

Editorial

People with disabilities helping themselves

I called the agency to tell them that I found a job and needed support to learn how to do it. They told me I had to wait my turn after the many people ahead of me on the list of services. Does that mean I have to turn the job down?

I keep asking for more support on the job, but the professionals say they do not have enough funding to give me what I need. How can I get the type and amount of support that will help me be able to do my job?

I have a job, but I don't like it, and the professionals say they can't help me find another as long as I am employed. What can I do to find the job that I want?

My present job is boring and doesn't pay enough. I would like a job with more responsibility, more hours, and more money. Where can I go for help to advance my career?

All too often, individuals with severe disabilities can be heard voicing issues like these and expressing similar frustrations with their employment situations and personal experiences with the service delivery systems. Systems often are not designed to achieve their fundamental purpose: to provide individuals with assistance in achieving specific, requested goals. For example, some people want first jobs, others want to change jobs, still others want to change some aspect of their jobs, whereas others want to pursue career advancement opportunities similar to the rest of the labor force. But unlike the general population, people with disabilities face substantial obstacles and red tape that makes seemingly natural life progressions difficult to accomplish. Agency regulations, staff shortages, funding criteria, professional attitudes, and lack of knowledge contribute to the challenges associated with obtaining employment for individuals with disabilities and contribute to the challenges associated with receiving the critical supports that would allow these individuals to be successful on the job. As a result, more than two thirds of individuals with disabilities are unemployed, and many more are underemployed in low-paying, entry-level positions despite their desires for more advanced and varied career opportunities.

To many people, self-advocacy is defined as advocating on one's own behalf, but that definition only touches the surface. Self-advocacy is people individually and/or in groups speaking and/or acting on behalf of themselves, on behalf of others, or on behalf of issues that affect individuals with developmental disabilities. The keys to self-advocacy are people pursuing their own interests, being aware of their rights, and joining with others to pursue issues of the group and of individuals with disabilities in general.

It is important to understand the sense of community and unity of the self-advocacy movement. Self-advocacy is not self-involved or self-centered. It is a statement by people with disabilities that they want to be seen as people who have something to offer and skills to share, rather than to be seen as people with "handicaps" or "limitations". Self-advocacy is a social rights movement that is about building alliances and coalitions and about working together to achieve personal and group goals. Self-advocates look out for one another, learn from each other, and fight discrimination against great odds and often at a high personal cost.

Why should people with disabilities self-advocate? Are there not kind and caring advocates who could speak for individuals with disabilities? Perhaps the best reason is that individuals with disabilities are the experts about their disabilities. Every day they learn things, teach things, and see things from the point of view of people with disabilities.

People with disabilities cannot rely on others to enhance their life opportunities, to promote progressive public policies and research, and to advance services that address individual choices and human rights. To accomplish these goals, it is imperative that individuals with disabilities self-advocate so that policy makers, educators, service providers, and any other person who supports them, hears and understands the point of view of people with disabilities. Decisions that affect and that have an impact on the future of people with disabilities must reflect their input and guidance.

In general, self-advocacy is important in the area of employment because if an individual is not working,

self-advocacy will help him or her find a job; and if an individual's current employment is not meeting his or her needs, self-advocacy will help him or her locate better opportunities. Specifically, people who self-advocate during an employment search will be able to identify the job they want, specify the working conditions, determine the wage level, select the job location, and decide the hours that will be worked. When self-advocating leads to obtaining competitive employment, an individual – often for the first time – has a choice in the labor force, earns a decent wage, develops a real work history, and realizes community inclusiveness.

The bottom line is that if an individual with a disability is going to benefit from employment, that person must be supportive of, involved with, and have input into every phase of the employment process. Learning the skills necessary to be an effective self-advocate is one sound strategy for ensuring that a person's interests, choices, preferences, and decisions are heard and followed.

Paul Wehman
Editor, JVR