

LITTLE PAPERS:

BRIEF PAPERS TO PROMPT DISCUSSION AND REFLECTION AMONG DIRECT SERVICE WORKERS

THE WORK OF PROVIDING DAY TO DAY SUPPORT TO ADULTS WITH DEVELOPMENTAL DISABILITIES IS COMPLEX, VARIABLE, AND REQUIRES A BROAD RANGE OF SKILLS AND PERSONAL QUALITIES. WHAT STANDS OUT ABOUT THE WORK IS THAT IS PERSONAL. THE WORK INVOLVES THE HEART AS WELL AS THE MIND.

TO UNDERSTAND THE WORK, TO MANAGE IT SO THAT IT IS BENEFICIAL TO THE PERSON WHO RECEIVES THE SUPPORT AND STRENGTHENING TO THE WORKER WHO PROVIDES IT, ONE MUST RECOGNIZE THAT THE DEFINING ASPECT IS THE RELATIONSHIP FORGED BETWEEN THE WORKER AND THE PERSON RELYING ON HIS OR HER SUPPORT. SUCCESS IN DIRECT SUPPORT HAS LESS TO DO WITH THE MASTERY OF TASKS AND MORE TO DO WITH THE BUILDING OF TRUSTING, SUPPORTIVE, RESPECTFUL RELATIONSHIPS.

THESE PAPERS OFFER A VARIETY OF LAUNCHING POINTS FOR REFLECTION AND DISCUSSION ABOUT THE RELATIONAL QUALITY OF DIRECT SUPPORT. EACH ASKS QUESTIONS THAT HELP WORKERS TAKE A FRESH LOOK AT THEIR WORK. THE QUESTIONS PROMPT THINKING AND SHARING OF PERSPECTIVES ON THE VALUE OF THIS WORK. EACH PAPER OFFERS AN OPPORTUNITY FOR WORKERS TO DECIDE THAT THIS WORK IS A GOOD MATCH FOR THEM AND THAT DIRECT SERVICE WORK CAN BE GOOD WORK WORTHY OF LONG TERM COMMITMENT.

THESE PAPERS ARE DESIGNED TO BE READ AND DISCUSSED IN SMALL GROUPS OF DIRECT SERVICE WORKERS.

THE PAPERS ARE SHARED AS A PART OF THE DIRECT SERVICE WORKFORCE INITIATIVE OF THE WISCONSIN COUNCIL ON DEVELOPMENTAL DISABILITIES AND THE DEVELOPMENTAL DISABILITIES SECTION OF THE DHFS DIVISION OF DISABILITY AND ELDER SERVICES.

***Marcie Brost and Howard Mandeville, Editors,
Community Supported Living Series***

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TABLE OF CONTENTS

10 Things I'd Like to Tell My Employer by Peter Leidy	3
Bringing Who We Are to What We Do by Peter Leidy	8
When Are You Going to Get a REAL Job? by Peter Leidy	11
Making Connections: Direct Support Staff as Bridge Builders by Peter Leidy	14
Whose Life Is It, Anyway? by Peter Leidy	18
What'd I Say? by Peter Leidy	23
Finding the Lines: Relationship Boundaries By Phoebe Hefko	26
About the Little Papers and their Authors	30

10 Things I'd Like to Tell My Employer

By Peter Leidy

There is much to be learned from the experiences of direct support workers. For agencies supporting people with developmental disabilities; for elected officials deciding how public money is spent; for people with disabilities and their families. If you are reading this, you are likely aware that support workers generally have low pay, low benefits, and low status. Yet they do very important work.

As more citizens previously separated from the community begin to have meaningful lives, and as options increase for individuals to move out from their family's home, we see a greater need for direct support workers. It is a happy fact that as more people with disabilities gain opportunities for individualized support to live and work in the community, more personal assistants are needed.

As agencies employing direct care staff learn to listen more closely to them, there is more reason to be hopeful about the future of community life for people with disabilities. Hearing what staff on the frontlines have to say can and should lead to better support of staff *and* people with disabilities.

Despite the great diversity among direct support staff, certain messages continue to rise to the surface. These recurring themes, if heard and acted upon, can result in better support to staff, a reduction in turnover, and improved quality of life for people being served. This "Top Ten" list reflects many of these themes, as heard over time from support workers in Wisconsin and elsewhere. It is not an exhaustive list, nor are the points in a particular order. (Please note: "Take this job and shove it" didn't make the top 10.)

Let's look at the list from the point of view of "Barb", a direct support worker who assists "Theresa", and what she would say to the agency she works for. They have worked together for two years, since Theresa moved out of a large facility into her own home.

1. Help me get off to a good start.

Here are some thoughts as I reflect on when I began working with Theresa, and knowing what I know now. There's a lot to absorb at the start of a new job. I need to learn about the agency, and mostly I need to learn about Theresa. And she needs to learn about me. Remember when you started – that feeling of being new? I am excited, and I am happy to have been offered this job, and I'm a bit scared. Everything is new, I have a lot of responsibility, and I want to do a good job.

I would like you to tell me all about Theresa, and give Theresa plenty of room to tell me all about herself, in whatever ways she can. I mean the things I need to know to do my job, and the things Theresa wants me to know. I don't expect Theresa's life to be an open book for me to read – after all, we're just meeting each other. But there are things I need to know, most of which are things Theresa wants me to know. What's important to her? What are the musts and the must-nots? Help me learn how these influence my required job duties, and be specific about what those duties are.

2. Be aware of my isolation.

This is a one-to-one job. I like it that way. Being able to spend time assisting Theresa and having the kind of relationship we do works for me. Most of the time, it is a satisfying way to spend my work time. But sometimes I feel pretty alone. I don't have co-workers around much. I don't often experience working with a team, even though there are others who support Theresa.

