



Temple University  
**Collaborative**

On Community Inclusion of Individuals with Psychiatric Disabilities

# The Past and Future Career Patterns of People with Serious Mental Illness

**Richard C. Baron, MA**



**The Past and Future Career Patterns  
Of People with Serious Mental Illness:**

**A Qualitative Inquiry**

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## I. INTRODUCTION

*Bernice Scarborough is a 61-year-old Black woman from Chicago, currently living alone in a house originally owned by her late mother. After finishing high school, Bernice began working for her mother selling hair care products door-to-door, something she has done on and off for the past 40 years. She also worked as a punch press operator for one summer, but then had a job operating a folding machine for four years, until the company went out of business. At that point Bernice was drinking a good deal, which led to a stay in a psychiatric hospital for nearly three years. After discharge she quickly picked up a job as a dishwasher, which she left after two years for a job as a blower for a fur coat manufacturer, where she was laid off after six months. A five-year job working on pin ball machines ended when the company went out of business, which then led to more drinking and a second hospitalization. At discharge, Bernice went on SSA, but after a few years she was referred to a psychosocial rehabilitation program, which helped her to find a full-time factory job at the National Shaving Company, where she worked two years until Social Security 'caught up with her' and threatened to remove her from their rolls. She worked part-time for several more years at NSC, but now works part-time at a day care center for preschoolers. At this point Bernice is thinking about retirement, ". . . but to tell the truth, I'd rather be working than not working."*

*Myria Manfred is a fifty-year-old White woman from the midwest with a Bachelor's degree from the University of Minnesota, where she pursued her interests in music. Following graduation, Myria taught for one year in a 'travelling arts program' for high school students in South Dakota, but left after one year to travel with a boyfriend who had other plans. A year or so later she returned to graduate school, and while there worked as an assistant in the Philosophy Department. At this point Myria was having fairly severe emotional problems, so she dropped out of school, and left her job: she was feeling disconnected from people, hearing voices, and struggling with drugs. Myria did very little for a number of years, seeing a psychiatrist, travelling, and living with her parents. In 1984 she began receiving SSA support, and for another decade nothing much changed. "It just didn't seem like anybody was saying to me that I had to go to work, and for some reason I wasn't bothering to find a job myself either." After a series of short term hospitalizations Myria began working with a psychosocial rehabilitation program, which assigned her to a number of part-time community jobs. Myria usually left those jobs after three months because of the menial nature of the work and the dishearteningly low pay. More recently, she has begun working part-time for a mental health consumer self-help program, but intends to return to school one day and resume her career in music education.*

### **The Focus of the Study**

This study of the past career patterns and future career prospects of persons with serious mental illness provides a longitudinal portrait of the ways in which those who are often characterized as having an unsuccessful work history and only modest vocational prospects in the years ahead relate to the world of competitive employment. Its emphasis is on discerning long term patterns: where have these folks been and where are they going? Oddly enough, neither our mental health nor our vocational rehabilitation systems have complete answers to these questions. On the one

hand, mental health intake forms rarely capture much of a new client's work history beyond his or her current work status and the last job or two. On the other hand, vocational rehabilitation providers haven't tended to look very far ahead, focusing on placement and stabilization on the job and assuming that the future will take care of itself. As a result, this study suggests, we may have some inaccurate and potentially damaging notions about both the past careers and the future prospects of people with serious mental illness.

Two sub-themes have emerged in the process of doing this study First, the study also examines the degree to which mental illness has played a role in shaping past work histories and whether interviewees anticipate mental illness intruding into their careers in the future. Second, however, the study explores the degree to which the past and future careers of persons with mental illness differ from their coworkers without disabilities, particularly those in the entry-level and unskilled job categories where so many people with serious mental illness are working.

The study addresses a number of other issues of course: Are people motivated to work or not? What kind of training and rehabilitation programming did people receive? Were their on-the-job experiences terrible or wonderful, or just okay? Why did people leave their jobs? And what impact does the financial and medical support of the Social Security Administration have on work patterns? The answers to each of these questions provided by Bernice Scarborough were quite different from the answers provided by Myria Manfred: I would not have guessed that Bernice had worked so hard for so long, and I can't imagine what Myria did with her time all those years without a job. Understanding the similarities and differences in their relationship to the world of work is at the core of this exploration.

