Quality of Life and Supported Employment: A Case Study of Three Women With Developmental Disabilities

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This paper presents the findings of a qualitative case study of the quality of life of three women with developmental disabilities. In-depth interview data were collected from the women who had previously worked in a sheltered workshop environment and were, at the time of study, working in supported employment in the community. Interviews were also conducted with each woman's job coach and a family member or close friend. On-site observations of the women in their supported employment environments were also undertaken. Results show that the women's own perceptions about their quality of life were not always as family members and job coaches expected, and that the purported benefits of supported employment for the three women with developmental disabilities were not always realized. Occupational therapists have an opportunity to facilitate the occupational performance of adults with developmental disabilities but they must be willing to engage in wider health and social policy change if they are to make significant gains.


Rehabilitation researchers and clinicians have seen an exponential growth in programs aimed at enhancing the quality of life of persons with disabilities. A driving force in this process has been the widespread belief that traditional medical services do not adequately address the many social needs of persons with disabilities, and that over the longer term, underlying pathology and treatment of symptoms matter less than issues of social health and participation in a meaningful community life (Dijkers, Whiteneck, & El-Jaroudi, 2000). Persons with disabilities themselves say that these less tangible outcomes of rehabilitation services make a large contribution to their wellness (Deegan, 1992; Hagner & Marrone, 1995).

Within the last 2 decades, many efforts have been undertaken to enhance quality of life for adults with developmental disabilities (Hotaling, 1998; Nibert, 1995; Seltzer & Krauss, 2001), including programs to enhance their work skills (Simmons & Flexer, 1992). The embrace of quality of life as a guiding philosophy has led to a complete turn in the models of vocational rehabilitation deemed appropriate in the field. The primary purpose of this study, therefore, was to better understand the issue of quality of life for adults with developmental disabilities and to examine the professional contention that quality of life increases with participation in supported employment.

From Sheltered Workshop to Supported Employment

To better understand the newer models of vocational training for persons with developmental disabilities, it is important to understand that the longstanding model was the sheltered workshop (Nibert, 1995; Scotch, 1988). Sheltered work-
shops were designed to provide a protected work environment where basic vocational skills could be learned, and behavioral interventions could be provided if needed (Rusch, 1986). Sheltered workshops typically offered a combination of piecework and “make work”—when subcontract work was limited, people often performed “simulated tasks” or did no work at all (Lutfiyya, Rogan, & Shoultz, 1988). Thus, although the ideal of the sheltered workshop was to serve as a kind of stepping stone toward greater job and social skill development, this was not always realized in practice.

By the early 1970s, concepts such as normalization (Wolfensberger, 1970) and mainstreaming challenged the tenets of the segregated environment of the sheltered workshop (Grob, 1995). Those who favored new alternatives found in “supported employment” the attractive possibility of improving employment outcomes for persons with disabilities in tandem with overall quality of life. The job coach model of supported employment is the mechanism by which many individuals with significant disabilities have obtained competitive employment (Rusch, 1986). In this model, the job coach is the primary provider of support to an individual with disability for the duration of the individual’s supported community employment (Rusch).

After its inception as a federal program with the authorization of the Rehabilitation Act Amendments in 1986, supported employment fully emerged and its purported benefits were made explicit (Rehabilitation Act Amendments of 1986). First, within the supported employment environment, new social relationships between individuals with disabilities and their coworkers without disability were anticipated (Bellamy, Rhodes, Bourbeau, & Mank, 1988). Beyond the work setting, persons with disabilities were expected to experience greater social inclusion, including new friends (Sinnott-Oswald et al., 1991). It was further thought that program participants would learn sufficient new skills to enable them to gain access to a range of community activities and services (e.g., grocery shopping, public transportation, religious services) considered by able-bodied citizens as routine aspects of daily life (Pedlar, Lord, & Van Loon, 1990). Powell et al. (1991) wrote that for all types of supported work opportunities, the intended outcomes are earned wages, participation in valued work, the development of friendships among diverse individuals, participation in community, learning new skills, and making a contribution to society. Finally, supported employment was expected to provide a higher wage (Simmons & Flexer, 1992), and a starting point toward greater financial independence.

Supported Employment and Quality of Life

Quality of life is a concept that requires an operational definition. Taylor and Racino (1991) note that philosophers throughout time have failed to agree on the meaning of this term. However, quality of life was defined for research purposes in the area of developmental disabilities by Blunden (1988) who equates quality of life with well being and includes four major dimensions in the definition: (1) physical well being, including health and fitness, (2) cognitive well being, including personal satisfaction, (3) material well being, including adequate income, a home, and transportation, and (4) social well being, including community presence, choice, respect, competence, and valued relationships. This definition, with its four dimensions, guided the study.

