

Doing Our Best Work

10 Ingredients of Quality Support

Peter Leidy
2922 Lakeland Ave
Madison, WI 53704
www.peterleidy.com

I would like to share some thoughts with you about the important roles that direct support professionals* can play in the lives of people with disabilities.

But first, a word about the match between the person being supported and the person doing the supporting: it matters. A lot. It can be hard to make the right match. I spent many years recruiting people to provide direct support when I worked for Options in Community Living in Madison, Wisconsin. I learned that there are wonderful, determined, creative people who find their way into the world of direct support. And I learned there are people who show interest but who are not well suited for this work. Sometimes the desperation to “fill shifts” or “find coverage” can lead to lowered standards. We need to aim high and pay close attention to the quality of the match, because it makes a real difference.

*There are many terms for this kind of position. Some people prefer “direct support professional” because they feel it reflects a higher status of the job. Others don’t like being called a professional because they feel it puts distance between them and the person they support. As with most aspects of the work, one size does not fit all.

This paper and companion video began as a keynote speech given at the 12th Annual New Hampshire Direct Support Professionals Conference, October 27, 2006, in Bartlett, New Hampshire. A grant from the New Hampshire Council on Developmental Disabilities supported production of the video.

Many people in one way or another contributed to the ideas offered here, and I would like to acknowledge, in addition to the New Hampshire DD Council: Robin Carlson, David Ouellette, and many New Hampshire direct support professionals; Options in Community Living, Christine Mayer, Joanne O’Meara, and Marcie Brost of Wisconsin; John O’Brien and Connie Lyle O’Brien from Georgia; David Pitonyak from Virginia, and Jack Yates from Massachusetts.

My hope is that readers (and viewers of the video) will use this as a discussion starter. This is not “the final word” on quality, but rather a collection of ideas and opinions based on what I have learned from people with disabilities, families, assistants, and many teachers from many places.

I wrote this when I was recruiting staff, trying to find the right matches;
these were some real people who called but were not hired:

Help Wanted

(based on "Tom's Diner" by Suzanne Vega)

*I am sitting in my office having poured a cup of coffee
Monday morning waiting for the phone to ring with eager callers
Responding to the ad that I placed in the Sunday paper
I hope they call me soon, we have a lot of jobs to fill*

*Any moment they'll start calling I just know it I can feel it
There's no reason for them not to, I'm a friendly guy to talk to
Waiting for the telephone and for the caffeine stimulation
And then the phone is ringing and I lunge with both my hands*

*This rapid movement spills my coffee so I wipe as I am talking
To the man who is inquiring of positions we have open
He says he wants a job but can't remember just which type,
And could I tell him what our ad says so he remembers why he called*

*I take another call, it is a woman who seems qualified
The caffeine's working well, I speak with great enthusiasm
I ask her to come interview, she says she'll be right over
I tell her where we are, and then the argument begins*

*She tells me our location is right next to Westgate Mall
But I correct her saying no, we are two miles east of Downtown
She's absolutely sure she's right, I say I've worked here 10 years
But she persists so I give up, and tell her she is right*

*Next thing that I know I find I'm talking to a woman
Says she worked a couple years in a carnival that travels
I can't call them for a reference – they're on the road in Indiana
And she says her medication blurs her vision and they won't
renew her license but she still drives her car*

*Another caller tells me of her criminal convictions
She says they should not matter 'cause she really wants to work here
Besides that there's a story behind each and every one of them
Plus they happened very long ago—except the recent ones*

*Speaking of convictions I remember once this man
Who came over to our office in his search for employment
His application listed his address as the county jail
And references to contact were 3 sheriff's deputies...*

**"Help Wanted" is on Greetings from Human Serviceland (CD), Peter Leidy, 2001.
Available, along with Peter's other CDs, at www.peterleidy.com**

Again, finding the right match is not easy. And once we do find it, it's important that we do what we can to support it, recognizing how powerful and precious a good match is. So part of the responsibility for nurturing direct support workers who are going to be at their best belongs to those who support and supervise them. This can be people with disabilities, family members, guardians, and/or supervisors and other staff. Together, the person being supported, the supporter, and those teaching and supporting them can develop the qualities that make an excellent direct support worker.

So, when are we at our best? What are the beliefs and practices that lead to a higher degree of quality? I'm glad you asked! I would like to suggest these 10 ingredients of quality support:

1. We believe in positive possibilities for the person we support.

Believing in positive possibilities means we see potential. We see a person's gifts and capacities. We all have something to offer. Good support means we believe good things can happen for anyone and everyone. We imagine a bright future!