## **Background to the Study**

Riding the train from Philadelphia to New York City one January morning to give a talk at a conference about employment for persons with serious mental illness, I spent most of my time staring out the window. This was a midweek 7:05 am train, and it was crowded with people on their way into 'The City' for the day: from the conversations around me I learned I was with stockbrokers and manufacturing supervisors and teachers going to their regular jobs, but also architects lugging their drawings to a presentation later in the morning, buyers for a clothing chain checking out new fashions, and potential workers going in for interviews. As I peered out the window, I was aware of the traffic build-up at every intersection we passed: it was still before eight in the morning, but the daily rush-hour crush was already at full tilt, and while it was heavy enough in the small towns and commuter suburbs we passed, the closer we got to New York the more phenomenal was the volume of movement of people toward their jobs.

The press of people in New York itself was, of course, still more remarkable. Penn Station was a sea of workers on their way to their daily assignments. Changing subway trains on my way to my conference, I discovered such a mass of people changing from the E train to the Number 6 train that it took ten minutes to get from the train door to the stairs leading off the platform. My mild claustrophobia about this situation was alleviated by the sounds of a dreadlocked young man at the other end of the platform playing a steel drum, banging out, incongruously enough, the theme of *Bonanza* in a calypso rhythm: he was already at work, while the rest of us were still

on our way. This is the way it is for most of us, almost every day of our adult lives: we get up early, we get out of the house on time, we make our way – across town, over the highway, or through the suburbs – to our jobs.

Even those who don't rush off to the job – homemakers, consultants, telecommuters, etc. – tend to be busily engaged in one form of work or another throughout the day. Homemakers, however, have entered the job market in increasing numbers over the last generation, often soon after their children start school, and the still-small but growing number of consultants operating their own businesses or telecommuters who work out of the house often complain that they are busier than ever. Ours is a culture, for good or ill, that emphasizes productive employment, and does so with such pervasiveness that many people define themselves, at least in part, in terms of their jobs.

Except, of course, for those few who do not have jobs, and – in particular – except for the vast majority of persons with serious mental illness, who are not working. With work so central to the lives of almost everyone else, what is the meaning of unemployment and underemployment in the lives of those who suffer from a significant psychiatric disability? If our careers – from our twenties to our sixties – occupy an enormous amount of our time and energy, what is it like for persons who work much less over that same adult life span? Despite its frustrations and anxieties, work still provides most with a level of both intrinsic and extrinsic rewards that people find hard to replace once they have retired: what then are the circumstances and satisfactions of working-age people who have a more tangential relationship to the nation's labor market?

This study sought some greater understanding of these questions by attempting to look in two directions – backward and forward – at the same time. In looking backward, the study explored the long-term career patterns of people with serious mental illness in order to develop a more complete portrait of their past involvement in the world of work. In looking forward, the study sought to shift the programmatic preoccupation with 'placement rates' to the longer-term perspective of 'career development:' new entrants to the nation's mental health systems, typically arriving in their late teens or early twenties, may have stretching before them another thirty, forty or fifty years before retirement is a reasonable alternative, yet we have given little attention to what their careers are going to be like.

Indeed, it is often noted that for people with serious mental illness 'vocational careers' have been replaced with 'mental patient careers,' but it doesn't take much sensitivity to recognize that this cannot be a satisfactory substitute career for most people, given the centrality of work in our culture. For most of us, work is a major source of income, ego strength, and activity, and we would be lost without it. Nearly two millennia ago Galen noted, in 172 AD, that "employment is nature's best physician and is essential to human happiness" (in Strauss, 1968, p. 663), and Freud famously argued that much of our life is devoted to seeking satisfaction in love and work (Freud, 1953). Surely such observations must apply as well to those with serious psychiatric disabilities. Marrone and Golowka (1999) have recently argued, persuasively and passionately, that work is critical for persons with serious mental illness by noting its economic, mental health, citizenship, and status benefits. In addition to such esoteric arguments, they note as well that work is also "a way to help people develop possibilities for intimacies, love, and sex" as well as "a better start on the rest of the 'American Dream' than unemployment and poverty."