It would be nice to occasionally have get-togethers with other people who do this kind of work, to find out what it's like for them, or why they got involved doing this. Or to talk about what a great day Theresa and I just had – or what a difficult day we just had. A lot of people meet friends through work, and with direct support that can be difficult.

3. Ask for my input on issues related to my job.

As Theresa and I get to know each other better over time, I will gain some valuable insights about her. My knowledge and understanding could be useful in the support we're all providing for her. See my role over time with Theresa evolve from "Tell me what I need to know and do" in the beginning to "Let me tell you what I'm learning that we all need to know" as time goes on. I become a valuable resource for determining with you and Theresa what the agency's support should look like. Also, I begin to seek ways that I can stretch in my job – to try new things, to learn more, and to grow.

4. Communication and supervision are important to me.

There are several people directly involved with Theresa's support. We need to get together on a regular basis, both for sharing important information and for supporting each other.

As my supervisor, talk with me about supervision. It may mean something different to me than it does to you. Getting to know each other is important. Having regular contact is important. Checking in with me (rather than checking *up* on me) is important. Letting me know when you think things are going well, and not just when something is wrong, is important. Being available when I need to talk to you, or making sure someone else is, and getting back to me in a timely fashion when I try to reach you – these are all important.

When we do talk, I need you to hear what I'm saying. I know you're busy, and time is tight. But please listen to me. Find out what's on my mind. If you tell me you are going to do something, follow up with me about it. Let me know you did it, or whether there will be a delay. If we have not talked in a while, don't assume everything is okay. In this type of work, no news is not necessarily good news.

5. Offer training opportunities beyond what's required.

I *love* the blood borne pathogens training!! Who doesn't? But there are so many more learning opportunities available (or which could be developed) that would be beneficial to me. I realize resources are limited. I know that time taken away from being with Theresa means finding someone else to work with her. Still, ongoing learning experiences are important to support workers – to gain knowledge, to help me do my job better, to get rejuvenated, to meet other people.

6. I like my job and I want to keep it.

I like Theresa, and I like spending time with her. It is a good job, I do it well, and this is important to me. I don't want to work in a job that I don't like simply because I need income. I want to look forward to my job, at least most of the time, and be able to put positive energy into it. I'm telling you this because I

think it's important that you know how I feel about my work. I want you to know that I want to keep doing it, because if you know I'm invested in it, there is a greater chance that you'll invest more in me, and that's good for all of us.

7. Acknowledge my work and me.

Sometimes my work is extremely challenging. Sometimes, others don't seem to believe that what I am doing is very important. There are days when it feels like no one cares that I'm here, doing my job – even Theresa. Please understand that at times I need encouragement or a pat on the back, or just someone to say, "What you do is important and valuable." I may get messages from family, friends, society that tell me otherwise. So I need *you* to show me you care, that what I do makes a difference.

8. I don't get paid a fair wage.

I'm not whining; I'm stating a fact. I knew the pay when I started, and I realize it may take a long time before this changes. But what can I do, and what can Theresa do, and what will *you* do, to work for change? Have you worked on this issue before? If so, tell me about it.

I know it's not as simple as asking you for a raise. There is an institutional bias in this country, and community services, already under-funded, have seen cuts at state and local levels. Meanwhile, the cost of health insurance has skyrocketed. Who do I write to? Who do I call? Let's advocate together.

9. I understand the need for an organizational hierarchy, but....

All employees have a place in the hierarchy; the buck has to stop somewhere. It looks to me like my job is at the bottom of the totem pole, or darn close to it.

If there must be a hierarchy, help me to not always *feel* that I'm at the bottom. My position here, and the others like it, is the closest on a daily basis to people with disabilities. We're important. So, if on the organizational chart we need to be low, find ways to lift us up. Frankly, the chart doesn't matter all that much to me. What matters is how I'm treated as an employee. Consider that it may also be best for Theresa if those of us from different places on the chart work collaboratively – if we acknowledge the chain of command but don't dwell on it. If we mix it up here and there when possible. I'm not suggesting I begin telling the Executive Director what to do (though I'm not

opposed to the idea!) but rather, that those of you “above” us direct support workers respect us enough to understand what the hierarchy can sometimes feel like to us.

Here is one example: I’d been working with Theresa for a year when her case manager, my supervisor, quit. A new case manager was hired (with no input from me or Theresa, by the way) and began getting to know Theresa. It got a little awkward, me knowing Theresa pretty well by then and teaching my new supervisor some things, but my new supervisor telling me what to do. She needed to learn her job, which included supervising me, yet there were some things I knew more about. She had a hard time accepting that it would take her a while to learn everything she’d need to, and wanted to quickly put on the “supervisor hat.” I wanted to say, “Chill out! You’ll have plenty of opportunities to direct me!” But I didn’t.

10. Some flexibility is good for everybody.

My flexibility is important to you, and to Theresa. The need for it is inherent in this kind of work. So many things that go on in Theresa’s life rely on people to make them happen – people who, being humans, make mistakes and get stuck in traffic and get sick and oversleep.

So you ask me to be flexible, and this is reasonable. I think there are times when flexibility on your part is also needed. Not always, in every situation, no matter what. That would not be reasonable—just as it would not be reasonable for you to expect that I would be willing or able to change plans or schedules all the time. But it’s worth thinking about ways in which you, my agency, and you, my supervisor, can show flexibility toward me. After all, I’ve been here two years now, longer than the average direct support worker. And I’ve done a good job. I’m reliable, I have a good relationship with Theresa, and I bring a lot to my work.