And it all starts with the belief that the person is 100% there. We presume competence. We see a whole person, not someone who needs to be fixed, not a "40-year-old with the mental age of a 2-year-old." We believe that people are *all there*. We humans have our differences, but we're all -- *all there*. When you believe that, and can imagine a positive future, you can really make a difference in someone's life.

Great direct support providers I know question our system's practice of compartmentalizing people, of distinguishing between "high functioning" and "low functioning." They have what I consider a healthy suspicion of the value of such designations.

When we are at our best, we allow people to surprise us with their abilities and accomplishments. We expect the person to learn and grow, and we are open to learning and growing as well.

Robin Carlson, who supports two men in New Hampshire, writes: *"Everyone has a gift to offer this world, and everyone wants to love, be loved, and belong. As a Direct Support Professional, once you are awakened to putting the human into service, the positive possibilities in life are endless!"*

2. Our work is about helping people build relationships and take their rightful place as community members.

Good direct support is a balancing act: we are part of the human service system but skeptical of it at the same time. We see its limits and we work to prevent it from being all there is for people.

In human serviceland, there is the risk that people will be seen as clients, residents, cases—lost in the maze of labels, acronyms, and a sprawling bureaucracy. In community, people are sisters, brothers, citizens, friends, coworkers, and neighbors. When we are doing our best, we see the community as welcoming and full of opportunities.

Supporting people to build relationships and become real community members – **this** is what the work is all about. Experiencing community is much more than going on “outing.” It is about relationships and valued roles.

I often hear people talk about their work as “doing cares,” and meet people who are in fact receiving good personal care assistance but don’t have much of a life. What good is “good care” if the person is lonely?

People are at great risk of loneliness. Quality direct support means taking an active role in moving from segregation to integration, from seclusion and exclusion to inclusion. As a direct support professional, as a personal assistant, you are well positioned to help a person be known, to shine, to share their gifts and skills with others outside of the service system. People “out there” often don’t even know what they are missing, and you can be the bridge.

3. We listen deeply.

Good support requires us to be good listeners. One of the best ways I have heard this described came from Christine Mayer of Madison, Wisconsin. I have known Christine since 1987 when a team of us helped her move from one of the many institutions in which she had lived to her first real home in the community. She said:

If you’re going to work with me, you have to listen to me. And you can’t just listen with your ears, or it will go to your head too fast. You have to listen with your whole body. If you listen slow, with your whole self, some of what I say will enter your heart.

Wow, right? Doing our best means actively listening, being fully present, and letting what a person communicates to us – whether with words or not – deeply touch us. Some people do not communicate with words. Some, like

Christine, use words but have old deep wounds that may be too painful to talk about. So we have to listen with our whole body.

I often meet people in my work who engage in some form of challenging behavior. Very often this behavior is the person's way of communicating something they feel strongly about. "I don't like living here," or "This staff person scares me," or "I am bored out of my mind," or "I am in physical pain."

Someone I met who was called an eloper frequently left his group home without bothering to tell anyone. This caused a problem for staff, because they were told their job was to make sure he stayed put. It turns out he hated living there. He was bored, he did not like his housemates, and no one really listened to him or tried to address his concerns. He figured his only way out was to just leave. This behavior – which we might actually see as reasonable, given the situation (what would YOU do if you were in his shoes?) – gets him in trouble, irritates staff, gains him a new label and reputation, and creates more work for everyone. His "challenging behavior" is a direct result of not being listened to and not being supported in a way that worked for him.

When we are doing our best work, we are actively listening to the person -- with more than just our ears.

4. We value teamwork and are willing to work as part of a team.

In my experience, the best support to people comes through teamwork. No one doing this work should feel alone or isolated. It's important to work together, support each other, collaborate, and feel we are connected to a team that shares a common vision. When we're working together, *and* when we feel supported and valued, we're able to better support others.

Working well together does not mean always agreeing with each other. It does not mean an absence of conflict. The most effective teams practice good communication, question each other, sometimes agree to disagree, and respect and appreciate each other's unique contributions. They accept responsibility to address difficult issues that arise.

When our teamwork is at its best, we help each other out when we can. We back each other up. We question each other when we don't understand. We show self-awareness, recognizing our individual limitations as well as our strengths. We hope our teammates are flexible, so we try to be flexible. We work collaboratively. We expect support and guidance from supervisors.

