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Each year, NYSACRA sponsors six regional educational conferences for Direct Support Professionals in New York State. But, in 2008, the tables were turned when Direct Support Professionals were offered open forums at each conference to speak about issues on which they are rarely invited to comment.

Beginning with the Western Regional Conference, where participants helped hone questions of importance to them as Direct Support Professionals (see Appendix A), over 700 Direct Support Professionals across the state participated in the open forums.¹ The rules were simple:

- There are no right or wrong answers, everyone’s perspective, experience, and opinion is valued.
- Respect each other’s viewpoint and their opportunity to speak.
- Although notes would be taken, no individual or agency would be identified.

The forums were not designed as research tools to yield hard data, rather they were intended to give Direct Support Professionals the chance to network across agency lines and discuss issues of mutual interest and concern. Staff from the New York State Office of Mental Retardation and Developmental Disabilities helped facilitate some of the sessions and attended each forum to listen and learn.

Evaluations completed by conference participants 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 4.44. Over 25% of the participants ranked the forums as the “most useful” part of the full-day agenda; others ranked them as second, usually to the key note speaker, in a day which offered five or more other sessions.

But the forums’ larger value lies in what can be learned in listening to the voices from the frontlines. We invite program operators and policy makers to join us in listening, beginning with this document, as Direct Support Professionals speak directly, and often eloquently, about their mission, accomplishments, and challenges.

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¹ The open forums were approximately one-and-a-half hours in length. Participants were also invited to submit written comments.
n discussing what they view their mission to be, the participants, almost universally, focused on the individuals served, describing person-centered aims and activities. Only a handful defined their mission in terms of tasks, such as “Keeping the house clean,” or “Doing what I can while I’m there,” or “Getting the job done.”

Statements such as “Helping people reach personal goals,” or “Helping them reach their potential” peppered the discussions and written comments. Some who provided written comments described their mission at length, such as this one: “To help each individual consumer reach a level of self-sufficiency; empowering consumers to be as independent as possible.” Others were more concise: “Empowerment!” “Promote independence.” But they all shared a common theme: the individual with a disability whom they support.

The focus on the individuals they support also permeated discussions of what Direct Support Professionals found to be the most satisfying part of their job. While, again, a few participants focused on task completion — “Making sure the next shift is well informed coming to work” — the vast majority indicated that the most satisfying part of the job was grounded in the individuals they support everyday:

- Seeing the expressions of individuals doing a task independently for the first time.
- Making a difference in their lives; bringing out their potential.
- When our QMRPs give consumers new goals because they have mastered their previous ones.
- When I see someone make progress after they have been working on a goal for a long time.
- Watching individuals grow.

Some Direct Support Professionals found satisfaction in how the individuals whom they support changed them, such as this participant in the New York City conference who indicated that he found satisfaction in “What the consumers are teaching me,” and this Capital Region participant who found satisfaction in “My own personal transformation…my changes, what I’ve learned.”
Participants were asked what they liked about the organizations where they worked. Approximately 150 responses were recorded. Leading the list, with nearly a quarter of the responses, was the organization’s focus on the individual served and the quality of services that they deliver. Comments such as, “They care about consumers,” “They put the consumer first,” “It fits the needs of individuals,” and “It strives to be the best every day,” were not uncommon.

Benefits (health and dental insurance, etc.) and flexibility of scheduling work hours received an almost equal number of responses.

Satisfaction with opportunities for training and growth was voiced in a significant number (19%) of the responses as illustrated in these comments:

- It offers good training.
- They have monthly training sessions.
- They support me in continuing my education.
- They give opportunities to go to college.
- They promote from within.
- The agency gives employees the opportunity to move up.
- It allows you to grow.
- You are able to move up the ladder.

An almost equal number of responses cited the fact that Direct Support Professionals felt supported and were allowed to be creative and free to share new ideas, “Management picks up open shifts,” “They’re open-minded when you want to try new things,” “Creativity is allowed,” and “Administration has an open door policy.”