Systematic evaluations of the benefits of supported employment, including benefits to quality of life, are few. Sinnott-Oswald et al. (1991) found that participation in leisure activities; personal self-esteem and perceptions about job skills and income were positively related to supported employment. They also hypothesized that the quality of life expressed by disabled individuals in supported employment would approximate the quality of life of nondisabled subjects in a control group. However, they found no significant improvement in the quality of life of those in the developmentally disabled group following a transition from sheltered workshop to supported employment and concluded that a change in one area of a person’s life did not necessarily lead to a positive change in another.

In a study of 12 individuals with developmental disabilities, Pedlar, Lord, and Van Loon (1990) found that the perceived quality of life of all of the study participants was “considerably enhanced” as a result of supported employment. Nonetheless, they conceded there were difficulties facilitating the social integration of the employee in the workplace. Additional studies have confirmed that workers with developmental disabilities experience limited nonwork task social interaction with their nondisabled counterparts (Butterworth & Strauch, 1994; Chadsey, 1990), and, in most situations, report few interactions and friendships outside of the workplace (Eggleton, Robertson, Ryan, & Kober, 1999; Storey & Homer, 1991). These studies have led many to ask whether it is reasonable to expect consumers with developmental disabilities to exert greater control over their lives, develop latent competencies and talents, and even enjoy greater quality of life, as a result of their participation in supported employment.

The case for a positive relationship between supported employment and quality of life remains questionable. Further, while focused on the quality of life of the supported employment worker, few studies have included the
subjective opinions of persons with developmental disabili-
ties themselves or defined quality of life from their per-
spective. In part, this is due to the methodological chal-
lenges related to obtaining meaningful data from persons
who may have difficulty conceptualizing and expressing
their personal opinions and preferences, due to the nature
of their disability. Methodologically speaking, however,
there is much to be gained by obtaining an “insider’s view”
on qualitative phenomena (Abel & Sankar, 1995), includ-
ing quality of life. From an occupational therapy perspec-
tive too, we are obligated to find ways for individuals with
disabilities to express their needs and wishes and to identi-
fy activities, relationships, and environments that hold
value and meaning (Law, 1998; Reilly, 1962). As Yerxa
(1994) has argued, ours (occupational therapy) is a holis-
tic, empowering, and optimistic view of human life. In
practice, this means that our interventions must support
the goals of our patients and clients, and be defined on
their terms (Wilcock, 1993). Unfortunately, research on
supported employment has lacked this consumer perspec-
tive (Clark, Scott, & Krupa, 1993). There is a pressing
need now to more closely examine the quality of life ques-
tion to determine the extent to which professionally
defined services are truly meeting the needs of people with
developmental disabilities.

The purpose of this paper is to report the major find-
ings of a study focused on the quality of life perceived by
people with developmental disabilities. This research
focused on the situational contexts of 3 women with devel-
opmental disabilities in an effort to better understand the
experience of supported employment and a wide range of
other factors that affect quality of life.

Methods

Study Design

This research was carried out as a qualitative case study, an
appropriate match for the exploratory nature of the study
(Abel & Sankar, 1995). Since there is very little published
research on quality of life in people with developmental dis-
abilities from the consumer perspective, generating new
hypotheses about quality of life as it relates to supported
employment was thought to be especially useful. The qual-
itative case study approach was particularly selected for its
emphasis on on-site observations of the real-life contexts of
study participants, and the opportunity to detail incidents
and decisions made around particular issues, individuals,
and situations, in recognition that the boundaries between
phenomenon and context are not always clearly evident
(Yin, 1994). The qualitative case study approach is impor-
tant because it extends beyond the individual to link micro
(person-level) issues with macro structures for policy pur-
poses (Yin).

Study Participants

The primary participants in this study were 3 women with
developmental disabilities. Participants were recruited by
the first author from a community agency that provided a
variety of Medicaid-funded programming for persons with
disabilities: sheltered workshops, supported employment
enclaves, individual work placements, and assessments of
readiness to work. Eligible participants were women who
had previously worked in a sheltered workshop and were
currently working in a supported employment setting. The
supported employment option at the agency where partici-
pants were recruited consisted of several work “enclaves” of
8–10 adults, each supervised by one job coach. The most
popular types of work performed by enclave workers were
hotel housekeeping, janitorial services in commercial facili-
ties, and entry-level food service jobs at Burger King and
McDonald’s. Given the small-scale and exploratory nature
of the study and the complexity of analyzing findings across
gender and culture, participants included Caucasian
women only. The 3 study participants were selected to pro-
vide a range of family and living situations. Additionally,
eligible study participants were restricted to individuals who
were legally able to make their own decisions, including
provision of informed consent.

