

Whose Life Is It, Anyway?

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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?