

The Meaning of Work in the Lives of People with Significant Disabilities: Consumer and Family Perspectives

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Abstract: This article reports the findings of a qualitative research study utilizing focus groups which obtained the perspectives of people with significant disabilities and family members about their overall employment experiences, concerns, and expectations. Focus group participants responded to questions about job outcomes and satisfaction, work relationships, support at work, job obstacles, and job expectations. This paper summarizes the key themes which emerged in response to the focus group questions and highlights the similarities and differences among consumer and family perspectives on these issues. The implications of these findings for professionals working with individuals with disabilities and their families are summarized.

Since the passage of the Americans with Disabilities Act and the Rehabilitation Amendments of 1992, there has been increased public attention to the employment of people with disabilities. Most research on the employment outcomes of people with disabilities has focused on quantitative variables such as dollars earned, hours worked, length of time employed, and/or nature of the job (Bolton, 1981; DeStefano, 1991; Moseley, 1988). Emphasis has shifted recently to the integration of people with disabilities into the culture and support systems of the workplace (Butterworth, 1992; Chadsey-Rusch, 1992; Hagner & Dileo, 1993), as measured by qualitative employment outcomes such as job satisfaction, quality of life, social inclusion, and informal supports in the workplace (Goode, 1989; Inge, Banks, Wehman, Hill, & Shafer, 1988; Moseley, 1988; Schalock, Keith, Hoffman, & Karan, 1989).

People with disabilities are essential sources of information about these qualitative aspects of employment, including the meaning of work in their lives. One of the basic elements of "participatory action research," a concept promoted by the National Institute on Disability and Rehabilitation Research, is participation by the persons most affected by the phenomenon under study (Bruyere, 1993; Walker, 1993). Yet there is a scarcity of research in the vocational rehabilitation field based upon the perspectives of people with disabilities.

Perspectives of family members are also important to obtain, since they often play a critical role in supporting relatives with disabilities in the community. Although there has been some research on the importance of families and friends in the informal support networks of people with disabilities (Knox

& Parmenter, 1993; Kutner, 1987; Mitchell, 1982; Nisbet, 1992; Wesolowski, 1987), and on the influence of families on rehabilitation outcomes in general (Cook & Ferritor, 1985; Kelley & Lambert, 1992; Lindenberg, 1980; Moore, 1984), little is known about the specific roles families may play in the employment experiences and outcomes of relatives with disabilities (Hill, Seyfarth, Banks, Wehman, & Orelove, 1987; Turnbull & Turnbull, 1988).

This article reports the findings of a qualitative research study which obtained the perspectives of people with significant disabilities and their family members about their overall employment experiences, outcomes, and expectations. The focus group method, a means of collecting qualitative data through group discussions, was selected for this exploratory research because of its demonstrated utility in obtaining consumer opinions and preferences (Krueger, 1988; Stewart & Shamdasani, 1990) and its value as a tool in participatory action research in the rehabilitation field (Walker, 1993).

Methods

Four focus groups were convened in 1994 as a component of research activities for the Center on Promoting Employment, a Rehabilitation Research and Training Center at Children's Hospital in Boston, Massachusetts. The purpose of the focus groups was to identify key issues regarding the meaning of work for individuals with significant disabilities and their families. Based upon these participant-identified issues, an additional goal was to generate research questions for future Rehabilitation Research and Training Center activities.

Two of the focus groups consisted of people with significant disabilities and two groups consisted of parents or spouses of people with disabilities. One consumer and one family focus group were held in Boston at Children's Hospital and at Boston University Center on Work and Family and another set of family and consumer sessions were held in Hartford, Connecticut at the state rehabilitation agency. Each focus group met one time for approximately two hours. Participants were paid a stipend of \$25.

Focus group participants discussed the following set of questions, developed by the researchers based upon a review of literature about job placement and rehabilitation outcomes:

1. Job Outcomes/Satisfaction: How do you like your job? What is important to you about your job?
2. Job Relationships: How well do you get along with people at work? Do you feel like you belong and are included at work?
3. Support at Work: Who has been most helpful to you in learning how to do your job and getting along at work?
4. Job Obstacles: Have there been problems or obstacles which you have faced in finding or keeping a job?
5. Job Expectations: Do you have work plans for the future? How long would you like to stay at your current job?

These questions were used as discussion guides in the consumer focus groups. Similar versions of these questions were also asked of family focus group participants, based on their perceptions of their family member with a disability - e.g., "How does your family member like his/her job? Have there

been obstacles which your family member has faced in finding or keeping a job?"