In addition to the 3 primary participants, a job coach
and a family member or group home manager who was
close to each woman participated in the study. Job coach-
es had to have worked with their consumer counterparts
for a minimum of 3 months. This timeframe was selected
to ensure sufficient time for experiences to be shared and
relationships to deepen, and for the reflections and opin-
ions of the job coaches to be more informed. Close fami-
ly members were also very important to the study as they
added unique and specific data about how these three
women lived and “managed” on a day-to-day basis both in
the work setting and in the wider community. Since
reflection on the meaning of quality of life was anticipat-
ed to pose at least some degree of challenge for the 3
women, these additional perspectives provided triangula-
tion, or an additional check on the reliability of study data
to aid in understanding this elusive construct (Falkner,
1999). Prior to the commencement of data collection, the
study was approved by the Behavioral Investigation
Committee/Institutional Review Board at the authors’
institution and signed informed consent forms were
obtained from study participants.
Data Collection

Open-ended interviews and on-site observations were methods of data collection in this study. Interviews were conducted with each of the 9 participants, 3 women, 3 job coaches, and a family member, at a time of their choosing in their home or in an office in their workplace. Interviews with the 3 women with developmental disabilities were conducted first. Special care was taken to ensure that these interviews took place without people present who might influence the women’s responses, recognizing that special care must always be taken in research with vulnerable populations (Llewellyn, 1995). The interviews, guided by a series of prepared questions, were audiotaped and transcribed verbatim. Observations were also made of each woman in her enclave work setting, focusing on how each performed their assigned tasks, including: following directions, conceptualizing steps in each task, independent thinking, reacting to suggestions from their job coach, and finally, interacting with others in their enclave and the “regular” employees of the hotel. Each observation period lasted approximately 2 hours and observations were recorded as field notes. While this time period may seem brief, the lead investigator brought more than 15 years of experience working with adults with developmental disabilities in the community to the study.

The first author conducted all study interviews and on-site field observations. It should be noted that although the first author collected all of the study data, and was familiar with the agency from which the participants came, she had not previously known, or had any type of relationship (therapeutic or otherwise) with the 3 primary study participants or their families. The community agency recruited the volunteers from which the study participants were selected. The job coaches were similarly unknown to the first author. She met each job coach for the first time when she conducted the on-site field observations. At the conclusion of each field observation, individual interviews were scheduled with each job coach.

Data Analysis

The data were analyzed using qualitative methods, specifically, a constant comparative method (Glaser & Strauss, 1967; Strauss, 1987). In this process, the transcribed interview data and hand-written field notes were read and reread by both investigators to identify patterns and themes directly related to the main study topic, quality of life. The sections of text that represented salient ideas and topics were highlighted or “coded” directly on the transcripts and notes. Salient concepts were informed by the literature and the investigators’ past experience with persons with developmental disabilities in the clinical setting. All of the interview and observational data were reviewed by both investigators repeatedly to refine the parameters of the themes identified and determine appropriate labels or codes for the categories of content identified. Thus, the process of coding was that of iteratively refining the boundaries of the data and assigning descriptors for different portions of these data, and finally organizing all of these data into a meaningful whole (Morse & Field, 1995). Participant quotes were selected from the interviews and field notes to serve as exemplars of each woman’s quality of life experience, and served to link the researchers’ interpretations of the women’s meanings of quality of life to their direct accounts.

The final and most difficult steps of data analysis using the constant comparative method are “delimiting the theory” and then “writing theory” (i.e., deciding what counts as results and then reporting them) (Glaser & Strauss, 1967; Strauss, 1987). At this stage, the patterns of meanings in the data were organized into theoretically defensible structures. The final task was carefully representing the spoken words of the participants in the form of case descriptions in the tradition of the descriptive case study (Yin, 1994). The authors conducted their analysis “within cases” and thus the study results are presented as three distinct case descriptions reflecting an integration of the interview and on-site observational data for each primary research participant.

Results

Shelley: Trying Hard to Succeed

Shelley (pseudonyms are used throughout), 49 years of age, was participating in her first supported employment experience. When interviewed, she had been working for 2 years in an enclave as a housekeeper at a local hotel. Shelley lived with a roommate in a supervised apartment building, managed her own money, and paid her own bills. Shelley was proud of these accomplishments. Her income consisted of Social Security payments, food stamps, and her supported employment paycheck, which were not always sufficient to sustain her through each month. Although her parents and siblings provided additional financial support, she preferred not to ask them for money.