Yet, most persons with serious mental illness in the public sector are currently unemployed. Repeated studies over a twenty-five year period show both a staggering rate of unemployment (in the 80% – 90% range) and little change in the rate of unemployment over all those years (Anthony, 1978, NIDRR, 1992). It has been argued (Baron, 1999) that a “culture of unemployment” exists within the community of serious mental illness that is quite pervasive.

*Looking Back.* In looking back, the reasons for such a marked level of unemployment vary, but four broad clusters of reasons are generally cited: the impact of symptoms, the inattention of systems, the lure of subsistence level financial support, and the routine discrimination of employers and co-workers.

First, the symptoms of mental illness do indeed make it difficult for people to work: paralyzing depression, abusive voices, visual hallucinations, paranoia, and overwhelming anxiety can all readily be understood as significant barriers to vocational performance. Although there is a steady advance in the development of new psychopharmacologies that alleviate many symptoms, a ‘cure’ continues to elude us, and many people face daunting challenges to their ability to concentrate and contribute in the workplace. This study sought to learn more about the impact of the symptoms of serious mental illness on past work experiences.

Second, however, the dramatically high rates of unemployment that still plague the field may also be caused by the way in which many human service professionals have consistently discouraged employment in the past. Within the mental health field, clinicians, counselors and case managers have tended either to delay discussions of employment until substantial progress has been made in alleviating or overcoming the illness itself or to actively discourage employment as a threat to symptom stability. In addition, personnel in the state vocational rehabilitation systems have often discouraged both rehabilitation and work for those clients with the most severe mental illness, believing that any significant symptoms make it unlikely that the individual seeking services will benefit substantially from rehabilitation programming. In such an environment, people with mental illness begin to doubt their own capacity for work. This study sought to learn more about whether or not interviewees still found that mental health and vocational rehabilitation systems discouraged employment.

Third, there continues to be great concern about the degree to which people with serious mental illness rely on the subsistence level of financial and medical support that comes with eligibility for the Social Security Administration’s SSI and SSDI program. While the ‘work incentives’ written into the SSA Act in the 1980s did make it possible for people to work to some degree without losing their eligibility, the regulations surrounding these work incentives were often impenetrable and few people have taken advantage of the opportunities provided. The impact of the recently enacted work incentives, which go much farther than ever before in protecting the income and medical benefits of SSI recipients and SSDI beneficiaries who work, is still unknown. This study, however, sought more information about the impact of subsistence-level support on past careers.

Fourth, there remains a strong conviction that an additional problem has been the prejudice of employers and co-workers to the presence of people with serious mental illness in the workplace, focusing on the reluctance of employers to hire and the tendency of coworkers to harass.

Although the Americans with Disabilities Act was designed to help solve such problems, there remain many subtle ways for employers and coworkers to keep people with serious mental illness from entering or succeeding on the job. This study sought more information about the impact of such prejudices on career patterns.

*Looking Forward.* Even in those programs where work has become an important goal to which both clinical and vocational personnel devote themselves, the focus is often, as noted above, on ‘placement,’ a short-term goal with little long-term vision. Part of this preoccupation with placement rates reflects the way in which programs are funded and evaluated by federal and state grants: a chronically short-term demand for ‘results’ that can be cited in the next budget request leave rehabilitation staff with little time to consider the longer-term ‘career’ possibilities for those they serve.

Part of the problem, as well, is rooted in the history of career counseling as a field, in which the assumptions of career stability that may have once been quite accurate no longer adequately explain how careers develop. The traditional model is one in which personal characteristics in combination with the demands of the labor market move young adults, after a relatively brief period of experimentation, into a chosen field of work that leads to a lifetime career. Much of the research into career development has concerned itself in the past with understanding how those personal characteristics or labor market exigencies steer people into their lifetime careers (Syzmanski and Hershenson, 1998), and career counseling has sought to clarify that process for people. But the labor market has changed dramatically in the last generation, with both job mobility and career foci changing far more rapidly than in the past: not only do most people hold far more jobs over their lifetime than was true a generation or two ago, they also are likely to move from one career to another as their needs, or the needs of the marketplace, alter over time.