In each focus group, one of the researchers served as discussion leader, while the other took notes. A semi-structured group interview format was used, beginning with a brief warm-up period of introductions and a general question concerning the job search process, followed by the specific questions listed above. The leader used additional probe questions when necessary to expand discussion, and was responsible for ensuring that all the research questions were addressed in the discussion and that all participants had the opportunity to express their views.

Participants

Participants were recruited through referrals from state and local family and consumer advocacy groups and vocational rehabilitation programs. Individuals selected to participate in the consumer focus groups met the following criteria: had a disability (mental retardation, mental illness, substance

abuse, sensory impairment, and/or physical disabilities); required significant assistance in job placement and/or accommodation in the workplace; had been employed for at least 60 days and at least 15 hours per week; and was paid by the employer. Parents and spouses were selected for the family focus groups who had a family member with a disability who met the selection criteria described above.

A total of 13 people participated in the two consumer focus groups, five women and eight men. In the two family focus groups, a total of 16 people participated, representing family members of 13 people with disabilities. In three cases the individual who was in the consumer group also had a family member in the family member group; therefore the information from the focus groups represent a total of 23 individuals with disabilities. The ages of consumers or family members with a disability ranged from 24 to 68 years, with the median age being 34 years. Despite efforts to recruit individuals from culturally diverse backgrounds, all but one of the participants were Caucasian, and one individual was African-American.

The types of jobs performed by consumers represented in the focus groups included: surveyor, child care aide, food service worker, secretary, mechanic, tele-sales, retail, computer programmer, driver/delivery, janitor, microfilm technician, office assistant, and assembler. Information on earnings, hours and length of time employed follows.

Analysis

Focus group sessions were audio-taped and transcribed. Analysis of the content of the focus group discussions involved multiple steps (Stewart and Shamdasani, 1990). First, based on the transcripts and focus group notes, the researchers prepared a summary of key discussion points of each focus group which was sent to participants for feedback regarding accuracy of content. Corrections or comments received from the participants were added to the discussion summary. Secondly, the researchers independently reviewed and analyzed the content of the transcripts and discussion summaries, and developed a list of key themes and sub-categories within themes that emerged in response to the focus group questions. They then compared their lists to identify consistencies and reconcile discrepancies in their initial analysis.

Finally, the researchers reanalyzed the transcripts based upon their revised themes and coding

categories, looking for connections and divergence among the themes identified, and among the responses of consumers and family members.

Findings

This paper summarizes the key themes which emerged in response to the focus group questions and highlights the similarities and differences among consumer and family perspectives on these issues.

Job Outcomes/Satisfaction

Both consumers and family members indicated that feeling productive and keeping busy were essential aspects of work. This involved doing meaningful work, having a routine and structure, assuming responsibility, doing a variety of tasks, and completing work on time. One consumer noted the following aspects of work which he felt were important: "doing the work, concentrating on doing a good job, trying to remember things, and working at a steady pace - that's all." Self-esteem and well-being of individuals was also rated by both consumers and family members as critical to job outcome. There was a commonly voiced sentiment that "what you do is what you are" and that work implies having a place in society and feeling constructive. Many consumers expressed pride in knowing that they had the ability to do their jobs, and that they could do the work as well or better than anyone else.

Characteristics of Focus Group Participants

Number in Consumer Groups(a)	13
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Male	8
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Female	5
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Number in Family Groups(a)	16
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Mothers	9
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Fathers	5
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Spouses	2
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Disability Groups Represented(b)	
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Developmental Disabilities	9
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Sensory Impairments	2
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Mental Illness	8
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Physical Disabilities	4
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Age of Consumers(b)	
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Median	34 years
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Range	24 to 68 years
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Hours/Week Employed(b)

Mean	28 hrs/week
Range	15 to 40 hrs/week

Length of Time on Job(b)

Mean	2.68 years
Range	2 months to 8 years

Salary(b)

Median	\$7.08/hour
Range	\$4.24 to \$17.00/hour

- a Number of participants in two focus groups combined.
- b Includes data on participants in the consumer focus groups and family members with disabilities represented in the family focus groups.

For consumers, compensation and benefits were important job outcomes. Decent pay, regular pay checks, steady hours, and flexible work schedules were identified by consumers as were employee benefits, such as merchandise discounts, free meals, transportation vouchers, and company holiday parties.

Family members perceived socialization as a major element of job outcome for their relatives with disabilities. 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.