Interviews with Shelley and her family revealed that Shelley had worked in two different sheltered workshops in the past, first in 1982 and then again in 1993. At that time she was living at home with her parents. Neither work experience was described as especially agreeable. When asked about the kind of work activities she performed in the sheltered workshops she reported “mostly assembly tasks.” She was paid either per piece or hourly, depending on the job.
This was not a pleasant time for Shelley who said, “It was stressful and very noisy. Lots of times people used bad language. I’m not used to that. Sometimes there were even fights.” She complained about “having no work to do” and stated that she and other workers “just had to sit there doing nothing or pretend to work.”

More than 5 years after her last sheltered workshop experience, Shelley joined a supported employment enclave. Despite early optimism, Shelley’s father reported no increase in Shelley’s circle of friends in the time since, claiming her friends were mostly the same people she already knew from years of bowling in a league for people with disabilities. Shelley herself reported she had made no friends with any of the “regular hotel employees.” Although her parents thought they had seen some improvements in Shelley’s quality of life after Shelley entered supported employment, they believed these changes were mostly due to the independence she achieved by moving out of the family home and into her own apartment. Shelley’s job coach, who had known Shelley for nearly a year, agreed completely with the parents’ view.

Shelley’s parents voiced considerable disappointment with the supported employment program their daughter was involved in. They had expected the program to teach specific work skills that Shelley could use later, in a more independent job placement. They also expected her to attend classes that would teach her basic grooming and social skills, and relevant competitive employment skills such as job interviewing. Shelley’s job coach disclosed that classes such as these were once part of the agency’s programming but were now handled on a “need basis only.” Reduced agency funding and staff shortages precluded anything more. He also expressed the concern that Shelley’s “unpredictable personality” made it challenging to think how she would ever gain the skills required for competitive employment. On the day of the field observations, the meaning of his comments became clearer.

On the day of the on-site field observation, Shelley’s job coach started the morning as usual, with orientation and hotel room assignments. Shelley found her housekeeping cart without difficulty, but went to the wrong hotel room. Another enclave worker pointed her to the correct room. Once in the room, Shelley began her duties, which were focused on the bathroom: changing the towels, cleaning the floor, sink, and tub, restocking the coffee supplies, and finally, cleaning the mirror over the vanity and the washing the coffee pot. Most tasks were completed without incident and with care. However, toward the end of her 2-hour shift, Shelley selected the wrong cleaning product from her housekeeping cart and proceeded to clean the coffee pot in a hotel guestroom. The bottle was clearly labeled “DO NOT DRINK.” The research investigator, concerned that this might be a serious problem, pointed out the error to Shelley and then explained the situation to Shelley’s job coach. When her job coach approached Shelley to discuss the mistake, Shelley became noticeably upset and began to cry. At the peak of her interaction with her job coach, Shelley shouted “So much for what I know about cleaning rooms!” stomped her feet and promptly walked away. It took 30 minutes for the job coach to console Shelley sufficiently to allow her to return to her duties. Later, the job coach reported that Shelley “could become very emotional at times” and reacted this way when he identified problems with her work. He commented that this was a “major deterrent to her being able to work independently in the community.”

**Ruth: Wanting Something More**

Ruth was 61 years of age. She had one brother (her legal guardian) and one sister, neither of whom she saw very frequently. Ruth lived in a large group home (24 residents) where she was responsible for keeping her room clean, doing her own laundry, and helping out with household chores. Ruth stated, “Someday I would like to move to my own place, but my brother thinks this is the best place for me. He thinks I’m learning a lot here. They have security here.” Ruth was quite pleased with the range of activities at her group home and reported with some anticipation that “Three nights from now we are having a Christmas Party!” When asked if she thought she could possibly take care of an apartment on her own, Ruth spoke with some hesitation, although it was an idea that had appeared to interest her. “Not by myself, but maybe with a couple of other friends of mine who feel the same way I feel.” Ruth’s financial support consisted of Social Security payments, disability income (related to a mild stroke several years ago), and her paycheck from her supported employment job.

