People with Disabilities

To work or not–the choice is yours

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A Real-Life Story

One day in Kansas, a man who'd been a quadriplegic for 30+ years went to the doctor. He took off his clothing for an examination. When the surgical resident, who had never met the man, came in, he did not see the man's expensive clothing. All he noticed was the power wheelchair. The doctor started a conversation by asking. "**So, do you work or are you just disabled?**" The doctor did not know he was talking to the director of a state agency — a person who had worked all his life. He saw the disability and lowered his expectations about the man's ability to work. His personal bias or perceptions were colored by the **myth** that people with disabilities can't work; that they are unable to provide for themselves or contribute to the community.

Adults are expected to work to provide for themselves, their families, their community and others. Psychologists and philosophers include work or contributions to community as a critical part of what it takes for humans to be happy. Work gives meaning in the world and contributes to one's sense of self and self esteem.

Unless you have a disability … then society's expectations change.

This is another way people with disabilities experience oppression and discrimination. Society gives disability cash benefits (although not nearly enough to live on) to those who are the most significantly disabled. While having government cash benefits for the short term may be necessary, Social Security data on disability and employment, examined by the Disability Statistics Center in 1996, showed that for 99.5% of recipients it becomes a long term trap – a poverty trap.

However, other approaches are taking hold. Bryon MacDonald, program director of the California Work Incentives Initiative at the World Institute on Disabilities puts it this way, "People with disabilities are shifting their view of government benefit programs from "early retirement mode" to the concept of 'employment supports.' In other words, health and benefit programs, from both the government and the employer, can create a better quality of life … that is clearly a paradigm shift. All the reforms are not in place, but many are."

If you are thinking of getting on public assistance or wondering if you should work, **this information is for you.**

What do people with disabilities who work say?

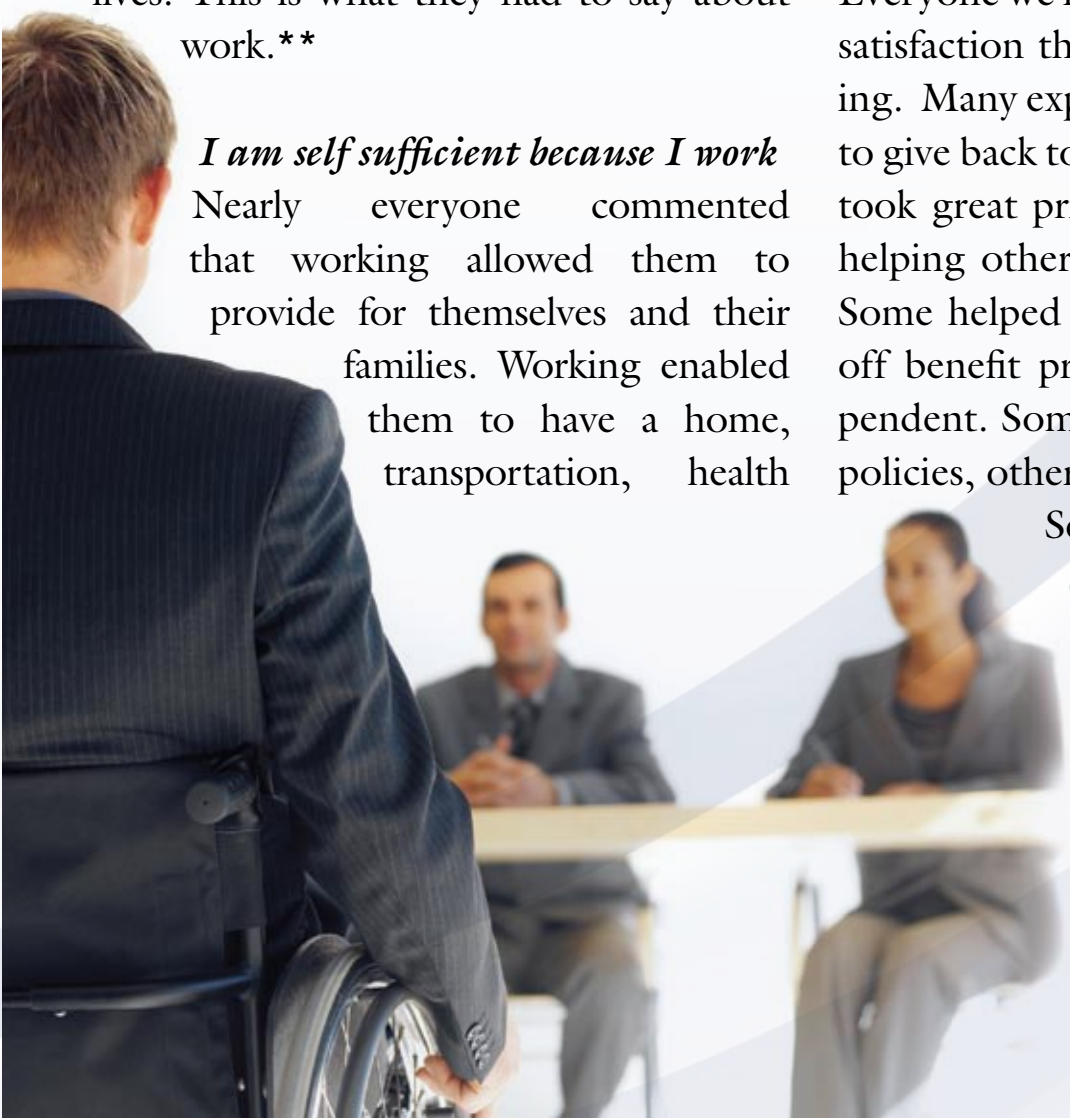
We interviewed 21 adults with severe disabilities in four states to see what it means to be disabled and working.* All of those interviewed were eligible for government benefits. Some received benefits for a period of time but were able to leave the rolls because they earned a good income. One receives retirement benefits but still works; three are receiving government benefits and working part-time because their disabilities prevent them from working full time. All are passionate about working and its importance to their lives. This is what they had to say about work.**