Relationships at Work

Although opportunities for socialization were not cited as an important job outcome in the consumer focus groups, when consumers were asked about their own relationships at work, many of them discussed their feelings of belonging or acceptance at work. One person liked the informal joking with co-workers as well as the fact that his group of co-workers "stuck together" at work and had lunch and breaks together. One person noted that he got along with co-workers but did not have "real friends" at work; another said that she was shy and introverted by nature and therefore did not seek out social relationships with co-workers.

Co-workers' reactions to the consumers' disabilities varied. Most people felt that they were accepted and treated like any other employee. One consumer considered it a compliment when her boss said, "sometimes we forget that you are disabled." 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. Two individuals felt that coworkers and bosses tried to discourage and hold them back from trying for promotions or new jobs.

Some people felt that the praise they received from customers and employers made them feel that they were valued and accepted. One woman reported with pride that customers will "walk by five other people and come to my line especially" and will tell her supervisor that they "like this cashier, she's one of the best."

Many parents and spouses discussed the difficulty and pain in seeing the lack of societal acceptance of their relative. There was concern that the person might be socially isolated at work, taken advantage of, or hurt by comments or actions of other co-workers. Other parents were concerned that their relative might get in with the "wrong crowd" at work.

Support at Work

Both consumers and family members identified professional staff as critical sources of support at work. Most consumers felt that these staff people provided a feeling of security and reinforcement on the job. As one consumer stated, "If I had a problem, I'd pick up the phone and call my counselor. My counselor was right there." Another person mentioned that he felt less dependent on his boss, because he received his training from the job coach. Consumers valued the fact that their job coaches came to the work site each day, if needed, and checked in with the boss to determine if there were any problems. They viewed job coaches as backups to ensure jobs got done.

Many family members stated that the ongoing support provided by job coaches to their relatives was also supportive to them, since they had access to the job coach as well if they had any concerns or questions about their relative's employment experience. They 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. There were numerous examples of employers providing support, understanding, flexibility, reinforcement, and praise to consumers. Several consumers noted the encouragement provided by their employers - for example, "he makes me feel that there is nothing I can't do" and "he told me I know the job better than anyone else."

Job Obstacles

Many consumers faced problems in getting or keeping jobs due, they believed, to the stigma surrounding their disabilities and discrimination on the part of the public, including employers and professionals. Several consumers had been told that they could not do particular jobs or tasks because of their disabilities. One person faced possible firing from his job, due to on-site drug testing in which he tested positive due to his seizure medications. As discussed earlier, two consumers felt that they were "held back" in their jobs from assuming new responsibilities or from seeking promotions due to negative attitudes of co-workers or supervisors. Two consumers sought legal action related to their job discrimination experiences and prevailed in these actions. One consumer, a state employee, was active in the state's Affirmative Action Committee, where he attempted to address employee concerns about work discrimination.

In the consumer focus groups, a key concern related to disclosure of disability and job history. Many people, particularly those with "hidden" disabilities such as mental illness, seizures, and traumatic brain injury, expressed fear about disclosing their disabilities to their bosses or prospective employers. As one participant said, "you just don't walk in and say, 'I am a manic depressive and a recovering alcoholic. How would you like to hire me?'" Some individuals were concerned about asking for accommodations that might be necessary on a new job. Although a few people expressed knowledge of their legal rights for accommodation under the Americans with Disabilities Act, they felt that there could be repercussions from making this kind of request. One person felt the need to hide the fact that he had seizures, for fear of being "blacklisted" by his boss and colleagues.

Others worried that potential employers would be afraid to hire them because they might pose a risk in terms of health insurance coverage. As one consumer said, "it's tough finding an employer who understands what you have, without fighting the whole world."

Many people were concerned about preparing job resumes and applications, particularly how to explain gaps in their job history due to periodic episodes of mental illness or hospitalizations. One participant said, "the last time I was permanently hired was in 1985. It lasted 3 months. So what do you say in an interview?" He indicated that he sought employment through temporary agencies, since they did not require long-term job histories and resumes. Several consumers stressed the value of the rehabilitation agency, in which the agency or job coach provided the entry for the job and then served as the buffer if necessary.

Another major barrier to employment identified by consumers was the lack of available, appropriate services by state vocational rehabilitation agencies, including a lack of staff follow-through. For example, consumers often did not receive assistance with job search activities, once their initial vocational evaluations were completed. Once placed on a job, some clients felt that their cases were closed too quickly by rehabilitation agencies. Many consumers expressed frustration with apparently inconsistent agency guidelines and rules. One person stated, "nobody knows what the guidelines are, you know, what your rights are with them, what they're supposed to do, what they're not supposed to do." Vocational rehabilitation services seemed to vary, depending upon the particular regional office or counselor involved with one's case.