Contemporary realities have begun to reshape academic and programmatic approaches, and there is today a far more complex sense of the dynamics of both mental illness and the labor market. On the one hand, the mental health community increasingly recognizes the way in which individuals with serious mental illness change over the years, with pharmacologic treatment, rehabilitation programming, and the passage of time all tending both to alleviate symptoms and to allow for the development of effective coping skills. The disabled individual who is seeking help in finding a job today may be ready to move to a new and more demanding job within a year or two, making ‘placement’ only a short-term approach to a long-term career. On the other hand, the national economy’s volatility only heightens job mobility: long-established businesses disappear and wholly new industries take shape, making old skills obsolescent and demanding worker flexibility in meeting new responsibilities.

This study, then, sought to learn more about the *vision* that people with serious mental illness had about their own vocational futures. It has become essential for the mental health and vocational rehabilitation fields to consider the long-term careers of people with serious psychiatric disabilities much more intensively, to develop a vision of the *distant* employment possibilities that transcend this placement, or the next. This study was designed to help develop that vision of the long-term career possibilities of people with serious mental illness.

## Current Information

In looking forward, of course, it is always useful to take stock of what we already know. In this sense, there is both good news and bad news: on the positive side, we know that people with serious mental illness *should, would, and could* work, but on the negative side we are also acutely aware of the substantial barriers to employment and the difficulty even the best rehabilitation programs have had in helping people to succeed in the competitive labor market.

On the positive side, then, there are grounds for considerable hope. Many authors have commented on the growing evidence that people with serious mental illness *should* work. Marrone (1999) points out that “no hard data exist showing that helping people move into employment (even nagging them into it) is bad,” while there is sufficient data that work is valuable in strengthening positive self-concepts, improving self-mastery, increasing life satisfaction, and relieving symptoms (Harding, et.al, 1987, Van Dongen, 1996, Blankertz, 1997, Rutman, 1992), in addition to the income and lifestyle advances that may result. The benefits of employment, and the disadvantages of unemployment, are of course not limited to people with serious mental illness. For the general population, it has been shown that prolonged unemployment leads to diminished perceptions of self-worth (Cohn, 1978) and higher rates of suicide, mental illness and substance abuse (Mallinckrodt and Fretz, 1988), as well as a drop in expectations and motivation to seek work (Feather and Davenport, 1981). It should not be surprising that these problems are similar, or perhaps intensified, for people already suffering from mental illness.

That people with serious mental illness *would* work, if the opportunities and supports they need were available, is a finding repeated in most surveys of consumers of mental illness (Rogers, et.al., 1992), in which work endures as a primary marker of one’s relative health and normality.

But even if people should and would work, *could* they? Hospital-based programs, sheltered workshops, and a wide range of community agencies with in-house work crews have demonstrated little success in moving people out of these segregated vocational programs and into competitive employment. However, the last thirty years have witnessed the emergence of a number of more effective rehabilitation program models for people with mental illness. Such programs have different names and particularities but very common principles.

The major models being used around the country today include: *Transitional Employment* (TE), which typically ‘acquires’ jobs from employers and then makes them available on a half-time, six-month basis to clients of psychosocial rehabilitation programs; *Supported Employment* (SE), which seeks long-term placements, but provides both intensive on-the-job support initially and as-needed backup to client and employer over the long-term; *Individual Placement and Support* (IPS) programs, which utilize both TE and SE approaches, but also emphasize the importance of ensuring a strong clinical/vocational linkage over time; *Mentoring Programs*, which place people with academic or experiential qualifications into white collar positions with the help of on-site co-workers who agree to mentor them; *Programs for Assertive Community Treatment* (PACT), which utilize similar approaches within the context of group case management designed to ensure cross-systems cooperation; and *Consumer-Operated Programs*, which also tend to work

along the same lines, but with a much stronger peer-support and peer-counseling programmatic emphasis.

The common principles that make these programs so effective are relatively straightforward: a) rapid placement into a job in the mainstream workforce is preferable to extended training and endless preparation within a non-integrated workshop setting; b) extensive support – for the client, for co-workers, and for the employer – should be available initially, upon the client’s request, to assist with stabilization on the job; and c) long-term support is critical, both to help clients hold onto jobs in difficult times and to help clients move on to new jobs whenever it is appropriate. Utilizing such common principles has enabled the best of these programs to make substantial progress, placing an average of 50% of those they serve into competitive employment (Bond, 1997, Cook, 1995).