Like Shelley, Ruth’s prior experience in the sheltered workshop was not especially positive. Ruth indicated that she was often bored with her work and that many times “there was no work,” so “I just sat.” Still, she thought the job had some value saying, “If you looked at my work, it was pretty greasy and messy stuff. But, it was my job and it was very important to me and to my parents.” She recognized too that the sheltered workshop job provided the extra, albeit small, amount of money she needed to purchase desired items like craft supplies and small gifts for friends and family. When asked about her friendships at that time, Ruth replied that she “had a couple of friends from the workshop” but she only saw them “at work.” Ruth did not visit with them outside of work hours, and said they never phoned each other. When asked about her friends now, Ruth’s enthusiastic reply was “My housemates. I go a lot of places with people from my house.”
Observations of Ruth at her supported employment setting (hotel housekeeping) confirmed both her sociability and her job proficiency. Ruth was independent, helpful, and thoughtful. She assisted other enclave housekeepers when they were having difficulties and undertook additional tasks to the pleasure of her workmates and her job coach. Observed wiping down several closet doorknobs in the hotel hallway, Ruth stopped to tell the investigator: “I even clean this. Nobody told me to, I just do it.” Ruth related an incident when she found a pair of eyeglasses while changing pillowcases in one of the hotel rooms. She explained in detail how the eyeglasses could have been damaged if “I had not been as attentive as I was.” Then she continued to talk at length about the types of things she had seen in people’s hotel rooms, including computers and how she had to be “extra careful” that time so as “not to disturb its settings.” She added, “There is so much responsibility for not touching things.” Ruth said she enjoyed her work at the hotel much more than her work in the sheltered workshop years earlier: “It’s more challenging…I’m not kidding. It’s challenging because every room never looks the same. They might look the same to everyone else, but they are not the same…it keeps us real busy.”

Ruth said that her housekeeping job made her happy, but she was not satisfied with every aspect of the job. One of her major concerns was money and whether she would ever find a way to move beyond her current circumstances. Her paycheck was automatically deposited into a bank account established by her brother and arrangements were made for Ruth to receive an allowance of $8.00 per week from this account. Ruth said she was “grateful for the extras” provided by her wages, but was aware that her supported employment wages could put her government benefits in jeopardy. Ruth stated, “If I get a raise at work and make too much money, they are going to take benefits away from me. I need those benefits to help me through the year. My job coach wants to time me again. If I do better, I’ll get a raise. If I get a raise, I’ll be up a creek with the government. They pay for some of the things I need, like if I get new glasses, they will pay half. I couldn’t afford it otherwise. What a scam the government does!”

Considering her relatively small allowance, Ruth was skillful at saving and budgeting. She regularly saved $4.00 per week for special purchases, including some souvenirs she had recently purchased for herself after a weekend trip with friends and staff of her group. She also found ways to pursue her interest in crafts, finding ways to use “free stuff” like paper clips to make a variety of attractive items including bracelets of her own design. Ruth said: “The materials were easy to get because nobody much cares about paper clips. My group home manager gives them to me. I can get them at work, too.” Pleased with her friends and her hobbies, Ruth in many ways was a “success story.” Yet, she expressed a desire to do better for herself. At the conclusion of the interview she confided, “I don’t want to spend the rest of my life doing this job, you know. And I just have to get away from this dust! If I found the right man, I’d grab him and leave this hotel right away, you bet!”

Denise: Doing What I’m Told

Denise was 46 years of age and lived with her parents. Her parents, active travelers, often left Denise at home alone. Although a neighbor reportedly “checked in on her,” staff at Denise’s supported employment program were concerned she should not be left alone overnight. Denise’s job coach expressed concerns about there being “conflict in the home.” Interactions between Denise and her mother, observed by the first author, suggested family relationships were sometimes strained.

Nearly 10 years ago, Denise worked in a sheltered workshop where she performed many assembly jobs subcontracted to the workshop from the auto industry. When asked if there were things that she did not like about her days in the workshop, Denise replied emphatically “the people…they weren’t very nice!” Denise said she never socialized with anyone from the workshop. What made her most unhappy though, was “never being able to select the jobs I wanted.” She said “a trainer” always assigned her work tasks and she was not able to select the jobs that she wanted to do. Denise also complained that the pay “was awful.” As well as inquiring as to what Denise did not like about the workshop, the researcher also specifically asked her if there was anything she liked about her workshop experience. Denise replied, “It was all right, I guess, if I had to be there, but I like cleaning rooms better. See, I can clean them by myself.”

Denise entered supported employment as an enclave housekeeper in 1999. Reflecting on the difference between the two settings Denise said, “I like work in the hotel better” because sometimes she could work “by myself” or choose to just “help out other people in my group.” In response to a question about new skills she had learned, she said, “I know how to clean bathrooms real good because I do them here and all the time at home.” Continuing, Denise added, “Now, I know how the beds are supposed to be done too and I help to teach the new people. I’m a helper and stuff like that.” In contrast to Shelley and Ruth who socialized with nobody in their respective enclaves, Denise currently did socialize with two women from her group. The parents of one of Denise’s friends regularly drove over to bring their daughter to visit Denise, or alternatively, to pick up Denise and bring her to their home. Other times, Denise and her friend went shop-
ping at the mall or saw a movie together. Denise socialized with her second friend by phone but never at her home since Denise's parents were concerned that this woman did not live in a safe neighborhood. The researcher also inquired about friendships with coworkers that did not have disabilities. Specifically, the researcher asked, "What about the other people who work here—the ones that are not from your agency? Are you friends with any of them? Do you see them socially, away from work?" Denise replied that she had no friends “from the regular workers” at the hotel.

