direct support professionals, albeit not of the monetary kind. As one Mid-Hudson region participant said: “The reward is much more than a job with a paycheck.”

Forum participants spoke of the joys they experience in the journey:

<table>
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<tr>
<th>THE JOYS OF THE JOURNEY AND BUMPS IN THE ROAD</th>
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<tr>
<td>“Seeing individuals become more involved in their community…going to the library, using public transportation, doing volunteer work, having neighbors as friends, etc.”</td>
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<td>“Family members seeing the individuals’ accomplishments.”</td>
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<td>“Seeing joy in an individual’s face.”</td>
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<td>“Knowing I made a difference.”</td>
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<tr>
<td>“Becoming one part of another person’s life. And they a part of yours.”</td>
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<tr>
<td>“When we can find something that works for that person so he can be more independent and grow. Also when we can enjoy fun times.”</td>
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<td>“If you are having a bad day, the individuals brighten it up.”</td>
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<td>“Seeing people achieve their goals. Small strides make a huge difference.”</td>
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<td>“The people we support are really concerned about us.”</td>
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<td>“The individual I support gave me joy at my wedding, empathy during my pregnancy, and sympathy over deaths in my family.”</td>
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<tr>
<td>“Parents saying they are not worried about leaving this earth because their kid will be OK.”</td>
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<tr>
<td>“The joy of watching them grow.”</td>
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NYSACRA Regional Color Key:  
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But there are bumps in the road—obstacles that test the mettle of direct support professional’s allegiance to the individual first and above all; realities that make the journey difficult.

Forum participants spoke honestly, often passionately, and sometimes tearfully about the issues they confront, and struggle with, in living out their mission and their obligations to the people they support. These issues ranged from general “community acceptance,” to roadblocks encountered within their agencies, to their own innermost feelings arising from their relationships with the people they support.

**Community Issues**

Participants recounted stories of having to advocate for changes in community-based doctors, dentists, or other health professionals who simply would not pay attention to individuals’ needs; having to intervene with shop keepers who would take advantage of, short change, or generally disrespect individuals; and having to be proactive in searching for community-based organizations and activities which would be welcoming of the individuals. They spoke of their disappointments in walking the path of community inclusion.

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<thead>
<tr>
<th><strong>COMMUNITY ISSUES</strong></th>
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<tr>
<td>“Outside clinicians and hospital staff don't listen to me when I speak on behalf of the people I support, whom I know the best.”</td>
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<td>“The everyday disrespect that the individuals are shown by the man on the street is not right.”</td>
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<td>“People seeing me as non-disabled and the individual I support as disabled. The injustice that they experience affects me...people not respecting them. The biggest insult is someone outside thanking me for 'what I do.'”</td>
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<td>“Clinicians acting like the individuals won't ever change is frustrating.”</td>
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<td>“When you are outside, and people walk away from them. It hurts me when I experience this.”</td>
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<tr>
<td>“When you feel they are being treated unjustly, and you still have to be professional. It's hard juggling the emotional vs. professional feelings.”</td>
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_NYSACRA Regional Color Key: _Capital _Long Island _Mid-Hudson _New York _Northern _Western_
Issues Internal to Agencies

In living out the Code of Ethics and their allegiance to the individuals they support, direct support professionals encounter difficulties within their agencies. Sometimes they feel that administrators and managers are not listening to them when they speak on behalf of the individuals. At other times, agency policies or rules get in the way, such as when the wish of a particular individual has to be put aside because “it is not a billable service” or a “group activity is scheduled.” Reporting fellow staff for misdeeds is a painful but necessary duty many forum participants experienced in living out their allegiance to the individual first. Equally painful is staff turnover and its impact of the individuals supported. Family dynamics, and the lack of supports when the wishes of an individual are in conflict with those of the family, also pose obstacles. Here are some participants’ comments on these matters:

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<tr>
<th>ISSUES INTERNAL TO AGENCIES</th>
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<tr>
<td>“Management seems to indicate that my priority is not theirs. The things we say are pushed to the back burner. But my priority is the individual that I have a relationship with and an allegiance to.”</td>
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<td>“Direct support professionals are the closest to the persons being supported. They should be listened to by the higher ups.”</td>
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<td>“Certain policies make it hard to do the job. Policies get in the way.”</td>
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<td>“Try to live normal, quality lives when the rules/requirements get in the way. For example, you try to take just one individual out who wants to go bowling on a Friday night and you’re told, ‘No, everyone goes, or no one goes.’”</td>
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<td>“The documentation is a big obstacle. With all this paperwork, there is never enough time dedicated to spend with the individuals.”</td>
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<td>“Sometimes it seems that a ‘perfect audit’ is more important than the relationships that are built.”</td>
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<td>“Managers should listen to direct support professionals.”</td>
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<td>“Some co-workers are not giving the support the way it should be given.”</td>
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<td>“Some new staff just don’t get it. They don’t understand the profession. They don’t get their allegiance to the individual.”</td>
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<td>“It’s difficult, but necessary, to report fellow staff for not doing right by an individual. If you don’t, you’re not keeping your commitment to the individual as your first allegiance.”</td>
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<tr>
<td>“The individuals have friendships, trust, then staff go: poof!”</td>
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Feelings Arising from Relationships