Often, a breakdown in support occurs not because of something directly related to the person being supported, but rather because of conflicts among

team members. Sometimes the person's needs and desires get lost in the clamor of a team in chaos or out of touch with its true purpose. Effective teams recognize this risk and work to communicate well and to keep the focus clear. "Mike's team" is first and foremost about Mike and the support he wants and needs. Mike needs to stay at the center!

And a note on communication books – the logs often used to share information among staff: In my experience, often these cause more problems than they prevent or solve. I have seen "I HOPE EVERYONE HAS A WONDERFUL DAY!!" written in all capitals interpreted as a sarcastic, "Yeah, right – she didn't mean that – she's mad at everyone." Or how helpful do you think this is: "Thanks for leaving the trash (once again) for me to take out! No, really, I don't mind." Or: "Paul didn't look very good when he got to work...does anyone there do laundry??" Written notes may be necessary, but they are not always a good substitute for talking.

5. We are curious.

Quality support involves asking and wondering. We wonder what is important—really fundamentally important to people. We strive to learn about what choice and control and relationships and power and freedom mean to each person.

I think we should ask more questions, and not always feel like we need all the answers right now. In the realm of relationships, which is what our work is about, there is a lot of murkiness. Human interaction can be complicated!

Let's be comfortable admitting we don't have all the answers. Let's wonder together.

Wonder things like: What could we do better? What could we try that we haven't thought of yet? What's a more creative way of spending time with this person? How can we listen more effectively? How can we support her to have some ties to others? What might be the underlying cause of this aggressive behavior? What could unlock the door for Anne? How can we really help? What unique gifts does this person have? Curiosity is a good thing!

There can be a lot of pressure in this work to know all the answers, and get it right the first time. We need to try our best not to make mistakes but we also need to accept that we are human. We don't know everything, so we ask, we explore, and we wonder.

Often, when someone is engaging in behavior that others might find problematic, the response is to intervene and try to stop it, or change it, without the crucial step of wondering what is causing this to happen.

Curiosity involves being open to learning, and considering new ideas. As people doing this important work, we have to listen for opportunities for our own learning, for growth, and for raising the status of direct support work as we help raise the status of people with disabilities in our communities.

6. We pay attention to how we communicate with -- and about -- people we support.

When we are doing our best work, we are treating people we support with respect. We all should expect to be treated with respect. Language is one of the ways we demonstrate this.

Do we lift people up, or bring people down? Do we help raise people's status in our community? How do we introduce people to others--like they are our equals, or like they are somehow not quite normal?

If assisting people to have deeper relationships is important to us, then we need to be cognizant of how we are helping people present themselves. Depending on the person's method of communication or life experience, we may play an important role as a bridge to connect people to others. Thoughtful supporters consider how to best say to neighbors and other community members, "This is someone you might like to get to know."

I was facilitating a meeting recently with a team of staff supporting two women who had just moved from a county nursing home. People were sharing how they felt things were going so far. Beth said, "I would appreciate it if we could get away from the baby talk. These are grown women. When I hear staff talking to them like children, I cringe."

We need to see a whole person. If we are supporting an adult, our tone of voice, our mannerisms, our language should reflect that. This is important whether we are with the person at home, at work, at an appointment, at a café, at a recreational activity – anywhere.

With our words, tone, and attitude, we send powerful messages to the person we support and to family and community members we encounter.

7. Good support comes from good relationships

We support people best by having good relationships with them. Maybe this sounds obvious, but it is not the norm in the human service biz. Our system tends to think of direct support roles as "coverage." As long as we have passed inspection, as long as we are "hirable", we are good to go – and we provide coverage.

But quality comes through relationships. It comes by paying attention to the match. The match between you and a person you support makes all the difference. Christine and Joanne are a match. When Joanne is supporting Christine, what she does and who she is to Christine is based on a long period of getting to know each other and caring about each other. Not just anyone can show up to support Christine. And Christine does not need coverage; she needs trusting, enduring relationships.

Often, the way service providers organize themselves does not allow for good relationships to develop. Consider this: "We need to pull you from Matt and Tony's house to fill a hole somewhere else." If this sounds unfamiliar, good! But it happens a lot. Staff are moved around without much thought given to their relationship with people they are supporting.

If we really listen to people on the receiving end of support, we understand that supporters are not interchangeable. People say things like, "I like Tammy and the way she does what I need. We have a good time together. It took a while for me to trust her. When she can't be here and someone else has to fill in, it's not the same." Now, we don't always have the perfect match, and life is unpredictable. But when the importance of the relationship is understood – if we can prioritize a good match over coverage – the quality is higher.