Finally, a good number of responses touched upon the intangible… the “feel” of the agency… summed up in this one comment from a New York City conference participant: “They make you feel like a family. It is just a warm feel.”
During the forums, participants were asked, “Are your job duties what you expected?” Although formal tallies were not taken, it appeared that in region after region there was no consensus as to either “yes” or “no.” Rather, the responses from participants seemed to be nearly evenly divided. This was also reflected in the written comments. Of the 44 individuals who provided written comments, 42 answered this question; 19 indicated that their duties were what they expected and 23 indicated that they were not.

In discussing their experiences, participants who indicated that the job was not what they expected offered a variety of reasons. Some indicated that the intensity of direct support activities, such as the medical care or behavioral interventions which the individuals who receive support would require, was more than they expected. Others indicated that it was the volume of non-direct support duties, such as the paperwork, yard work, cooking, housekeeping, etc., which took them by surprise. Some indicated that it seemed that managers “sugar-coated” job details during interviews. And, whereas one Capital District participant said, “If [the interview] were too informational, it might scare the employee away,” another responded, “In broad strokes, the duties were clear, but they didn’t give specifics…we need details.”

One theme which emerged from the discussion of experiences vs. expectations was the issue of bonding with the individuals served. Many Direct Support Professionals in the open forum discussions, and 25% of those who responded in writing, indicated the primary reason that the job was not what they expected was because they never anticipated becoming so close to the individuals they support, as reflected in the following comments:

*My duties are more because you become like family to the individuals.*
*I never expected to become so close to the consumers.*
*Didn’t expect to receive hugs…consumers really care about you.*
*I didn’t expect to get so close and involved.*
During the open forum discussions and in written comments, participants expressed what they felt were the most stressful parts of their jobs as Direct Support Professionals. Direct support activities, such as managing challenging behaviors and administering medications, were sometimes, but very infrequently cited. (Of the 136 verbal comments recorded and the 44 written responses received, these issues were cited in only 10 instances.)

The vast majority of stressors they articulated dealt with non-direct care matters — such as paperwork, salaries, community relations, etc. — with a clear majority (62%) falling into the following three categories: conduct of fellow Direct Support Professionals; staff turnover; and lack of support/recognition from clinicians, managers, and others.

The conduct of fellow Direct Support Professionals was the most frequently cited source of stress expressed by participants. They voiced frustration with fellow staff that “are difficult,” “are not team players,” “fail to follow service plans,” “don’t care,” and “are there just for the paycheck.” Nearly one-third of the responses recorded during the open forums focused on this problem, as did half of the written comments submitted by participants.

Staff turnover — with the resulting high demands placed on staff that don’t leave, or must work mandatory overtime, or otherwise pick up the slack — was the second most frequently cited source of stress, expressed in 16% of the recorded responses.

Rivaling staff turnover as a primary source of stress was the lack of support/respect felt by Direct Support Professionals. Fifteen percent of the recorded responses addressed this issue. Comments such as the following were not uncommon:

**Clinicians don’t listen to us.**

*Information from direct care staff isn’t taken seriously.*

*We are more in tune with consumers and how to express their needs.*

*Supervisors don’t take into account the 24-7 hands-on knowledge of direct support staff.*

*Our opinions are not valued by administration…we’re low on the totem pole.*

*Teams don’t ask for our opinions; changes are made without our input.*
During the forums, Direct Support Professionals were asked, “What type of recognition is important to you?” Keeping in mind that across the regions nearly one-half to three-quarters of the participants reported having to work a second job to boost their income, it was not surprising to hear responses such as: “more money,” “bonuses,” and “merit-based raises.”

While all Direct Support Professionals may appreciate and warrant a boost in their income, most conference participants indicated the other types of recognition that they valued. Outnumbering responses dealing with salary increases were responses which indicated that a “thank you!” in various ways, shapes, and forms would go a long way. The following responses to the question are illustrative:

- A ‘thank you’ once in a while. The verbal acknowledgement: ‘You did a good job.’
- People — supervisors and co-workers — giving praise.
- A ‘thank you’ from the consumers.
- A pat on the back and being told, ‘Thank you for a wonderful job.’
- An e-mail of encouragement.
- A bug or just being told ‘thank you.’
- A note of thanks from a supervisor.
- Staff appreciation days, with supervisors and consumers.
- Award ceremonies.
- Thank you from families.
- Write up positives, put them in our personnel files.
- Participating in decision making.
- Management communicating with staff. This shows staff that management is listening and valuing your input. It shows you are respected.