Forum participants indicated that they also struggle with feelings arising from the relationships they forge with the people they support. At one forum, a participant stated that her agency told her, “Don’t get attached.” She went on to say, “But that’s just impossible.” When asked, approximately half the participants at that forum indicated that they were told the same thing by their agencies: “Don’t get attached.” They also had the same conclusion: “That’s just impossible.” While the relationships bring joy, they also bring difficulties, particularly with regard to role conflict, death and dying issues, and not being able to assist individuals all the time. Here are some of the sentiments participants shared.

“Feelings arising from relationships, continued”

| “It’s hard picking up the pieces in individuals’ lives when someone else leaves.” |
| “It’s difficult when families want nothing to do with the individual.” |
| “I wish the families who are ‘mildly involved’ would ask more questions and think about their family members’ needs more.” |
| “Families are sometimes an obstacle. During the weekend a family can undo what the staff worked on all week.” |
| “Families are supportive, for the most part. They can be very involved and helpful. But there are fine lines between roles (family, direct support professional, individual, agency administrators) that need to be taken care of, nurtured to ensure good relations among all parties…so we’re all pulling in the same direction.” |

NYSACRA Regional Color Key: [Capital] [Long Island] [Mid-Hudson] [New York] [Northern] [Western]
FEELINGS ARISING FROM RELATIONSHIPS

“Thank is a role conflict of staff vs. friend. It’s tough being asked by an individual to do things that I can’t, given the professional boundaries.”

“How can they say, ‘Don’t get too close, it’s just a job’?”

“Sometimes it’s hard not to take things personally.”

“Relationships can be misconstrued.”

“Stepping back from your own emotions is hard.”

“The hardest part is losing people as they age and pass. Watching them deteriorate from what they once were or were able to do and can no longer do.”

“An individual I supported had cancer. He progressed so fast. I didn’t get a chance to really say goodbye. I was so sad.”

“Going into a room after an individual has died and they’ve already moved another consumer in. That’s hard.”

“I find it difficult having to explain a loss or having to sit with an individual on their death bed.”

“I had a hard time having to comfort an individual over his grandmother’s passing.”

“You share in their sadness.”

“The individuals’ disappointment when they can’t meet a goal saddens me.”

“I find it difficult not being able to stop self injurious behaviors.”

“Communication barriers are difficult…not being able to communicate with non-verbal individuals.”

“Working with challenging behaviors is difficult. It’s hard being consistent.”

“Watching an individual give up on himself is very hard.”

“Keeping a level headed approach when behaviors are at their worst. And knowing that there are some things you can’t help with. That is difficult.”
Our group home first opened its doors six years ago and became home to six young boys with autism. Each had difficulties adjusting to life away from their families (many for the first time) and adjusting to life in a strange new home filled with strange new faces. It was new for staff too!

Over the years we had our share of challenging behaviors. None of the staff were sure how long we would last or whether we would really make a difference in the boys' lives. We sometimes wondered if what we were trying to accomplish mattered much, as our smiles were sometimes greeted with screams and our hugs were sometimes greeted with hits.

I would love to say that there was some great epiphany we each experienced that turned things around for the better but I cannot. What I can say is that the little, consistent things in life made all the difference.

Although it took some time, as the boys turned to men, they realized that they could trust staff because most of us were not going anywhere; although we may leave for a short time, we would come back.

What I can say is that, as the boys turned to men, they came to honor themselves and came to accept and expect that they would wear stuffy suits, ties, and dress shoes during graduations, proms, and holidays, while we staff would gush over them and take endless pictures; and they did so without much complaint.

What I can say is that, as the boys turned to men, they realized that the same old people expected them to clean up after themselves, eat their vegetables, and insisted that they drink from a glass and not directly from the pitcher; and they did so, albeit begrudgingly, and they developed respect.

What I can say is that, as the boys turned to men, we have grown to need them just as much as they need us and it is expressed through their smiles, hugs, and laughter which have, for the most part, replaced the challenging behaviors; and we have developed love.

I don’t know what the future holds but I know that our lives have been indelibly changed for the better because of the boys we have watched turn to men.
In discussing obstacles encountered in their journey walking with and supporting individuals with developmental disabilities, the forums’ participants also offered suggestions on the types of assistance that would help them on the path. The suggestions touched on issues including administrative supports, enhanced training, and staff recruitment.

