

Perspectives

Shoulder to Shoulder: Celebrating the Important Work of Direct Support Workers

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I want to talk about supporting staff, particularly direct support workers, about why it is important and why it is hard to do well, about how we all move forward together when we do, about what we are learning.

What *are* we learning? We are learning to listen better to what staff members are saying: Tell me what my job is, help me get to know this person, offer meaningful training, help me understand how my role fits into the larger scheme of things, give me opportunities to talk about my work, value me and what I do. These are some of the things I like to talk about and sing about.

I live in Madison, Wisconsin, with my wife and two daughters. I work for Options in Community Living (2001), which is a nonprofit supported living agency. We are involved with about 100 people who all live in their own homes in and around Madison. Some people have contact with Options staff just once or twice a week; others have staff members with them around the clock. There are about 150 people who work for Options, the vast majority of whom are direct support workers. As we carry out our day-to-day work with people, these are the values that guide us:

- People have the right to live in their own home.
- People have a desire for community, a need for relationships and connections.
- People have the right to make their own decisions, to have real choices.

We want people to be able to live in their own homes, running their own lives, participating in meaningful ways in community life, having opportunities to contribute, and sharing their gifts (because everybody has a gift). Our challenge is to understand how to do this with 100 very different people in ways that are supportive and honest and life-affirming.

Where I work, we believe that supporting people with disabilities well involves—*requires*—sup-

porting staff well. When we fall short in our efforts, not only do staff members lose out, but so do the people who are getting services from us. Our staff plays a crucial role in carrying out our mission. At Options, when it comes to supporting staff, we do not have it all figured out. I want to be clear about this. I cannot share a recipe that we have perfected, but I can share some of the ingredients that are essential to the recipe. We continue to experiment with the portions and the way the ingredients are measured and added. Sometimes we feel like we are getting it right; other times we do not plan well or get lazy and do not stir it long enough or take a short cut and use the microwave when we really need the stovetop.

Sometimes, even when we try hard, we make mistakes. We try to learn from those mistakes. We fail at times—fail to listen, fail to put into practice what we know to be important. Now, I do not want to dwell on our shortcomings, but they are very real, and these are some of the reasons why supporting staff well is so hard: We do not do what we know we need to do, we say we do not have time for this or that, or a thousand other things get in the way—and it is hard. It takes time. It takes resources.

Not every employee wants or needs the same kind of support, but we keep trying, and we keep learning. It is all part of the journey, and over time we grow and change. We are in a better place than we were a few years ago, and I imagine that in a few years, we will be in a better place than we are today.

Do you remember, those of you who are now, or have been, employed in a support role, what it was like to start learning about the system? I made this journey 18 years ago, when Options hired me as a community support worker. Here is a song I wrote about entering humanserviceland and some of the language I learned along the way.

Learning My ABC's (Based on the Dwight Latham and Moe Jaffe song "I'm My Own Grandpa" with new lyrics by P. Leidy)

Well many years ago, before I lost my hair
Thought my vocabulary could get me anywhere
But human service workers, they speak a special code
So many acronyms, abbreviation overload. . . .

Refrain

I'm learning my ABC's from trained QMRPs I'm in the loop
with this alphabet soup, I'm learning my ABCs
I got a job working for a 501(c)3
I was a CSW did lots of ISPs
Got into CIP and COP and CIP 1-A and CIP 1-B
An RN gave us training about OSHA BBPs
I learned that MOC turned into MPA
SSDI and SSI come from the SSA
ACS at DCDHS controls our cash,
I'm on the mailing list of groups like Arc, ADAPT, and TASH

refrain

A woman with CP who also has MA
She went to her MD a member of the AMA
This MD's HMO was GHC I don't know why
At least she got an Rx for a painful UTI
One gentleman said "I've been told that I have OCD,
Not only that but also ALS and HIV,
They said that I have PMS and ADHD too—
I'm gonna try some LSD and see what that will do."

refrain

I wonder if this phone's a TTY or TDD
I wonder why that PPOC's such a BFD
I wonder if that CNA does MAPC
I wonder whether UCP has a UPC?
There is a woman that I know, she's writing her memoir
She lived inside a CBRF ICF/MR
Well she joined SDS when it was known as PDS
She's been through PFP and ELP and all the rest

refrain

RFDF CLA ICW
MARC VCS CCLS too,
RES and REM CWS,
WORC CSN and LSS
HCFA IEP AODA
BDDS VNS RWJ
I know a lot of letters, just not for what they stand
But what the hey, that's A-OK in Human Service Land!
(Leidy, 2001)

We need to remember that new staff are coming into a new world with new norms and a new language, and even though our work is about real life and assisting people to belong in the community, we need to figure out ways to help staff members understand the system they are joining—not only to survive in their job, but also so they can begin to learn ways to help prevent the system from running people's lives.