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2 During the forums, participants were asked whether they had to work second jobs to boost their income.
Conference participants discussed a number of training-related issues including: preferred training formats, trainings that have been most helpful, and topics about which they’d like to learn more.

Responses to preferred training methods and helpful training programs were as varied as were the participants. Some preferred on-site classroom training, others off-site training. Some preferred on-line learning, others hands-on and/or mentoring approaches. Some found behavior training the most helpful, others medication and health management, and still others training programs on specific disability issues. But all expressed a thirst to learn more.

Learning more about disability-related issues was most frequently voiced by participants. Topics on which they desired additional training included, but were not limited to:

- Sign language and/or alternative means of communication
- Individuals with dual diagnoses
- More in depth exposure to behavioral and medical issues
- Side-effects of medications
- The aging process and related issues
- Autism
- Seeing the “whole” person, not just the disability

Not surprisingly, considering what staff voiced as stressors, issues relating to managing their everyday work-life constituted the second most frequently cited category of training needs voiced by attendees. They expressed the desire for additional programs on stress management, time management, effective work habits, dealing with peers, and team work. Other, but less frequently cited training needs voiced by participants pertained to increasing their proficiency in service planning/documentation and their understanding of state or regulatory issues such as budgetary matters and incident management.

In short, the training needs are varied, but the desire for additional training was fundamental and universal, as illustrated by a comment from one Northern Region attendee: “There are always things to learn. Residents are always growing.”
Listening to Voices from the Frontlines

In listening to voices from the frontlines, NYSACRA was struck by the simple eloquence with which they expressed their sense of mission; their satisfaction and even joy in supporting individuals with developmental disabilities achieve their life’s goals and desires; the value they find in the organizations which enable them to pursue what to many is more than just a “job;” and their thirst to learn more, to be even better. Equally striking was their candidness in discussing stressors, frustrations, and sense of lack of appreciation.

We were also struck by the fact that, for many if not most, this was their first opportunity to share their experiences and viewpoints with Direct Support Professionals from other agencies. The heady experience of realizing “I am not alone” as they discussed mutual concerns was almost palpable and it is likely that this is the reason why this segment of NYSACRA’s conferences was given such high ratings.

Most striking, though, were the lessons learned. Direct Support Professionals are a valuable, but unfortunately often untapped, resource. They can serve as barometers of an agency’s value, sources of information on training needs, guides for expressing appreciation and recognition, and all important sounding boards for what others may think are in consumers’ best interests — but only if they are listened to.

As reflected by its regional conferences, NYSACRA is committed to listening to Direct Support Professionals. But more than just listening, we are committed to creating a self-sustaining vehicle through which Direct Support Professionals can continue their dialogue and others can hear and learn — the Direct Support Professional Alliance of New York State (DSPANYS).

We invite others to join us in listening, beginning with this document. What lessons can be learned?

- Have agencies availed themselves of all possible approaches in recognizing the value of Direct Support Professionals?
- To reduce the hiring of unqualified and unprepared employees, and ultimately, staff turnover, are recruitment efforts sufficiently rigorous in orienting prospective employees to the real mission and work entailed in the profession of direct support?
• Are there elements of an agency’s culture that can be cultivated even further to engender Direct Support Professional buy-in?
• Are training programs geared toward Direct Support Professionals’ self-professed needs and desires?
• Do agencies have forums or other mechanisms by which they can routinely solicit the input and advice of Direct Support Professionals?
• Do agencies provide Direct Support Professionals opportunities to network with other Direct Support Professionals to learn more about their profession and to continue in their professional growth?
## Direct Support Professional

### Open Forum Questions

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