### NEED FOR TRAINING AND ROADSIDE ASSISTANCE

- “We need administrators and managers who will listen to direct support professionals, ask questions of direct support professionals.”
- “We must lose the language/mindset of ‘higher ups’ (management) and lower/peon staff (direct support professionals). We are all about the same thing: the individual.”
- “We need to look at policies or rules that get in the way of helping an individual choose what he or she wants to do.”
- “Direct Support Professionals should have more input in the development of policies that impact on the individuals.”
- “When agencies are holding policy meetings, they should invite self advocates so staff and individuals can come up with solutions.”
- “The policies should ensure that individuals are given choices as to what they want to do.”
- “We need policies that create more quality time as opposed to paperwork.”
- “More training on helping individuals develop relationships would be helpful. Many times, you are the only person they have a close relationship with.”
- “Increased guidance in helping individuals become their own self-advocates.”
- “We could use more training and support on community integration and resources (finding churches, volunteer opportunities, etc.).”
- “Training on boundaries and relationships would be helpful.”
- “Training should include role playing situations, for example, what to do if an individual tries to hug you. Self advocates should also be involved in doing the training.”
- “Managers should attend the training because many of them have not been direct support professionals.”
- “More training around bereavement issues is needed.”
- “Additional training on disability specific issues and really difficult issues, such as interacting with non-verbal individuals or individuals with behavioral challenges, would help.”
- “We need increased training and skills on dealing with family issues, particularly when there is a conflict between what the family wants and the individual wants.”

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### NEED FOR TRAINING AND ROADSIDE ASSISTANCE, continued

| “More supervisory/management intervention when conflicts arise with families would help. You can’t burn the three way relationship of family, individual, and direct support worker.” |  |
| “We need better ways of recruiting and interviewing staff so they know the expectations of the job and don’t quit soon after arriving.” |  |
| “Have job applicants work a three hour shift, really get a feel for whether this job is right for them.” |  |
| “Direct support professionals should provide some of the new employee orientation and training.” |  |
| “Disability sensitivity training…‘walking in the individuals’ shoes’…should be a part of new employee training.” |  |
| “The Code of Ethics for direct support professionals should be promoted during the training.” |  |

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Voices from the Frontlines II: Our Journey is essentially a map. It describes the itinerary of direct support professionals walking in partnership with the individuals they support toward a life of opportunity, well-being, freedom, and contribution. This is not a journey everyone can make, as demonstrated by the high staff turnover rates in programs serving individuals with developmental disabilities. Paradoxically, it is also a journey many long-term direct support professionals stumbled upon, not fully understanding where it would lead. That is what makes a map like this important.

In discussing their experience of walking in partnership with the individuals they support, direct support professionals attending this year’s regional conferences described how they were transformed by the journey, the depth and genuine nature of their relationships, the love that exists between them and those they support, and how the expedition far surpassed their expectations. They described the rewards of the journey, which as anyone knows are not monetary; they are learning more about themselves, becoming a part of someone else’s life, seeing individuals grow and thrive, and having family members support them sometimes by simply saying “Thanks.” They also discussed the obstacles they encountered and offered suggestions about the assistance they need to carry on with their journey.

These discussions offer a map that many can use. Individuals considering a career in direct support should consult it to see if the journey is one that excites and intrigues them. Incumbent direct support professionals can use it as a reference tool to advocate for support within their agencies. Individuals with disabilities and
their families can use it as a guide as they walk in partnership with direct support professionals. And finally, program administrators and managers can use it to plot courses to make the journey easier.

The New York State Association of Community and Residential Agencies, the Direct Support Professional Alliance of New York State and the Self-Advocacy Association of New York State and are grateful to the men and women who attended this year’s regional conference and contributed to Voices from the Frontlines II: Our Journey. We hope that future and current direct support professionals, individuals and their families, program operators, and policy makers will use this map as a guide on our shared journey.
## Direct Support Professional Open Forum Questions

The first tenet of the Direct Support Professional Code of Ethics is: *My first allegiance is to the person I support*. That tenet, and the special relationships it speaks to between direct support professionals and the people they support, formed the foundation and background for the open forum questions and discussions.

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
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<tr>
<td>How many of you said “When I grow up, I want to be a direct support professional?”</td>
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<td>What led you to this work?</td>
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<td>Before starting your career, can you describe what you expected the relationships to be like between yourself and the individuals you support?</td>
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<tr>
<td>After working as a direct support professional, what are those relationships like now?</td>
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<td>What do you find rewarding about those relationships? What are the best parts?</td>
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<td>What are the hardest parts of those relationships?</td>
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<td>Reflecting on the first ethical standard of the Direct Support Professional Code of Ethics, can you give an example of how you live it or make it happen every day – something that you are proud of which illustrates this tenet?</td>
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<td>What obstacles do you or other direct support professionals encounter trying to live up to the standard?</td>
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<td>What can direct support professionals and others do to overcome these obstacles?</td>
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Appendix B

National Code of Ethics for Direct Support Professionals

Direct Supports Professionals (DSP) who support people in their communities are called upon to make independent judgments on a daily basis that involve both practical and ethical reasoning. The people who assume the support role must examine and call upon values and beliefs, as well as creative vision, to assist them in the complex work they perform.