People who provide direct support are saying three things (they are saying more than three things, but I am collapsing them into three categories).

They are saying, "Tell me what my job is." Who *are* the individuals you are hiring me to work with? Help me get to know them. Help me understand what their life has been like and what dreams we might work toward. Help me understand about difficult or unusual things. What are the expectations? What is my specific role? What kind of supervision can I expect? Who will be available when I need to talk to someone?

They are also saying "Give me opportunities to talk about my work." Do not leave me hanging out there. Those of you who have an office see each other a lot and can check in and get support more easily. I am spending the weekend with someone miles away from the office. Be available to me. Return my calls. Know that there are times when I want to engage with others who do this work. I want my supervisor to reach out to me, and not just when something is wrong. I want to attend training sessions, and not just trainings about rules and regulations and procedures. Some direct support workers are saying "I want this to be my career, and I want to talk to others about this because my family does not understand. Help me find ways to have these conversations. As I get to know my job and the people I am working with, let's talk about how it is going and if there are opportunities for me to stretch, to try new things, to grow." Or, "I'm a live-in worker, I want to talk about the challenge of sharing the space and having a job where my job is at my home, only it's not just my home."

The third thing people are saying is: "Value me and what I do." As we are all well aware, by and large, direct support workers are underpaid. The work carries a fairly low status (i.e., the way our society views this occupation). So when someone comes along who is a good match for this work, it is in everybody's interest to value that person and try to keep him or her. I think we would all agree that not just anybody could do this work well.

We want more people to apply, and we need to keep thinking of creative ways to attract them. We need, however, to think about what value *we* place on the work and how we communicate that to people "out there" if we care about influencing how our society views the work's importance. There is a radio ad that I hear from time to time, put out by a big service provider. The purpose of the ad is to get people to call and apply to be a direct support worker. One of the lines they use goes like this: "YOU can get PAID to go to movies!!!" ("Yeah, uh, I'm calling about that ad where, like, I can get paid to

go to movies 'n' stuff . . . yeah, I'm interested in that kind of a job").

Value me and what I do. Not just with words. If you value me and my role, you will support the relationship I have with Mary, whom I support. When we are supporting staff well, and when we are supporting the people who rely on us well, an important part of what we are doing is honoring these relationships. Gerri and Jolene have an important and deep relationship; Jolene has worked with Gerri for 10 years. Together, they have gone through many of the things that people who are in a relationship go through together: joy, sorrow, anger, boredom, unpredictability, predictability. For each of them, it is important that we work to support the relationship. People like Jolene tell us, if we will listen, that one of the primary reasons they are still in the work after many years is because of the relationships. Here is something Jolene, who is in her mid-50s, said: "I could probably find a job where I make more money and a job that isn't as hard, but I get so much out of this. I feel like without even trying to, I stumbled across the most meaningful work I've ever had." A huge part of what makes it meaningful for Jolene is the *relationship*.

If you value me and what I do, you will help advocate with the state or county or the corporate office, advocate for benefits, for a living wage. You will listen to me if I need you to, even if you have had a long day and it is the last thing you want to do at the moment. I have had a long day too; maybe longer than yours. If you value me you will consider my ideas, suggestions for improving support. You'll hear what I'm saying, even if we disagree.

One of the things that I do in my job is contact staff members: part time or full time or live-in folks—and just ask how things are going, not as their supervisor, because I am not their supervisor, but as one of the ways to create a link between direct support staff and our management team and because sometimes we *all* need to be asked, "How's it going?"