Denise was a skilled housekeeper and earned approximately $50 per week at her hotel job. She explained that, in the past, she had earned too much money sometimes and had to pay it back to Social Security (a concern for Ruth as well). Denise said she was grateful to have medical benefits despite her supported employment paycheck but told the investigator on several occasions “It is very difficult to find a good doctor who accepts Medicaid.” Denise chose to use her paycheck for clothing, occasional dinners at local restaurants, and movies. When asked if she would like to have a more independent job, Denise first stated that she would like that, but then changed her mind. She said she would only do that when “her parents thought the time was right.” After the interview, the investigators learned that Denise had previously held a job in the community that she liked very much (an assistant in a veterinarian’s office), but had to quit because her mother “thought it was too much for her.”

The actual reasons for ending this job were never determined. Denise also stated a desire to live in her own apartment, and wanted to leave her housekeeping job. She said she could not do either because “My mother thinks it’s better for me to stay where I am.” Denise expressed the hope that she would be able to do these things in the future. Denise’s job coach felt Denise would be capable of working at a more independent placement and suggested that Denise’s parents were hindering her progress: “A lot of parents just will not allow their child to go into the public. I believe that they are possibly more afraid than our consumers are.”

On the day the investigator observed Denise at her worksite, Denise was visibly upset. The investigator learned that Denise had argued with her mother several hours earlier over a mistake Denise had made at home. According to Denise, her mother had thrown away a pair of her favorite pants because Denise had accidentally put dirty dishes into the dishwasher when there were still clean ones inside. Later, in the interview with Denise’s job coach, the job coach stated that the program staff often heard reports of events like this from Denise. He restated his belief that Denise was capable of living in a supported apartment and that “it would be good for her to live independently, as an adult.”

Observations of Denise at work were informative. Her work to clean the bathtub and sink was meticulous. She removed the dirty towels, found fresh towels, and placed them on the towel rack saying: “I refold the towels when I take them off the cart because sometimes they aren’t folded good enough and they won’t fit on the racks.” When she noticed she had mistakenly picked up two clean bathmats from the cart rather than one, she carefully replaced the second mat and said: “Excuse me. I have to go put one back. Nobody really needs two.” However, when it came to cleaning the toilet, Denise did a hurried job. When the investigator asked Denise why she did the toilet-cleaning task so quickly and perhaps not as well as the rest of the bathroom, an angry Denise answered, “I really don’t like cleaning the toilet. It’s one of my jobs at home. You would think that I would not have to do this in two places!”

Discussion

Analysis of the context and nature of these three women’s supported employment experiences suggest that the women preferred their current work in the housekeeping enclave to the work and “simulated work” they had previously performed in the sheltered workshop. The authors conclude that their quality of life was higher under the supported employment model. The women cited a variety of examples of how they found satisfaction in both their specific work assignments as well as their relationships with others in the housekeeping enclaves. Shelley remarked that the workshop was “stressful and noisy” while the hotel was “clean and quiet.” She also stated that many times, in the workshop, there was not any “real work” to be done, and many days she “just sat,” whereas in the hotel, she was busy with real work all the time. Ruth said the workshop jobs were often dirty and that the hotel work was more interesting because “You never know who you will run in to. We ran into the guy who sang ‘Achy Breaky Heart.’ He was right here in the hotel.” Another important concept for Ruth was responsibility and the respect she earned as a result of her performance. She thought that working in the hotel was more challenging too, because “you aren’t supposed to touch other people’s things.” Ruth enjoyed the freedom that the hotel work gave her. For example, after completing her assignments in a particular room, she went on to clean the doorknobs with disinfectant. “This kills germs. Nobody told me to do this. I just do it.” Echoing some of these same sentiments, Denise reported she often helped other people in her group and showed them how to clean. She enjoyed this position of “teacher.”

In addition, there were several unanticipated results. For example, analysis of results showed how difficult it was
to provide an appropriate level of challenge to workers in supported employment enclaves, and at the same time foster consumer autonomy and control. Results showed too, how key policies and regulations beyond supported employment, including Social Security policies, directly affected the quality of life of supported employment workers.

**Fostering Individual Autonomy and Choice in Supported Employment**

Schalock (1996) and Browne (1999) have argued that when individuals have more opportunities to make decisions regarding their own lives, they perceive their quality of life as higher. There is evidence in this study that the ability to have one’s preferences considered in the workplace mattered greatly. For example, Denise’s greatest complaint about her years in sheltered employment was being told what to do—she wanted more choice. However, enclave work assignments were highly structured with few opportunities to customize the tasks to the individual workers. The time constraints of the job required enclave workers to work at the same pace irrespective of their level of cognitive and physical ability. Thus, job dissatisfaction was expressed at times.