Whether it concerns my job duties, or my schedule, or a time off request—whatever it may be, please consider the circumstances. Working together, with give and take, benefits all of us: you, Theresa, and me.

Bringing Who We Are to What We Do

By Peter Leidy

Who are you?

Think about that for a minute. When have you been asked this before? Or should I say, *have* you been asked it before? It seems to be an uncommon question. Roger Daltrey sang it over and over in the Who's *Who Are You*, but he wasn't asking you or me.

When we meet someone we often start with "What's your name?" and proceed from there. What do you do, where are you from, have you read any good books lately – all of which may help us begin to learn who someone is.

Yet "Who are you?" is a wonderful question. I like the simplicity and the possibility in those three words.

Who *are* you?

How do you identify yourself? Imagine an assignment where you were asked to fill a page answering that one question. What would you say? Perhaps you would consider who and what is most important in your life, and how that connects to what's inside of you. What makes you feel most alive? Fortunately, these questions have no wrong answers, and there can even be many answers for each of us.

I've been curious lately about how this question relates to our work. Do we bring who we are to our jobs? In what ways? Does your job allow you to be who you are, or do you check your real self at the door and put on your job self? And what are the limits to being yourself at work? (Because surely there are some.) I wonder how we strike a balance on the job between being who we are *outside* of work and being "professional."

I heard someone in Georgia say that one of the reasons she loves her job is because she feels a sense of being "at home" in her organization. It is a good match for her, a work environment where she feels comfortable and where there is room to be herself. One example: she can wear open-toed shoes and

blue toenail polish, unlike in the corporate world where she once was headed. For her, there is not the expectation that she “check” herself at the door.

Many support workers I’ve listened to say their work with people with disabilities allows them to live their values in their job. That who they are and what they believe to be important are reflected in the good work they are doing. Some might even experience author Frederick Buechner’s definition of true vocation: “Where your deep gladness meets the world’s deep need.” And further, some say that what they bring – their true self, their gifts, their unique personality – is not only accepted, but even *sought out* by those around them at work.

But others have a different experience. Some direct support staff say that, despite believing in the importance of their work, there are few opportunities to share what they bring with them to their job. Sometimes this is because they are isolated in their work. No one is around much to ask the “Who are you?” or even “How’s your family?” or “How’s your dog?” Others find that there are plenty of people around, but the organizational culture does not invite or encourage more than “This is the job you are expected to do.” I would bet that these are the people most apt to be keeping their eyes open for a different job.

I want to clarify that I am not talking about, say, a situation where service coordinator Brian, an accordion fanatic, is encouraged to play his accordion every day at work. Or where support worker Mary, a Rush Limbaugh fan, is permitted to listen to his program each day over the objections of the person she is supporting. There are limits to what we may bring to – or do at – work.

But, (and this is a big but) isn’t it possible for Brian and Mary’s employer to recognize their interests, talents, beliefs and see them as important to Brian and Mary? And maybe even find occasions from time to time where Brian can share his musical gift, and Mary could engage others in a political dialogue?

Can we respect, honor, even celebrate our differences? Can we get to know each other and appreciate the rich diversity in our organizations? Brian loves the accordion. Maybe I don’t, but Brian does. Mary likes Rush Limbaugh. Maybe I don’t, but I’m not Mary.

So we have Brian and Mary. And Jennifer who is a gifted seamstress. And Paul, who is gay, and Pam the baker, and Denise, whose great-great grandmother was a slave in South Carolina. They all have perspectives or

talents or gifts that are not only important to who *they* are, but which may be important to others around them.

Then there's Carl, an artist. Not long after he began working for his supported living agency, his artistic gift started to become known. "Artist" would probably show up near the top of Carl's page-long answer to "Who are you?" Carl's agency values this part of who he is, and although hardly any of his job duties relate directly to art, the agency encourages Carl's artistic sense to come forth in his work, in many ways: offering his perspective with some people he supports in *their* art work, displaying pieces of his art at the office, lending his talents to agency projects.

Carl does not make his living as an artist; he makes it as a support worker. Still, he is an artist, and his agency understands that everybody wins when Carl weaves the artist in with the support worker. Everybody: Carl, the people he supports, his co-workers, and the organization.

Carl says he appreciates that he can be himself at work. In fact, he is grateful, because he knows it is a rare experience. He found a match, a "home" like the woman in Georgia. He is valued for the work he does and for who he is – for being the only Carl there. And this is a primary reason why he has remained in his job for seven years.

If Carl is right in thinking this is rare, can we "de-rarify" it? We're all too familiar with the workforce crisis. Pay is low. Status is low. Turnover is high. So it serves us well ("us" being people with disabilities, their families and friends, the service system and the community) to consider the reasons why some staff beat the odds and stay in their jobs longer than average.

I'm beginning to think that one reason is that, together with their employer, some support workers have figured out how to more fully integrate who they are with what they do. And I think we can learn from them.

What do YOU think?

When Are You Going to Get a REAL Job?

By Peter Leidy

I'm sitting here thinking about the work that goes into supporting people with disabilities to live and work in the community. In particular, the important work that direct service staff do.

Mostly, I am thinking about your and others' perceptions of your work. I wonder what you think about your job, and the kind of work you do. I wonder what *others* think about your job, particularly others who may be close to you but removed from the work you do—your family or friends. I wonder whether other people's opinion or knowledge of your work affects the way *you* feel about it.

So here I am, thinking and wondering. And drinking coffee.

This wondering comes from my own experiences of working directly with people with disabilities, and from conversations I've had with direct support staff that work part time and full time, those new to the work as well as veterans.