So one day I called Kelly, who had been working weekends for 2 years and was a great support worker, an excellent employee. She said she would like to meet with me. So we met, and she told me she had decided to resign—not because she wanted to leave her job, but because she was tired of not being heard, not feeling valued, not being given opportunities to talk about important things with her coworkers and supervisor. Her supervisor, she

said, was always in a rush and it was *his* agenda that got discussed. She needed some time from him! She also had some ideas about improving support for the women she was working with, but no one was listening. She felt that the attitude towards her was "You're great, but you're just the weekend worker."

This went on for too long, so she left. By the time Options finally heard what she was saying, it was too late, too late for Kelly, but not too late for us to learn an important lesson. I came away from that meeting alarmed: "Oh my God! What are we doing?" The experience helped teach us as an organization and lit a fire for some needed change, including an organizational restructuring.

People are saying, I want to feel like I am doing something important and making a difference. If you value me you will demonstrate that my work matters, that you appreciate what I do. The person I support may or may not be able or willing to show me this; and it is important.

You can show this by telling me—that's one way, kind of simple, but too often forgotten. You can send a card! Again, something so simple, but when we do this, people say it makes them feel good. Doesn't it make you feel good to get a note of appreciation in the mail? The old fashioned mail, not e-mail. Thanks for what you do, you make a difference.

Sometimes we send people flowers. Now who doesn't love to get flowers unexpectedly? I'll tell you who: Deborah. She is allergic to them. We don't send her flowers; and I'll tell you who else—Charlene. She is not a flower person. We know this about her. So recently we sent Charlene a gift certificate to a restaurant most people I know do not really like, but Charlene does! One size does not fit all when it comes to showing appreciation.

We also have something called "surprise time off," which is pretty much what it sounds like. If somebody who has been working extra hard lately or going through a particularly challenging time with his or her job, we might call up and say, "How would you like to have Saturday off and still get paid?" (When they're done laughing, we tell them we are serious.)

A few years back we started having annual appreciation dinners for Options employees. These are modest, but meaningful and fun affairs where we rent a nice place and Options management team serves dinner to everyone who is there. A couple of short speeches by our Board president and direc-

tor, a few words about each staff person who attends, door prizes, song and dance.

We also formed a workgroup called the SWAT group, SWAT standing for Support Worker Action Team. The group was born after a survey of direct support workers a few years ago. It is open to any direct support worker and has about five regular members; and I am part of the group as well. Remember I mentioned that we changed our organizational structure? Part of that involved creating the position I now have, one purpose of which is to help increase our capacity to address these kinds of issues and try to keep them on the front burner.

SWAT—and with a name like SWAT, you just *gotta* believe these issues will stay on the front burner—takes responsibility for helping Options pay particular attention to issues of interest to direct support workers, and my presence is one way of providing a link to the office-based staff and management team. The group has focused on ways of improving communication, organizing social events and retreats, and bridging the gap that can be felt between direct support workers and other staff members.

What about flexibility? We ask people who do direct support work to be flexible. Do we show flexibility to them as well? Sure, there are limits, and I think we have encountered most of them! It is important, however, not to be too narrow in what those limits might be. Sue was a college student and had been a live-in support person for Beth for a year and a half. They had a good thing going. Then Sue had an opportunity to take a 6 week class—in Jordan, the country.

Would we consider holding her job so she could go away, and then come back to still be Beth's roommate? That was not a quick "Sure!" There was a lot to consider. Beth's feelings, and the impact on her, was the biggest consideration. Then the challenge, some would say nightmare, of scheduling people to fill in, and the added cost to do that. Sue was not expecting paid time off, but it would cost Options more to have others work in her place

Beth said yes. Options said yes. Had she only been working a few months, we most likely would have said no; but we knew her, and she and Beth had a good relationship. So in the end it made sense for us to say yes. (She *did* come back.)

Supporting people with disabilities well involves supporting staff well. It requires us to understand we truly are all in this together, all of us. It's not "us and them," it is just us—shoulder to shoulder to shoulder to shoulder. Moving forward *together* is the key. We do not move very far forward if we are trying to support people with disabilities without really paying attention to what staff members need, nor do we move forward when we find ourselves "supporting staff" at the expense of the person being served.

Hearing what staff members are saying is a vital part of the whole support picture. This takes real listening and a commitment to take action. When we listen and make a commitment and act on that commitment, we start to discover ways to meaningfully support staff, *and* we create ways of keeping it alive in our organizations.

Tell me what my job is. Give me opportunities to talk about it. Value me and the work I do.

References

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