I am self sufficient because I work

Nearly everyone commented that working allowed them to provide for themselves and their families. Working enabled them to have a home, transportation, health insurance, personal care, even a retirement fund. One man spoke eloquently about work allowing him to be a financial equal in his marriage. Working allowed the people we interviewed to have a family, provide their children with an education, take vacations and travel. One person spoke of work giving her money to "pay for my passions-the things I want to do." Work, commented another, "gives me the freedom to enjoy life."

Work provides satisfaction

Everyone we interviewed spoke about the satisfaction they experienced from working. Many expressed joy about being able to give back to others and to society. They took great pride in making a difference, helping others to realize their potential. Some helped people with disabilities get off benefit programs and become independent. Some worked to change public policies, others taught children or adults. Several said it felt good to solve problems and be valued by others for their contributions. Many received special satisfaction from challenging society's low expectations of people with disabilities.



Work improves my health

Many people reported improved physical and mental health because they worked. Work kept them from being bitter or restless. It taught them to "deal with life's ups and downs." Persons with mental health disabilities and cognitive disabilities and those with traumatic brain injuries most often credited work with keeping their minds off their disability and giving them a reason to get up and out. They spoke of work alleviating depression and negative feelings about their disability. One person indicated that work kept her out of a "mental institution." Another said his "cognitive abilities improved and my physical condition and coordination also improved because of work."

Work connects me to others

The opportunities to meet, help and play with others through their work were highly valued by many of the people we interviewed. Work reduced isolation and brought greater awareness of the world around them. They enjoyed meeting interesting people of different backgrounds. People become part of social networks at work. One person commented that work kept her from "sitting on the sidelines." Another commented on how he "enjoyed the connection that comes from talking to others about my work." Finally, one woman indicated that "I feel sad if not working-it upsets me to be alone too much!"

Work empowered me

Everyone was empowered in some way. Each could see that they made a difference in the world. "My voice counts." "I am part of "something bigger." "I am a contributing member of society; people look up to me because of the work I do." Others talked about how good it felt to be at the "table when decisions are made". They took pride in having played an important role in those decisions. One man spoke of learning to lead a team at work; he learned how to hire people and manage work flow. Another spoke about the joy in "regaining my financial independence." Finally, as one woman pointed out, "work makes you a citizen, otherwise you are left out."

Working makes me a good role model

A number of people talked about role modeling as workers. For some it was the chance to be a good role model for their kids; teaching them that work was important. For others it was the opportunity to demonstrate that people with disabilities can be independent and contribute in the workplace. One man spoke about not allowing others to dismiss him because he has a disability. "It allows me to be seen for what I can do, not my disability."