I wanted to write about this in hopes of sparking some conversations. I already know that some support workers relate to the ideas on these pages, but I'm curious how widespread the experience is. As you read this paper (which, you will notice, asks a lot of questions) think about yourself, and see what is or is not familiar.

Has anyone ever asked you the question that is the title of this paper, or raised the issue with a similar tone? Questions like this pop up from time to time in conversations some of us have with our families and friends. Sometimes the question is more subtle, like "Have you considered trying to move up in the company?" Or, "Do you still think about going back to school?" One person's father put it this way: "Why do you still have that job? You're wasting your education!" (That would be one of the *less* subtle examples.)

I think that most direct service workers believe their work is very important. I think that people who rely on them and agencies that employ them agree, even if it isn't always clearly demonstrated. I'd be curious to know what messages you as a support worker get from other people outside of your day

to day work, for example, your mom, or your brother, or your friend from high school. Do you ever get messages from others that the job you have is undesirable, or unimportant, or perhaps worthwhile—but more suited for someone else?

Recently, I was talking with a man who has made direct support work his career. The foundation is the relationships he has with the men he supports. Of course, it is more than the relationships, because he is paid to support them. He has figured out how to do what he loves despite the obstacles he faces along the way – the money, status, bewilderment of some family and friends. It's tiring, he says, having to “make a case” for why he is doing what he is doing.

One thing he worries about is that a few (not most) direct support workers he knows don't seem to value the work that much. Maybe this is because they've chosen the wrong work to do, or because they think of it as a temporary or part time job that just helps pay the bills. He's concerned that their attitudes may rub off on the people in their lives, thus coloring the perception and status. Have you experienced this?

Or, consider how society views people with disabilities. Many people experience second-class citizenship because of having a disability. Sometimes, adults with disabilities are treated like children. Others feel invisible. To the extent that people with disabilities are not fully valued, what does this mean for those who support them? If your job is to assist someone who is not considered a whole person, or a person with much worth, how important can your job be?

And what *is* a real job, anyway? How does that get defined? Who decides? Again, we get messages – from the media, from family, and from other sources. Chances are real good that your high school guidance counselor did not have direct support listed in the array of possible careers you may want to consider. We have to decide what to accept, what to take with a grain of salt, what to reject. Some direct support workers have said (see if you agree) that these messages define a “real job” as having some of these characteristics:

- A real job is a profession, with a fancy title that begins with “Senior Vice President” or “Director of”, or initials listed after your name (like R.N. or C.P.A.)
- A real job is full time, Monday through Friday

- A real job requires a certain education level
- A real job pays a salary, or a very respectable hourly wage, with good benefits

Most direct support workers I know—at least those who have stayed with the work and are committed to it—don't buy this prevailing sentiment. They believe their jobs ARE real jobs, even if by some measures, supporting someone with a disability does not fit society's definition. Yet even if you know that your job as a direct support worker is a real job, and an important one, the average person on the street may not have the same understanding.

Many support workers would argue that some of the above criteria for a “real job” are worth working toward, so that direct support becomes seen as a profession. I believe that many who do this work also understand the individual, unique nature of each job and relationship, and recognize the difficulty—if not danger—of trying to standardize jobs so they look more acceptable to others. In other words, they see the value and necessity of Susan's support worker being *Susan's* support worker—not just anybody's. Key to good community supports is keeping the support tailored to the individual, which includes designing direct support positions around what that person needs and wants (whether or not it results in jobs that look like what others might expect!)

As more and more people with disabilities rejoin their communities to live and work, the demand for personal assistants rises. Perhaps increased visibility and awareness of the contributions made by people with disabilities and those who support them, combined with increased advocacy efforts, will help change the perception and status of support workers. Then, some day, instead of direct support staff being asked, “When are you going to get a REAL job?” the question will be posed to people in other lines of work. Like telemarketers.

These are some of my thoughts and questions. What are yours?

Making Connections: Direct Support Staff as Bridge Builders

By Peter Leidy

Community.

Now *there's* a word we hear often. It's interesting how much the service system uses the word. Community Integration Program, Community Options Program, Adult Community Services, Community Based Residential Facility...you get the idea.

I think the system *should* use the word community, and of course go beyond words, so that community is actually reflected in the system's response to people with disabilities. I wonder, for a word so often spoken in our work, how much do we really think about what it means?

I would like to think with you about what community might mean in the lives of people with disabilities you support. My hope is that this paper will be a conversation starter: I have some ideas and some questions about what might lead to community membership—or at least produce a spark to start a relationship—and I'm curious what you think.

For now, let's think of community as meaningful relationships with people and places that exist outside the realm of the service system. Some of these relationships are occasional or temporary. Some are, or could be, deeper and long lasting. The *possibility* of relationship, of interacting with and getting to know someone, is what we're after. If we can at least expand the possibilities, we're on the right track.

Helping make community connections can be intimidating to some people who provide support. This might sound strange, depending on your point of view. If you're nodding, you know what I mean; if you're puzzled, let me explain. Twenty years ago I was sitting in a roomful of mostly case managers. We were listening to a speaker talk about "community building" with adults who have developmental disabilities. Some in the room were excited by this "new" idea—new to most of us anyway. Others were shaking their heads, or wearing concerned expressions. One person said, "I can't do that! I can't

even figure out my OWN community connections!” One said, “I’m too shy.” Another said, “To be honest, it makes me anxious to try and introduce people to each other, or to ask things of others.”

