"When Are You Going to Get a REAL Job?"

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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?