A primary purpose of the DSP is to assist people who need support to lead self-directed lives and to participate fully in our communities and nation. This emphasis on empowerment and participation is critical because the prejudices of society form powerful barriers that prevent many people with mental or physical disabilities from enjoying a high quality of life. And, too often, the very social policies and service systems designed to help can create other barriers.

Therefore, it must be the mission of the Direct Support Professional to follow the individual path suggested by the unique gifts, preferences, and needs of each person they support, and to walk in partnership with the person, and those who love him or her, toward a life of opportunity, well-being, freedom, and contribution.

Unfortunately, there have been no set criteria to guide these journeys as there are for other professional groups (such as doctors, nurses, service coordinators, and social workers) who have intimate knowledge of and responsibility for another person’s emotional, financial, or physical being. There is no other position today in which ethical practice and standards are more important than direct support. DSPs are often asked to serve as gatekeepers between people needing support and almost every aspect of their lives, including access to community, personal finances, physical well-being, relationships, employment, and everyday choices. The whole landscape of a person’s life can change with the coming and going of these critical support people.

As a result of these work duties, DSPs face ethical decisions on a daily basis and consistently feel the tension between the ideals of the profession and its practice. There are numerous pressures coming from organizations, government, social policy, and societal prejudice that can shift focus and allegiance away from those supported. In order to maintain the promise of partnership and respect that must exist in a helping relationship, a strong ethical foundation is critical to help DSPs navigate through the maze of influences that bombard them.

This issue has lead to the efforts on the part of the National Alliance of Direct Support Professionals to identify the kinds of ethical situations that DSPs face and to develop a set of ethical guidelines. The NADSP convened a national panel of DSPs, advocates, families, professionals, and researchers who constructed this code of ethics. Focus groups and surveys regarding the draft language were conducted throughout the country and were integrated to create the final code. This Code of Ethics is intended to serve as a straightforward and relevant ethical guide, shedding some light on the shared path to a self-directed life. It is intended to guide DSPs in resolving ethical dilemmas they face every day and to encourage DSPs to achieve the highest ideals of the profession.

The skills and knowledge of community support practice must be joined with the ethical principles to create the environment needed to fully support people. To do so effectively, we must all work toward recognizing DSPs as professionals who have skills, knowledge, and values that constitute a unique and important profession. There must be a commitment to hiring, developing, and supporting DSPs who have a healthy sense of their own worth and potential, and the worth and potential of the people they support, and who can infuse these beliefs into practice. DSPs themselves must know that it is part of their role to foster a spirit of cooperation and mutual responsibility with other DSPs regarding ethical practice.

Direct support professionals, agency leaders, policymakers, and people receiving services are urged to read the Code and to consider ways that these ethical statements can be incorporated into daily practice. The beliefs and attitudes that are associated with being an effective human service professional are the cornerstones of this code. This code is not the handbook of the profession, but rather a roadmap to assist us in staying the course of securing freedom, justice, and equality for all.
1. **Person-Centered Supports**
   As a direct support professional, my first allegiance is to the person I support; all other activities and functions I perform flow from this allegiance.

2. **Promoting Physical and Emotional Well-Being**
   As a direct support professional, I am responsible for supporting the emotional, physical, and personal well-being of the individuals receiving support. I will encourage growth and recognize the autonomy of the individuals receiving support while being attentive and energetic in reducing their risk of harm.

3. **Integrity and Responsibility**
   As a direct support professional, 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.

4. **Confidentiality**
   As a direct support professional, I will safeguard and respect the confidentiality and privacy of the people I support.

5. **Justice, Fairness and Equity**
   As a direct support professional, 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.

6. **Respect**
   As a direct support professional, 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.

7. **Relationships**
   As a direct support professional, I will assist the people I support to develop and maintain relationships.

8. **Self-Determination**
   As a direct support professional, I will assist the people I support to direct the course of their own lives.

9. **Advocacy**
   As a direct support professional, I will advocate with the people I support for justice, inclusion and full community participation.
“Direct Support Professionals are so important to those of us with disabilities. They are like a key to a locked door and on the other side of that door, they help us get to a whole new world. That’s how important direct support professionals are and that’s why we need to work together—to help people with disabilities lead fulfilling lives and to advance their profession.”

David Liscomb, President
Self-Advocacy Association of New York State