That was twenty years ago, but the wide range of feelings people have about their own ability to do this part of the work is no different today. Many people think only certain “personality types” can be community builders. While it may be true that some have more of a gift or inclination for it than others, we’ve seen how staff of all stripes can contribute. And THAT is what I want to key into here. The roles that direct support staff have with people put them in a unique position to notice the possibility of a connection, and to help initiate the first steps. From there, it may fizzle out or it may blossom into a wonderful reciprocal relationship. More likely, it will land somewhere in between. But how about testing the waters?

Let’s start with the assumption that you work with one, or two, or a few individuals who would benefit from knowing more people who are not paid to be with them. This could mean neighbors, family members, local business owners—the possibilities are many. I think it is safe to assume this because adults with developmental disabilities often have more relationships with paid support providers than they do with non-paid people. This is true even when people are living and working outside of large facilities. Many people are lonely and isolated, and as important as some paid relationships can be, they’re no replacement for friends, family, neighbors, and co-workers.

I also imagine that you keep busy in your job and may well feel there’s not much time for being a community builder. You work hard, have a lot of responsibilities, have some challenging days, and may feel pressed for time trying to accomplish what is required. So let’s focus on what may be a small yet significant role you could have in helping a person make a connection.

Start with how the person spends her time. Here are just a few questions to consider; the idea is to experiment. Where are there currently relationships or potential relationships? Who does she see throughout the week? Does she have a job? If so, where? How does she get there? Is there “down” time on certain days or evenings that could be used more creatively than, say, watching TV? Asking these kinds of questions can prompt some ideas, like building upon an existing acquaintance relationship with someone at work or on the bus.

Periods of leisure or unstructured time may also be a place to begin. There's a difference between going to a movie and going to a neighborhood hangout like a coffee shop. Nothing wrong with movies—there's just not much opportunity to get to know other people. The simple act of introducing the person you support to the shop owner (especially if it's a shop the person would enjoy returning to) could at least lead to one more acquaintance, and who knows—maybe more.

Also, consider the person's interests. What someone finds fun or cool or exciting is often the starting place for exploring connections. Does she like swimming? Gardening? Hip-hop? Being with kids?

Jason, a support worker I know, knew there were a few evenings each week when Don had nothing planned. Since Jason spent that time with Don, he initiated a conversation with Don about some ideas for getting out to have some fun together. Don loves polka music, so Jason did some investigating. He figured, "We're in Wisconsin—this shouldn't be too hard!" Before long, Don was a regular for Monday night polka at Vern's Club, where he met and got to know other polka lovers. They share a common interest and all look forward to Mondays. Notice how this example takes into account both the way Don had been spending his time *and* an interest he has.

Maybe the person you support sees a certain neighbor several times a week, but does not know the person beyond "Hi." You could help with a next step—and there are many possibilities. Invite the neighbor over for coffee, deliver some fresh-baked cookies, or simply linger a little the next time the "Hi" happens. One small step is still a step in the direction of community, and can make a big difference.

It is also important to remember that the person you've met (neighbor, co-worker, shop owner, etc) may be as interested as the person you support in this new possibility. Community members often say they are glad to be invited into someone's life, and they may not have initiated the contact on their own—for any number of reasons.

These invitations are not the formal, gold-plated type. I'm talking small, casual, friendly—and doable. You're not asking someone to make a big commitment here, at least not yet. Rather, you're helping make it *possible* for some type of relationship to unfold, which may or may not happen. Again, it is the possibility that's important.

Because of the amount of time and the kind of time you spend with the person, you may be best suited to be a bridge. Direct support staff have the opportunity to get to know people well and be present to watch for the possibilities, whether they are existing relationships that could be deeper, or brand new opportunities. Also, the person may communicate to you, rather than someone else, about an interest she has or someone she'd like to get to know better.

I invite you to think about the role you can have in bridging the gap that often separates people with disabilities from others in the community. Relationships and a greater sense of belonging for a person you support can begin by simply being present, and then taking a small step to encourage the possibilities.

Whose Life Is It, Anyway?

By Peter Leidy

Welcome to one in a series of papers on the work and experiences of direct support staff. In this one I would like to address power struggles between staff and people being supported. Like the others, this is intended as a conversation-starter for direct support workers, to promote discussion of issues staff face while engaged in this important work. You will notice there are questions throughout the paper; these, I hope, will prompt discussion.

My hope is that we can think together about power struggles because it's an important topic and because I believe we get "stuck" on this on a fairly regular basis. Why? Because many people with disabilities rely on provider agencies and/or support staff to help with a host of daily, weekly, and monthly tasks. These "helpers" have a lot to do, and are often under pressure from a variety of sources. Also, historically people with disabilities have wielded little control over their own lives, and although this is changing, the change comes slowly. And power struggles are present in virtually every relationship. There's no avoiding them, so the challenge is to learn how to respond to them.

Back in 1985 I was new to this work of supporting people with disabilities to live in their own homes. I went to work for Options in Community Living, a supported living agency in Dane County. As I tried to learn what Options and my job were all about, (which, to be honest, sometimes involved pretending that I understood more than I did) there was a phrase I'd hear occasionally when staff were talking about the work we do and how they thought about it. "We have to understand that we have power in people's lives," they would say. "We need to have power *with* people, not power *over* people."

I found this puzzling at first, because I thought of myself as offering support to help people get what they needed and wanted—not controlling them. I saw my co-workers supporting people rather than exercising power over them. But as I learned more about how the human service system operates, and about many people's vulnerability, I began to understand. And I started to look more closely at how we were doing our work with people.