Work helps me grow as a human being

Often what others say about us causes us to see ourselves differently and change our view of ourselves. Many of the people

we interviewed earned awards and commendations for their work. One was nominated to be on a Governor's committee to improve the state for people with her disability. They all acknowledged the impact of this praise and acknowledgement upon their self-image. Praise and acknowledgement for their work gave them the sense of accomplishment and dignity that comes from contributing to society.

People with disabilities who work found out they were just like everyone else and discovered a sense of accomplishment and dignity that comes with contributing to society.

Participants found out something about themselves. Several people discovered they were smart, were needed and people liked them. Others found they were just like everyone else; they could "make mistakes and fix them;" face their fears and reassure themselves. Some said they felt worthless on the public assistance system but learned they didn't need to depend on it. They "deserved to have a better life!"

As a result, people talked about **how work changed them**. Work "fills a big void in my life." Several people talked about how they felt more interesting because of work and they preferred friends who worked because they were more interesting too! Many discussed finding their identity through work: "How do you introduce yourself if you don't work?" Work sparked a number of different feelings. "Work made me feel accepted." Working gave me a "sense of accomplishment and self pride;" I felt "on purpose," "joy," and the "confidence to learn new things." One person talked about how work gave him the opportunity to choose his own path; another spoke about how work gave her hope to be a part of the world.

There are several statements that sum up what these people with disabilities have to say about the impact of work. First, that government benefits alone do not pay enough to have a choice in your lifestyle. Those public benefits are not enough to live on for the rest of your life and have any quality or choices. Second, many found that for them, "work was way beyond money" in importance. Finally, as one said, "I refuse to live my life within the boundaries of low expectations!"

The shift to allow people with disabilities on benefits to access **employment**

supports, using both government and employer benefits, is already happening. Additional factors are also making it easier for people with disabilities to work: availability of personal assistance, Social Security's work incentives program, Medicaid health insurance buy-in programs, access to assistive technology, jobs that can be done from home and self employment or micro enterprise ventures all increase opportunities for people with disabilities to be employed. Given the environment today there are fewer people who cannot engage in meaningful employment. Even people with significant disabilities are choosing a lifestyle that includes work.

Will you choose to work or will you allow people to perceive you as "just disabled?"

Finding your place in the world of work is an adventure that will provide you with opportunities to learn about yourself, contribute to your community, and provide a higher quality of life. If you choose to work there are many avenues open to you. If you choose not to work, then you may continue to contend with others' perceptions of you as "just disabled." Are you okay with that?

Choosing to work? Next steps:

You can start by getting support and guidance about your interests and aptitudes. This will show you the areas in which you might enjoy working. Find a mentor. A person with a disability who works can be an invaluable support to you. Consult with a vocational expert that understands disability, jobs and assistive technology (equipment to help with your functional limitations). Job training and education along with the knowledge of how to present yourself and your skills to an employer will also be important. Connecting with a benefits counselor will be crucial as you begin to create your system of employment supports. (See www.ssa.gov/work for a Community Work Incentives Coordinator near you.)

Check out local universities, community colleges, technical schools or vocational education facilities for training that appeal to you. Most have disability services offices to assist students with disabilities. Your local Vocational Rehabilitation office, Independent Living Center or One-Stop Workforce Development Center are all organizations with services to help you plan for employment and realize your goals. These organizations can provide benefits planning and counseling too. All can be found on the web or in your local phone book.

For more information about your rights and responsibilities as a worker with a disability, contact your regional ADA Center (Americans with Disabilities Act) at 800/949-4232 (V, TTY) or www.adata.org.

***About the people we interviewed**
We interviewed 11 men and 10 women who live in California (6), Colorado (5), Montana (5) and Utah (5). They range in age from 30 to 60+. Their jobs included clerical work, counselors of various types, teachers, computer programmers, machinists, advocates, directors of agencies and an attorney. Incomes ranged from less than $5,000 a year to over $50,000. Years worked range from three to more than 30. Their disabilities include mobility impairments, mental health disabilities, sensory impairments (blind, visually impaired, deaf and hard of hearing), physical disabilities such as dwarfism, cerebral palsy, epilepsy, cancer or back injury, and intellectual disabilities. Race or ethnicity included 3 Asian-Americans, 3 African American, 2 Hispanic-Americans, 2 Native Americans and 11 Caucasians.

****Material in quotes are direct comments made by the individuals interviewed.**

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