It is important, however, to remember ingredient #2 above. The relationship between you and the person(s) you support matters greatly, but it's not enough. Quality of life involves meaningful relationships with a variety of people – not just people in paid support roles. Here is a great way of saying it:

"By finding more and more interesting relationships with the people they assist, direct support workers become generators of possibility. This is most powerful when they...discover ways to extend and strengthen a person's network of relationships and valued social roles." John O'Brien, *An Ethics of Possibility*

8. We ask, "What brings out the best in this person?"

We can't begin to answer this important question if we do not have a relationship with the person. What do you notice over time? When is this person most alive, most herself, most content, most relaxed, most vibrant? Who in the person's life influences this? What conditions bring out the best?

You may talk about what you notice with the person, with your team, or with your supervisor. People who have direct support roles are in a good position to notice. If you keep the person first, show some curiosity, develop a

relationship built on trust, and keep showing up, you will likely learn a lot about who and what brings out the best.

I am reminded of Janet, whose days were spent at a sheltered workshop. She didn't like this work. It was not interesting to her, and those around Janet certainly did not bring out the best in her.

Eventually, people supporting Janet began to wonder how she could have a more meaningful job. How could she spend her work time in a way that would bring out her best? Following up on some of Janet's interests (loud music and good looking men) her supporters found her a job at a local nightclub. This good match between Janet and her job helped bring out her best. Not only did it help Janet feel happier and more excited about work, but she also became more fun and interesting to those around her. A new story emerged.

People supported by our system are often "placed" in their home or job or day activity, and often, the system gets this placement wrong. In fact, quality support is not *about* placement. It's about getting to know a person and having the desire and commitment to--together with the person--work on building a full life. We need to be on the lookout for ways to increase the opportunities for people to be with other people, places, and conditions that bring out the best.

9. We see ourselves as allies rather than managers or caretakers.

If you provide support to someone with a disability, how do you describe what you do? How do you see your role? The best examples of direct support that I have seen have the look and feel of people in alliance with one another. We're on the same side. We have power together rather than "I have power over you because I'm your staff." I assist you; I am your ally. I understand my role as a supporter, a relationship-builder, more than a manager of your life, more than simply a caretaker.

I am amazed—and distressed—at how often my work brings me in contact with situations where staff are spending most of their time telling people with disabilities what to do. Imagine how tiring that must be. And how limiting. And, very often, how disrespectful.

I met a woman named Teri, who was brought to my attention because she was running away from her group home, threatening staff, and becoming aggressive. I was asked to take a look at her support arrangement, spend some time with her, talk to her staff, and make some recommendations.

It became clear in almost no time that this charming and chatty woman was living under conditions almost any of us would reject. She did not like her

living arrangement. She did not feel comfortable with most of her support staff. She was bored most of the day. She was supposed to comply with a service plan and “house rules” that felt oppressive to her. It was not hard to see why she felt ornery a lot of the time, and why she took off when she got the chance.

Teri described a recent interaction with one of the group home staff. *“She told me to clean my room. I wasn’t in the mood to clean-- I told her I’d do it later. She said ‘You need to do it now.’ Finally I yelled at her. I said why are you always telling me what to do? I told her this was MY house and she is not my boss. Then I got in trouble.”*

I wish this were an isolated incident. But it’s an example of an “us-them” mentality that leaves no room for seeing the whole person, for seeing positive possibilities. It’s power over rather than power with. Quality direct support does not look like this.

When we can shift, and approach the work as allies with people, we see more of what we have in common as humans. This approach is more respectful and ultimately much more satisfying.

When direct support staff understand their roles primarily as paying attention to “cares” and caretaking, it not only may limit someone’s growth; it also may look to others– neighbors and other community members—like the person is not very capable.

John O’Brien writes about guards (the manager/supervisor type of direct support worker) and keepers (those who are oriented mostly to caretaking) and offers this:

*“Many direct support workers rise above showing up in people’s lives as guards or keepers and show up as **good company**.” John O’Brien, *An Ethics of Possibility**

The best direct support I know of comes about through relationships where people DO show up as good company, and see each other as allies -- not manager and managee, or caretaker and caretakee, but allies.

10. We question structures and policies that limit relationships or inhibit freedom.

If we can agree that relationships, freedom, and meaningful lives are things that we hold dear, and that people we support hold dear, then we work to build good relationships, and work for freedom, and work for meaningful ways for people to spend their days.