Having power *with* someone I supported meant to be an ally. Not to always agree, but to support the person with the understanding that it is Bob's life, not mine. It meant realizing that Bob is at risk of living a life directed by others,

and my role—*our* role—at Options was to offer assistance to Bob in a way that would let Bob’s life be a reflection of Bob and his hopes and dreams.

Of course, there were disagreements. If Bob chose not to bathe for a prolonged period of time, it would be doing him a disservice for his support staff to simply say, “Well, it’s Bob’s life, and if he wants to be dirty all the time it’s up to him.” It could be about hygiene, or how money is spent, or alcohol use, or interpersonal relationships, or umpteen other areas of a person’s life. Sometimes we will agree to disagree, but sometimes we can’t afford to stop there, because Bob’s health or safety might be at risk. These kinds of situations, which arise with great frequency, require us to not only be thoughtful and reflective about our mission and values, but also require us to communicate with each other. Sometimes a lot! With Bob, with our co-workers, a supervisor, perhaps other people important in Bob’s life.

As the people with disabilities I was getting to know talked about their lives, I listened to their stories. I learned some history of society’s response to disability. This was a history of confinement, of lives being controlled by others, of segregation. People talked about low expectations others had of them, mistreatment, and barriers in the physical world and in other people’s minds. We needed to acknowledge the history, to try and understand the control *by others* that most people with disabilities had experienced, in order for us to make change and do our work purposefully from a place of respect.

As I began to grasp these ideas, I found that it was often easier to think about it theoretically than apply it on a day-to-day basis. It was one thing to say, “I’m not going to control Arlene; she’s in control of her own life. I will support her to live the way she wants to live.” But it was another thing to realize that Arlene might well live her life—or at least today—in a way that was difficult for me to accept. What happened when Arlene’s personality or actions or decisions offended me or irritated me or angered me? After all, I felt a sense of responsibility in her life.

Or this: Arlene’s service plan, which is my responsibility to help carry out, contradicts what Arlene is saying she wants to do. A few months ago, Arlene and those of us supporting her all agreed on something, but now as time has gone by Arlene has changed her mind. My role, then, is either going to involve following the previously agreed upon plan, or following Arlene’s current wishes which are quite different. To whom

am I accountable? Can I get in trouble for not following the plan? Isn't Arlene allowed to change?

These Bob and Arlene questions, it turned out, were what Options team meetings were made of. Usually there were no easy answers, and mostly I found we were working in gray areas. I learned that this kind of work—where gray prevails over black and white—requires a lot of conversation, like talking with, and listening to, Arlene, the important people in her life, and other staff. And I learned that as support staff, we needed to be vigilant about Arlene's "place" in the running of her life. Same with Bob. We needed to ask the question: Whose life is it, anyway?

New questions emerged for us to consider: As we walk side by side with a person we support...

...how can we become (or remain) conscious of *their* role and *our* role in small and large interactions or decisions?

...what do we do when power struggles arise?

...how do we know when more than just the person we're supporting needs to have a voice in decision making?

...how do I keep myself from presuming that I know best?

...to what extent do we feel pressure to direct the person?

...what have we learned from co-workers, supervisors, and agency policies about the expectations of our role?

These are some of the questions we need to ask each other in conversations with people we support and the important people in their lives.

Sometimes struggles occur because of personalities or situations where there is no clearly visible reason. And sometimes we are, I think, not even aware that there is a power dynamic going on. For reasons of efficiency, or because we are doing what we think our supervisor or job description dictates, we assume more control in someone's life than is necessary or right. It is often quite subtle: for example, even a simple suggestion we make may carry a lot of weight to a person who feels relatively powerless.

I'd like to say something about the "M" word—manipulation. If I had a nickel for every time I've heard a form of this word as staff talk about their work, I'd be next to Bill Gates on the Forbes list. Okay, I'm exaggerating, but I'd have a couple hundred bucks anyway. "*Marilyn is so manipulative.*" Or, "*She'll do anything to get her way.*" Or, "*She likes to play one staff off another.*"

Sound familiar? This way of talking about people is so common that I think we often fail to look beneath the surface. What might be causing Marilyn to behave this way? Perhaps she feels strongly about something and is simply trying to make it happen using the “tools” at her disposal. What we may perceive as manipulation may really be determination to achieve a desired outcome—to get what she wants.

Most people with disabilities have not experienced balanced relationships when it comes to power. They have tended to have less power and less control in relationships, often being seen for their “deficits” rather than their capabilities. Perhaps a person has been told he can’t do something he really wants to do, or needs to do. Knowing what he wants or needs may lead him to pursue his desire in a way that results in the label of “manipulator.”

Some people have developed the skill of getting what they want to such a degree that they have earned a reputation as all-star manipulators. The more roadblocks others put up, the better they get at devising ways around them. It reminds me of something I read that is attributed to His Holiness the Dalai Lama: *“Learn the rules so you know how to break them properly.”* I think it is part of human nature to try and get what you believe to be important, whether it is a need or a want. And I think we can learn something from those who are really good at it.

Now, no one likes to feel manipulated by another person. But are we seeing those roadblocks, and questioning why they are there? Think about someone you support, about whom you or others have used the word “manipulation”. Think about “power over” versus “power with.” Is it possible that this person lives, or lived for a long period of time, a life where others have more control than she does? Where there are so many rules, regulations, and roadblocks that the person has developed a reputation as a manipulator? What is *your* role? Are you expected to enforce rules or expectations that she doesn’t like or agree with? If so, who made these rules?

Direct support staff play a key role in supporting people with disabilities to build meaningful lives. The quality of this support is enhanced when we make an effort to understand how these relationships are influenced by control and power in people’s lives...who should have it and who really does have it.