Outside of the work environment, personal autonomy emerged as a dominant theme again. For example, Denise, who was living with her parents, wanted to live in her own apartment and leave her supported employment job for something new. Ruth, although happy in at her group home and satisfied with her supported employment job, still wondered whether she could try to live on her own and find different work. Our point here is not so much that these issues contributed to negative quality of life, but rather more fundamentally to ask how professionals could facilitate the expression of individual preferences and their application in practice. A central finding from this study is that efforts must be continuously undertaken to reexamine the ways that persons with developmental disability may be able to exert more control over their lives, including decision making, so they can continue to build their work and social skills and gain independence, and ultimately enhance their quality of life. O’Shea and Kennelly (1996) contend that being robbed of choice denies people with disabilities a meaningful role in economic and social life, and therefore does not allow for a high quality of life. While some may contend that people with developmental disabilities do not have the ability to make such higher level judgments, findings suggest that most people with developmental disabilities do have a basic, concrete appreciation of their situation, and ought to be given as many opportunities to shape their own future as possible.

**Policies and Regulations That Impede Supported Employment Goals**

Much of the research literature on supported employment suggests that the economic independence of persons with disabilities will be increased under this model. The results of this study show that the situation is more complicated than simply earning a higher wage. For example, there is a clear downside to earning more money, including the fact that it could be “clawed back” and even disqualify a person from being eligible for important health services. Ruth was aware of this when she said: “If I get a raise and make too much money, they [the government] are going to take money away from me. I need that money to help me get through the year. Those benefits pay for my new glasses and other things I need.” As other researchers have recognized (Thompson, Powers, & Houchard, 1992), and this study affirms, there is a need for much more careful analysis of the wage issue in supported employment to determine whether policy changes are needed to prevent punishing workers with disabilities for whatever gains in salary they achieve as they gain new employment skills.

Closely related to the income issue is the influence of independent living. Shelley loved living with a roommate in a supervised apartment and making many of her own decisions about social activities, shopping, and homemaking. Shelley’s parents too were convinced that the single largest factor in their daughter’s personal growth was leaving home to live more independently. Ruth, on the other hand, reported some of her happiest social occasions in the company of her coresidents in her group home. This may mean that quality of life has less to do with the actual place that adults with developmental disabilities live and who pays for their home, than it does with the quality of living experience within that home. The investigators believe that future research, such as extending the work conducted by Heller, Miller, and Hsieh (2002) describing the impact of residential settings on adults with mental retardation, must be undertaken to explore the direct relationships between types of living arrangements and consumer quality of life, since it appears that there are many aspects of living situations that hold the potential to increase quality of life.

**What Outcomes of Supported Employment Should Be Valued Most?**

Each woman in this study participated in a variety of social activities with friends (e.g., bowling, hobbies, trips, movies) and found pleasure in them. Each woman was also friends with several persons with disabilities from their sheltered workshop days and their housekeeping enclave. None of the women expressed any sense of disappointment in either the
range of social activities they were engaged in or the number or quality of their personal friendships. Still, the supported employment literature suggests that friendships with non-disabled persons are the gold standard of social independence, in essence devaluing friendships with other people with disabilities. This stance in the literature seems all the more ironic when proposed by supported employment advocates who ought to hold the value of consumer self-determination most highly. We suggest that further research should be undertaken to examine the influence of all personally valued friendships on quality of life, and in particular, on ways to develop and strengthen such relationships.

According to researchers in developmental disability (Blunden, 1988; Browne, 1999), personal social skills are intimately entwined with long-term social well-being. Interviews and observations with the women in this study confirmed that while each woman usually conducted herself in a socially appropriate manner, there were many instances of behavior that would not be acceptable in the community at large, including in employment settings. Appropriate interpersonal communication, personal hygiene, punctuality, and anger management, for example, are all essential if competitive employment is the long-term goal. A key finding from this study is that simply placing people in supported employment enclaves in the community is inadequate as a strategy for conveying appropriate social behavior. Research suggests that social skills training needs to be explicitly taught to individuals with developmental disabilities, if improvements are to be realized (Sinnott-Oswald et al., 1991).

Implications for Occupational Therapy

Historically, occupational therapy services for adults with developmental disabilities have not been widely available in the community context (Powell, 1992). Many people with disability have also “fallen through the cracks” in the time between leaving the sheltered workshop environments over the past decade or more and entering their first placement in a vocational programs (if one is found). Taken together, this means that opportunities for occupational therapists to directly influence the quality of life of supported employment workers remain relatively limited.