When our service system is at its best, it can—in partnership with individuals, families, and community—do good work and change lives for the better. But much of the time, the system can and does erect barriers to people’s opportunities for good lives. These barriers come in many forms, including structures, behavior plans, policies, regulations, and attitudes. And when you – when WE – are aware of a barrier, we need to question it. Even if we don’t know what to do about it, we need to acknowledge it, talk with others, and look for ways around it.

Teri, whom I mentioned earlier, faces a major barrier to having a better life: She has to live in a house she doesn’t like with people she doesn’t like, and with most of the power resting in the hands of staff. We can choose to say, “This is the best we can do—life isn’t perfect for any of us.” Or we can say, “This is not right. We have a responsibility to do better on Teri’s behalf.” It may be hard to make all the necessary changes for Teri. But does that mean we don’t even try?

Most support workers I’ve talked to – and that’s a lot – say they are prevented in some way, whether by a government regulation or by their employer’s policies, from helping someone meet others and experience typical community life. They *want* to be able to do this (“It makes the work much more fun and interesting,” one person told me recently) but are stuck, held in check by some interpretation of confidentiality or liability that limits opportunities for real life experiences.

Sometimes when I’m talking with groups of people about this, I share a quote from the Dalai Lama: *“Learn the rules so you know how to break them properly.”* And of course I say that I am not advocating that everyone in the room go back to their workplace and start breaking rules. But we have to acknowledge that some of our rules are hurting people. They are keeping people in boxes. They are causing people to be treated like they are not fully human. And so, if we are going to be honest, there are some rules that need to be broken – or changed.

As direct support professionals, you may bump into unjust policies, misguided support plans, or support arrangements that are not serving the person’s best interest. Quality support involves raising questions when this happens. What too many managers and administrators fail to see, I’m afraid, is that personal assistants are often stuck between doing what they know is right and following a policy (or job expectation) they know is wrong. I have met dozens of people who ended up leaving their job (and the relationships with the people they supported) because of this very issue. We do not need to be contributing to already high turnover rates. More conversation is needed.

And so, as part of a movement that is gradually shifting from segregation to integration, from exclusion to inclusion, from sheltered lives to more meaningful and more real lives, we understand that part of our job is to question the barriers to relationships and freedom.

A final note:

Keep the conversation going! Do what you can, whoever you are and wherever you are, to see positive possibilities. Bring your gifts to the table and share them. There is a difference between existing and *really living*. There is a difference between surviving and *thriving*. It's about relationships. Remember that all of us, as Christine Mayer reminds us, need to be truly heard, and that all of us, as Robin Carlson reminds us, need to love, be loved, and belong. *All of us*.

Questions for discussion:

How do you describe your job?

In what ways do you see positive possibilities for someone you support?

In what ways do you help someone you support assume valued roles in their community?

What are some of the gifts you bring to the work you do and the relationships you have?

How do you describe the kind of relationship you have with someone you support? What do these words mean to you as you think of this relationship:

- caregiver
- friend
- professional
- assistant
- worker

What helps remind you why you are doing this work?

What makes for a good team?

What has been your response when you have faced a barrier that limits relationship building or inhibits a person's freedom?

What helps you feel respected, valued, and supported in your work?

Resources:

O'Brien, J, and Mount, B. *Make a Difference: A Guidebook for Person-Centered Direct Support*, Inclusion Press, 2005. www.inclusion.com

O'Brien, J. (January, 2007) An Ethics of Possibility In J. Strully, Ed. Special Issue on Systems Change in Adult Services TASH Connections 33:1/2, 13-14. (This article is also posted as a free download at <http://www.inclusion.com/jobrien.html>).

O'Brien, J. and Lyle O'Brien, C: Many must-read articles can be found at <http://thechp.syr.edu/rsapub.htm>

Carlson, R. "Walking the Talk: A DSP Perspective," www.nhdsp.org, April 2008

Pitonyak, D. "Toolbox for Change", available at David's website: www.dimage.com

Leidy, P. *Doing Our Best Work* video (2008) can be ordered from the New Hampshire Council on Developmental Disabilities www.nhcdd.org and from Inclusion Press www.inclusion.com as well as from Peter's site www.peterleidy.com

Leidy, P. *Shoulder to Shoulder: Celebrating the Importance of Direct Support Workers*, in the American Association of Intellectual and Developmental Disabilities (formerly AAMR) publication *MR*, August 2004. Also available at www.peterleidy.com

Messinger, G. and Mills, L. *Sharing Community: Strategies, Tips, and Lessons Learned from Community Building at Options*, 2005. See <http://www.optionsmadison.com/pages/publicat.html>

Learn more about Options in Community Living: www.optionsmadison.com