As we go about our work as individuals, allies, and teams to support and empower people with disabilities to live and work as members of the community, let's keep asking the question: Whose life is it, anyway?

What'd I Say?

By Peter Leidy

Think for a moment about how we talk about people we support. I've been listening to Ray Charles lately and just saw the movie *Ray*, so I couldn't help using a song of his as the title of this paper. But "What'd I say?" is more than a good song—it's a good question for us to ask ourselves. Our words are powerful. From what I've heard over many years in the service world, words spoken to or about people with disabilities are frequently limiting and not all that respectful. Usually, I think this happens without intending harm—I hope so anyway—but it happens.

There's a lot to this topic*; my hope is that this paper will start a discussion about the words we use, and the thoughts, beliefs, and feelings behind the words. We all know that direct support staff have important roles and close contact with the people they support; thus they—*you*—are key to the question of language.

There is no real list of language "do's and don'ts." This is not about what's politically correct – whatever that means these days. However, as we learn and evolve, attitudes change and the words we use change. Thankfully, words like "mongoloid" and "imbecile" and many others – words once widely considered acceptable descriptors of people with disabilities – have virtually disappeared from regular use. Hardly anyone would use them today in referring to someone with a disability. We are making progress—or are we?

Near the 2004 election, a radio host in Milwaukee used the word "wetbacks" while talking about illegal immigrants. There was a public outcry, because there is widespread agreement that you just don't do that. It's wrong. He was suspended, and after joking about apologizing, finally did apologize. A couple weeks later, a Madison radio host used derogatory terms about Condoleeza Rice and Colin Powell. A similar series of events followed. Andy Rooney, Howard Cosell, and numerous other public figures have found themselves in hot water over derogatory comments.

*There are a number of good resources on language and disabilities (see, for example, Kathie Snow's essay on people-first language www.disabilityisnatural.com, and Mayer Shevin's classic *The Language of Us and Them* at www.shevin.org/articles .)

What I'm wondering is, how do we gauge what's acceptable and respectful in the language we use in support work and about adults with disabilities? Teen entertainer Lindsay Lohan recently received a letter from the Arc-USA, one of the largest disability organizations in the country, gently scolding her for her frequent use of the word "retarded" as a synonym for stupid, as in "That is so *retarded!*" This use of the word occurs regularly on TV, in movies, and in popular music. (I heard it most recently on the radio in the song *My Band* by D12 -- but some will be more offended by other lyrics in the unedited version of that song.)

But enough about famous people—back to us. Have you noticed that adults with disabilities are sometimes referred to as if they were children? I wonder if we agree that an adult is an adult, regardless of disability. One's life experience or intellectual development may be different or limited, but the person is an adult.

Yet I hear things like, "Mary is so spoiled." Whatever it is about Mary that would make her staff person say that, calling her spoiled is demeaning. What's underneath that? Doesn't Mary deserve better? Or, "I'm taking my girls to the zoo." Your girls? First, they're not yours, and second, they're not girls. A case manager (and speaking of language, think about those two words together...who is managing what?) says, "My people...."

Or this one: "Bill has the mental age of a one-year-old." Is that accurate and relevant? Does it matter? Who decided this, and how well do they know Bill? How does this opinion or medical diagnosis affect what people imagine as possible for Bill? I think the odds are pretty good that as this piece of "information" becomes part of the story told about Bill, following him around forever, Bill will be treated as a one-year-old his whole life.

I hear people use "high functioning" and "low functioning". I gotta say, I'm really tired of those terms. It seems to me that we *all* function differently, better in some ways than in others. Then there are words like profound, severe, moderate, and mild. I can accept that these classifications may serve a purpose, somewhere, to someone, but in twenty years I've never known them to matter much in real life. I think our words can create roadblocks to helping people make meaningful, real lives in the community. Would *you*, as a community member, be eager to get to know someone called "severe"?

“She’s a Downs.” I heard this not long ago when a staff person was talking about a woman with Down syndrome she supports. It was said in an effort to explain a certain behavior that the staff person believed was typical of people with Down syndrome. What do you think?

Here’s a sentence taken from a newspaper story: “Wayne suffers from cerebral palsy.” It was a story about a man who had been institutionalized for a long time who is now living in his own home. It was good news! He was beginning to live a full life and was apparently pretty happy about it. Nothing in his story was about suffering. But to the reporter, having cerebral palsy means Wayne must suffer. The reader has to wade through pity-evoking imagery to realize Wayne’s life is good.

What the above examples have in common is that they tend to separate “them” from “us.” They can take some of a person’s humanity away. They sell people short.

To me, it’s worth thinking and talking about the language and style of speaking we use with and about people we support. Let’s listen to each other and ourselves. Let’s pay attention to how respectful we are being. I think we owe it to people we support.

As we go through our day, it might be worthwhile to occasionally stop and ask ourselves, “What’d I say?”

These are some of my thoughts. What are yours?

Finding the Lines: Relationship Boundaries for Direct Support Workers

By Phoebe Hefko

According to the Wisconsin Council on Developmental Disabilities (WCDD), a 2002 survey of direct service workers found that the best thing about direct care was the relationship with the person supported. Despite low pay and low status, many workers make a commitment to the people they support. It seems that for many workers, the relationship is the reward for the work they perform.

What does it mean to have a committed relationship with the person you support? Does this differ from commitment to other occupations? How does such a relationship compare with other types of committed relationships that you may have, such as marriage, friendships or familial relationships? Answers to these questions may vary widely depending on your experiences. But there is no doubt that this is an issue worth considering. At some point in your work in direct service, questions are bound to arise about the nature of your commitment to the people that you support.