Clients often experienced agency "run-around," being told at some point that they could receive certain services, and at other times, that these services would not be available. Consumers felt that there was inadequate information on availability of services, and on their rights regarding services.

Family members frequently cited lack of appropriate job matches as a major barrier for their relatives with disabilities. They were concerned that people with disabilities were placed in jobs because there were openings, not because of interest or aptitude for those jobs. Families felt that "dead-end," menial work was inappropriate for people who had held higher level jobs in the past, prior to their illness or disability. Another concern identified related to the placement of people with different levels of ability and disability in job training programs. This concern was expressed primarily by families of relatives with mental illness or physical disabilities, who felt that it was demoralizing for their relatives to be placed in training programs with people who were more cognitively limited. One

mother felt that program staff need to remember "that to categorize everyone in one group, because they have a certain disability is very unfair."

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 relatives. They felt that staff and the general public were too negative in their expectations for their relatives and that agencies needed to work with consumers to maximize their skills and functioning to the best of their capabilities. Lack of transportation was frequently cited by family members, since many relatives with disabilities were dependent upon public transportation to get to work, and were therefore limited in their job search to worksites accessible by bus or subways. Getting to work in inclement weather posed particular problems for people in wheelchairs or with mobility problems. A few people relied on family members for transportation, which required their parents to adjust their work schedules to accommodate the individual's transportation needs.

Job Expectations

Approximately half of the consumers were content with their jobs and expected that they would remain in their current positions. As one consumer said, "I want to stay where I am and stay part-time until I get really firm. And then maybe go full-time where I work, because there's good money, good benefits, and I love my job. So I can't see leaving it really." Others discussed plans to upgrade their skills and seek better jobs, felt capable of doing more than their current employment entailed, and wanted opportunities to learn more and assume new responsibilities. A few consumers discussed the dangers of staying too long at their current jobs, the problems of being in a "comfort zone," and not getting ahead. For example, one person noted, "I am in danger of staying too long just because I get comfortable to do so."

As previously discussed, many 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. How these limited opportunities were interpreted differed between family members and consumers. 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.

In terms of job expectations, consumers most frequently cited the importance of personal goal setting strategies. They stressed the need to set goals and find people to "support you in obtaining your goals." There was much discussion in the focus groups about motivation and inspiration in goal setting - for example, using one's abilities to the best one can, overcoming obstacles and challenges, not setting limits on one's goals, and taking opportunities to upgrade oneself through education or training.

In the family focus groups, there was little discussion about future plans and expectations regarding relatives with disabilities. One parent expressed the hope that her son could make a living independently, possibly based on his interest in crafts. She did not expect him to earn a "big living," but hoped he would make enough money to survive. Another parent said that he did not see potential for improvement given the son's long-term history of mental illness. Contrary to the positive plans and goals expressed by most consumers, most family members expressed concern about the lack of security in the future. One spouse stated this concern as not "knowing how long my husband's job will last and if this ends, then what's next? Does he stay home again?" Family members tended to express the desire for their relatives to stay on current jobs and keep things stable instead of moving on to new opportunities.

Discussion

Although consumers and families shared similar concerns on many issues, it is also clear from the above discussions that they differed in some key perspectives. To summarize, families expressed more concern about the psychological well-being, self-esteem, and socialization of their family member, in comparison to consumers who were more concerned about the importance of work productivity, job compensation and benefits, and overcoming issues of job discrimination and stigma. Whereas family members feared possible exploitation and/or isolation of their relative in the workplace, and

worried about future job opportunities, the consumers appeared more positive about their work relationships and about their future job prospects. In short, family members appeared more protective and consumers appeared more risk-taking in terms of current work situations and future work goals.

In addition to these similarities and differences between family and consumer participants, there were other interesting patterns which emerged in the analysis of focus group themes. One trend was that persons with psychiatric disabilities and their family members expressed more concern about issues

of "dead-end" or menial jobs than persons with other types of disability. This may be explained by the fact that many of these individuals had significant educational and work experience prior to becoming diagnosed with psychiatric conditions. They, therefore, perceived a large gap between their current

jobs and their actual potential, given prior experience and cognitive capacity.