To make matters worse, the agencies and organizations that currently provide supported employment services to individuals with developmental disabilities are also finding it more and more difficult to maintain a comprehensive level of service. With increasing budget cutbacks, caseloads have grown dramatically and individuals are waiting much longer for services. For example, in 2001, the mental health system in Oakland County, Michigan, faced an $18 to $20 million deficit and agencies that provided direct care services through this system were forced to cut one third of their staffing and reduce their operating budgets by $1 million per month (Loesch, 2001). Other states have been hit with similar funding cuts (Santini, 2003). Yet occupational therapy intervention is very relevant in this context and the role of occupational therapy is potentially far-reaching (Siporin, 1999). Researchers in the community have found that job readiness, motor skills function, cognitive function, social skills, activities of daily living, and adaptive equipment are all areas of great concern with people with developmental disabilities (Herger & Campbell, 2000; Hotaling, 1998). These are areas of considerable occupational therapy expertise. As experts in occupational performance, occupational therapists can contribute to closing the gap between the impairments of individuals with developmental disabilities and the complex demands of supported employment and even the competitive workplace.

The current climate of budget cutbacks and staff shortages for all community health services makes it more difficult to ensure that the opinions and wishes of people with developmental disabilities are heard (Hagner & Marrone, 1995). The results of this study remind us that persons with developmental disabilities can and do form their own opinions and when given an opportunity to contribute to the decisions that shape their lives, they do so. Therefore, occupational therapists who work in supported employment and community-based health programs must continue their efforts to be sure that the voices of those who cannot advocate for themselves are in fact heard, and that programs and services that are meant to be “consumer-driven” truly are.

Study Limitations

Because the study focused only on 3 Caucasian women, we do not know how differences in ethnicity and gender may have influenced study findings. The 3 women in the study were also recruited from a single community agency. Therefore, their views on quality of life may have been a reflection of the local organization or the specific housekeeping enclave in which each woman worked.

Mention should be made that the investigators had some difficulty designing the interview questions and asking them in such a way that they were clearly understood by the women in this study. The clinical experience of the first author, and her familiarity with the supported employment program, mitigated this limitation to some degree. Still, it took some time to rephrase questions during the interviews and on rare occasions, a question needed to be omitted. At other times, the investigators felt the study participants had “rehearsed their lines” and were repeating ideas that they had heard before, either by staff
or family. The inclusion of field observations in the study design was a deliberate effort to address this concern, and we believe that this strategy coupled with triangulation of data from other sources helped to minimize this threat to the validity of study findings.

Another study limitation related to the ability of the participants to clearly remember their sheltered workshop experiences, as it had been some time since their work in sheltered workshops. Although the participants were not able to answer some specific questions, such as how much they earned each week, they clearly had opinions on their work environment, coworkers, and the jobs they performed, and were able to express them clearly.

Finally, it should be noted that the parent of one of the participants (Denise) who was originally interested in the study, ultimately refused to be interviewed. The first author made repeated efforts in various ways to obtain or encourage an interview (e.g., phone calls, a letter presenting an alternate method of participation, etc.) but those attempts were not successful. While more data on the parental perspectives on quality of life in supported employment would have been valuable, our study’s main focus was on the perspectives of the women with developmental disabilities.

In conclusion, it has been said that the pursuit of research focused on quality of life, a concept lacking a clear-cut definition, will nearly always pose an insurmountable challenge (Liddle & McKenna, 2000). That said, the voices of people with developmental disabilities have rarely been heard in the efforts to design services for them (Grob, 1995). Hence, the findings of this study have taken us one step further in understanding how participating in supported employment may be related to quality of life. Still, additional research is needed. For example, larger studies need to be undertaken with men and people of other races to help determine if gender and race has an impact on supported employment outcomes. Research must focus on the job coach to explore the salient features of the relationship between the job coach and the person with developmental disability and determine their influence on supported employment outcomes. As mentioned above, research must also be conducted on the wage issue and the role of independent living. Finally, the authors hope that there will be opportunities for comparative studies of supported employment programs designed and delivered by occupational therapists to determine their effectiveness in improving quality of life for persons with developmental disabilities.

It is apparent from this study that even optimal efforts by occupational therapists practicing in this area will be insufficient to achieve wide-scale change in the lives of adults with developmental disability. Broad social policies and professional reimbursement mechanisms exert too strong an influence. To achieve real lasting gains for adults with developmental disabilities will require occupational therapists and other advocates to become more knowledgeable about a range of policies and funding issues and how to be effective advocates for social and health policy changes.

References