My first job providing direct support to people with disabilities in a community setting came at a time when, as a part-time graduate student with neither spouse nor kids, I had an abundance of time and energy to spare. “Fred” lived in a two-bedroom apartment, and while he had many friends, he had neither family nor significant other to take an active interest in his life. The live-in support worker that preceded me had developed a warm rapport with Fred, and he was sad to see her go. This was my first experience as a live-in caregiver, and the question of commitment was something that worried me from the outset. As I think back over our two years together, I realize that the job provided me with some important lessons about building relationships with the people in a supported living situation.

Unable to use his arms or hands due to cerebral palsy, Fred relied on a support worker to prepare and feed him meals, clean the house, dress and bathe him. I was in charge of helping him get ready for work in the morning.

And when he came home at the end of the day, I was there to help him with dinner and getting ready for bed. Fred enjoyed living in his own apartment, though the need for low-cost, barrier-free housing had forced him to live on the outskirts of town. He was proud of his independence. As I came to know his likes and dislikes, our time together took on a quiet rhythm and an easy intimacy. Over dinners, we exchanged countless stories about ourselves. During cares, we developed our own set of jokes and ways of getting things done. On the whole, it seemed to be an ideal situation.

After ten months on the job, I had a chance for some much-needed respite. It was time for Fred to leave for a week at summer camp, which he had attended every year since he was a little boy. I had packed his suitcase, carefully labeling everything, and he was ready to go. But before he boarded the Greyhound bus, he told me he wanted to give me something – a “goodbye” kiss on the cheek. I remember that I paused when he asked me that, and weighed my response. I clearly understood that to allow that kiss was to cross a line. On the other hand, I was acutely aware of being the only one there to wish him goodbye as he left by himself for a week with strangers. In the end, I relented and bent down for a kiss, but later I wondered again.

In my support agency’s Policy and Procedure Manual, under the heading “*Consumers Age 11 or Older*,” the guidelines read strictly as follows:

Appropriate Touch:

Touch on the hands, arms, shoulders, and back.

Not to be Done:

- *Hugs. (You may receive a spontaneous, voluntary hug from a consumer and put your arms on their upper back. You may not initiate or ask for the hug.)*
- *Kissing including “pecks” on the cheek or elsewhere. You may not receive a “peck” or any other sort of kiss from the consumer.*
- *Touch. No touching below the waist, on the lower back, on the front of the body, neck, head, hair, or anywhere except what is listed in the “appropriate” category.*

By accepting Fred’s goodbye kiss, I had broken these agency rules.

Good caregiving must be heartfelt. In the ideal situation, the money provided to the support worker by the agency serves as the fodder for an

interdependent and mutually beneficial relationship between the worker and the consumer that is primarily based upon caring and kindness.

However, at the same time, the relationship between a support worker and the individuals s/he serves is an inherently uneven one. The support relationship could not exist without some source of money, since it is most times a full-time and exhausting job. However, money cannot be the sole motivating factor.

As support workers, we benefit from the opportunity to offer care and kindness to individuals who need it. However, it is important that we always be mindful of the fact that any friendship that arises between us and the consumers that we help support takes place within the context of a professional employment situation.

I thought hard about the line that I had crossed when I accepted Fred's kiss. In this line of work, we all make mistakes, and the good thing is that we usually get more than one chance to do things right. The next time Fred asked me if he could kiss me on the cheek, I gently said no. "Fred," I said, "I've been thinking about it and I've decided that it is inappropriate for me to have a kiss from you. I care about you, but I am your support worker."

Fred understood, but he sighed and said, "Inappropriate. I hate that word."

Questions for Discussion

1. Agencies have reasons for making rules about touch between employees and the individuals they support. However, in certain situations those rules may strike us as unreasonable or unnecessary. Do the rules make sense in the situation described above? Why or why not?
2. Kisses can mean different things at different times.

Sometimes, a kiss is a sign of sexual desire or intimacy that would be completely inappropriate between a worker and an individual who relies upon him or her for support.

At other times, a kiss may be casually affectionate. For example, someone may show affection by kissing his or her grandmother.

How would you interpret the kiss in this story?

3. How do the agency rules in this story protect Fred? How do they protect Fred's worker?
4. Did the worker choose an effective way to deal with this situation? Can you think of anything else that she should have done to mend her relationship with Fred?
5. Like many people with disabilities, Fred struggles with social isolation and loneliness. What are some ways that the worker in this story could help Fred to find appropriate opportunities for social contact, affection, intimacy, or touch?

LITTLE PAPERS:

BRIEF PAPERS TO PROMPT DISCUSSION AND REFLECTION AMONG DIRECT SERVICE WORKERS

The Papers:

These brief papers were commissioned by the Wisconsin Council on Developmental Disabilities as a part of its direct service workforce initiative which it carries out in partnership with the DD Section of the DHFS Division of Disability and Elder Services.

The papers are designed to be read and discussed by small groups of direct service workers. Permission to photocopy the stories is granted by WCDD with the request and expectation that you will acknowledge WCDD and the authors.

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About the Wisconsin Council on Developmental Disabilities:

WCDD works to make Wisconsin a better place for people with developmental disabilities to live, learn, work, and participate as members of the community. It is a state agency funded by the federal government. WCDD has a state plan that list the ways WCDD will help improve support for people with developmental disabilities and advocate for their rights. One of the state plan priorities is to improve the status, pay and benefits of direct service workers.

About the Community Supported Living Series:

This series of publications provides many insights and points of view about the values and principles involved in supporting people with developmental disabilities to live good lives in the community. A list of titles is located at the WCDD website, www.wcdd.org. Many can be downloaded in PDF format.