Another pattern was that persons with "hidden" disabilities (such as psychiatric or seizure disorders) expressed more concern than persons with "visible" disabilities (such as physical or sensory disabilities) about issues relating to employer communication regarding their disabilities - whether and

how to disclose their disability, explain gaps in their job history due to hospitalizations, and/or ask for job accommodations. Persons with hidden disabilities faced a conscious choice about whether, when, and how to address the issue of their disability, whereas persons with visible disabilities felt that they needed to confront these issues up front with employers.

Implications

These focus group findings have important implications for professionals working with individuals

with disabilities. As expressed by consumers and family members, work plays an integral role in developing self esteem as well as contributing to a sense of being a part of "society." The central position work occupies in people's lives is consistent with the findings of Moseley (1988) who reviewed literature on job satisfaction of workers without disabilities. The sense of purposeful activity, compensation and socialization are factors identified in the focus groups as being essential to job satisfaction. While it is critical that individuals have opportunities to work, it is equally important that work match the interests and abilities of the individual. Work needs to be consistent with their goals and interests, not just compatible with available job openings.

Discrimination and stigma as identified in the focus groups were barriers that most consumers felt that they had encountered. This finding is consistent with research by Fraser and Shrey (1986) and Kiernan and Conley (1989) who cited negative attitudes and perceptions of employers, professionals, and families as obstacles to employment for people with disabilities. While some consumers in the focus groups expressed general awareness of their rights under the Americans with Disabilities Act, there was still overwhelming concern and fear about addressing disability issues with employers. Consumers seemed to feel isolated and on their own in deciding whether to inform current or potential employers of their disability and how to ask for accommodation. Counselors need to educate consumers about their employment rights under ADA and other legislation, and work with consumers on developing practical and individualized strategies for dealing with employers about issues of job

accommodation. Similarly, counselors can play a valuable role in educating employers about ways to accommodate people with disabilities in the workplace.

A third implication for rehabilitation professionals is the critical support role provided by job coaches and job counselors. Rehabilitation services need to have sufficient flexibility to respond to individuals' needs for support at different points in their career development. For some people, ongoing contact

by a job coach on the work site is appropriate, yet for others intermittent phone contact with program staff is sufficient. Some people may require support for a short period of time, while others may need support over an extended or indefinite period. Current funding policies and regulations that place restrictions on the type and duration of services and supports available make it difficult to address individualized needs.

Another important implication of these findings is the need for increased consumer involvement in the vocational rehabilitation system. Many consumers expressed difficulty in obtaining information about their rights and responsibilities in the vocational rehabilitation system. Counselors in vocational rehabilitation agencies typically have heavy caseloads and need to juggle many priorities; however through sharing the responsibility for successful outcomes with their client there will be greater opportunities for individuals with disabilities. The 1992 Amendments to the Rehabilitation Act call for greater involvement of consumers in the rehabilitation process, particularly in the development of the rehabilitation plan. These Amendments require that the rehabilitation system encourage and empower individuals to take more control over their services. Rehabilitation counselors can facilitate greater consumer involvement by educating consumers about the service system and providing them with opportunities to make informed choices about employment. The counselor needs to help facilitate more independence; consumers need to take greater responsibility to work cooperatively with the counselor and learn about their options and rights.

Finally, the role of the family needs to be taken into consideration in working with an individual

with a disability. The family can provide a historical perspective helpful in vocational planning as well as an expertise about what services have been successful in the past. Families also serve as a vital link in informal networking for job opportunities. Since families are frequently relied on to provide transportation and morale support to the relative with a disability, their support and commitment to the employment situation of their family member can make a difference in its success (Kerosky, 1984; Moore, 1984). Similarly, negative attitudes or expectations on the part of the family may impede or hinder an individual's employment success. Counselors need to be cognizant of family concerns and attitudes that may influence the individuals' adjustment to work. Offering support and information to families on ways to facilitate employment of relatives with disabilities may help address these

concerns (Cook & Ferritor, 1985; Lindenberg, 1980). Close family/professional communication may improve family attitudes and expectations regarding the employment potential of their relatives (Hill et al., 1987).

The development of community-based jobs where individuals are supported, included and valued is the goal of the rehabilitation process, but additional work is still necessary to achieve this goal. The astoundingly high unemployment rates (67%) of people with disabilities in the United States (ICD, 1986) indicate that a large segment of this population has been denied the opportunity to work. Cooperative efforts of professionals, consumers and family members are necessary to lead to greater employment opportunities and more successful outcomes.

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