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Research to Practice: Consumer and Family Perspectives on the Meaning of Work

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For consumers, compensation and benefits were important job outcomes. Parents and spouses felt that opportunities to interact and socialize at work with customers, co-workers, and employers contributed heavily to their family members’ feelings of job satisfaction and importance. Opportunities for socialization were not cited as an important job outcome in the consumer focus groups.

Obstacles
Consumers stated that they faced problems in getting or keeping jobs due to the stigma surrounding their disabilities and discrimination on the part of the public, including employers and professionals. Disclosure of disability status was a key concern.

The second major barrier to employment expressed by consumers was the lack of available, appropriate services by state vocational rehabilitation agencies, including a lack of staff follow-through.

Family members cited lack of appropriate job matches as a major barrier for their relatives with disabilities. Places were made in jobs because there were openings, not because consumers were interested in or had aptitude for that type of work. Lack of transportation was frequently cited by family members, since many relatives with disabilities depended upon public transportation to get to work and were therefore limited in their job search to worksites accessible by bus or subways.

Support at Work
Both consumers and family members identified professional staff as critical sources of support at work. Many consumers felt that these staff people provided a feeling of security and reinforcement on the job.

Some families expressed concerns about the time limited nature of job coaching, and were anxious about problems that could arise when a job coach was no longer available.

Consumers also frequently cited the important supportive roles assumed by some employers.

“They (the employer) gave me the encouragement. They didn’t let me sit back and feel there was nothing I couldn’t do...And from the experience, I found that it helped me branch out.”
**Relationships at Work**

Many consumers expressed their feelings of belonging or acceptance at work. Praise received from customers and employers made some consumers feel that they were valued and accepted.

One consumer stated:

“It’s very friendly where I work, but I’ve never made many friends. I have people I like and get along with, but no real friends.”

While most consumers did feel accepted in the workplace, a small number of consumers mentioned co-workers who were uncomfortable with or patronizing toward them.

**Goals and Expectations**

Many consumers were content with their jobs and expected that they would remain in their current positions. Others discussed plans to upgrade their skills and seek better jobs.

Consumers and family members expressed concern about “dead-end” jobs and the desire to upgrade to jobs that were more appropriate to their skills and interests. Some consumers expressed frustration with these jobs, but had plans to develop their skills and move on to more challenging opportunities. Others acknowledged that while they felt they were capable of more challenging work, they regarded their current job as an appropriate and necessary step for them at this time.

Family members, on the other hand, tended to see consumers as having limited potential for advancement from these jobs and envisioned that their family members would need to remain in these jobs long term.

**Family Concerns**

Parents expressed the conflict between wanting to encourage the independence and self-sufficiency of their adult children, yet at the same time, wanting to protect them from possible harm.

Strongly related to conflicting feelings about “letting go” were parental concern about the future. As one parent expressed,

“What’s going to happen when we’re not around? Is he going to be able to take care of himself?”

Family members expressed concern about the importance of maintaining the dignity and self-respect of their relatives with disabilities. Many parents and spouses were concerned about the negative impact of the disability “label” on their relative. In general, family members felt that the label of having a disability limited their relatives’ options, and that staff and the general public were too negative in their expectations for their relatives. This concern is consistent with the consumers’ concerns regarding stigma and job discrimination discussed earlier.

Family members felt that they played a vital “full-time” role in the lives of their relatives with disabilities, helping them find employment, explore job opportunities and resources, and keep up their morale. Family members felt that these responsibilities had an impact on overall family functioning.

Overall, family members expressed a need for support and understanding by the community. As one parent said,

“The family is in a cocoon and you’re looking out. No one is looking in or understands.”

**Implications**

Professionals working with individuals with disabilities need:

**To understand the importance of meaningful work in the lives of people with disabilities**

- Work plays an integral role in developing self-esteem as well as a sense of being part of society
- Work needs to be consistent with the individuals goals and interest, not just compatible with available job openings

**To address discrimination and stigma in the workplace**

- Importance of educating employers concerning issues for people with disabilities
- Education of consumers concerning their employment rights under ADA
- Need for counselors to work with consumers on individualized strategies to deal with disclosure issues

**A variety of individualized supports and opportunities on the job**

- Use of natural supports of co-workers and supervisors on job site
- Flexible job coach support that responds to individual and family needs

**Greater consumer and family involvement in the vocational rehabilitation system**

- Education of consumers as to their rights and responsibilities in the VR system
- Empowerment of consumers to take control over their decisions
- As appropriate, active family involvement of family in rehabilitation system through support and information sharing

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