On the negative side, however, there is as yet little evidence that these programs have succeeded much beyond increasing initial placement rates. While improved placement rates into competitive employment are hearty accomplishments on their own, they do not tell us very much about the underlying interests to which this study is addressed: what are the long-term career prospects of people with mental illness? While it is true that research funding has not encouraged the type of long-term follow-up studies that would answer such a question, what we do know is not very encouraging.

We know, for instance, that even these successful programs report that the wages their graduates earn are low (Botterbusch, 1999; Barry, 1999; Fabian, 1999; and Bond, 1996), low enough, in fact, that very few successful graduates have become ineligible for the support of the Social Security Administration. We know that the jobs that agencies assist clients to obtain, through either direct placement or through counseling individuals who find their own jobs, are often entry-level, low-wage, part-time, and poor-benefit positions (Bond, 1996, Gerver, 1998), which of course accounts for the consumers’ continuing level of economic dependence on Social Security. We know as well that job tenure is not extensive, with people rarely holding on to the job they obtained through the agency long enough for it to constitute a ‘career.’ What then, one might ask, are the likely long-term career prospects – the working pattern over the next 30 or 40 years – for the individual just now entering the mental health system? We don’t yet know. To help answer these questions, this study turned to people with mental illness themselves, with a series of questions about their past working careers and their future ambitions.

### **The Perspective of the Researcher**

While the qualitative research initiative reported on here seeks to present the views of a wide range of consumers on their past and future careers, it certainly reflects the researcher’s world view as well. I pursued the research with an eye toward two types of outcomes: first, what could consumers of mental health services tell us about the way in which mental health and rehabilitation *policy* could better support the employment aspirations of people with serious mental illness; and, second, what could the same group tell us about the essential aspects of the *counseling* relationship between individual rehabilitation workers and those they serve.

*Policy issues* were initially uppermost in my mind as I framed the research agenda. First, I had spent twenty-five years involved in research, training, public education and policy analysis at Matrix Research Institute (MRI), a private nonprofit information development and dissemination agency in Philadelphia, with an increasing focus over the past decade on employment issues for persons with psychiatric disabilities. Much of our work at MRI had concerned itself – from both a research and a training perspective – with the mental health and vocational rehabilitation policies that local, state, and federal governmental agencies framed to support the employment aspirations of those with disabilities. I had as well worked for many years with the International Association of Psychosocial Rehabilitation Services (IAPSRs), whose member agencies had long promoted employment for people with mental illness and whose agencies collectively provided many of the vocational rehabilitation services available across the country. IAPSRs has been active in helping to frame federal policy, in assessing the effectiveness of varying employment programming models, and in shaping employer attitudes toward people with serious mental illness.

Thus, from a professional perspective, I came to the project strongly supportive of the view that most people with a serious mental illness could be working if public policy provided real opportunities and assistance. At the same time, I came to the project with a strongly held set of beliefs about the ways in which public policy continues to either overlook or only mildly ameliorate the problems of poor people in general, a concern raised by a wide range of current economic analyses about the widening gap in the country between the economically advantaged and the economically disadvantaged. I was, therefore, interested in public policies that not only helped people to work but also gave them access, through work, to the economic prosperity that seems so abundantly available to the rest of the country today.

*Counseling issues* emerged as an area of focus as the study got underway. Without much clinical training or experience, I tended to view the important issues from a rehabilitation perspective: How well did clients function in their past jobs? What kind of rehabilitation services had been productive for them in the past, or would serve them well in the future? What aspirations did they have for their careers in the years ahead? And so I found myself, in interview after interview, wondering how I would respond as a counselor – as a job coach or as a case manager or as a clinician – to the history and hopes of the clients with whom I talked.

Part of what motivates any individual to seek and to sustain employment is a *vision* of the future for themselves, of what work will provide for them and of where work will take them over time. Because, it has been noted many times, one of the most distressing aspects of working with people who have suffered through serious mental illness is their lack of hope for a viable future, it is one of the fundamental aspects of the counselor's role to help generate an alternative vision. I had heard from hundreds of persons with mental illness over the years, in training programs and conference settings, how often and how clearly they remembered the first time someone – a psychiatrist or a social worker or a family member – had explained to them that they were seriously mentally ill and that this meant they “would never work.” At the same time, however, there were growing trends – in the recovery movement, in the emphasis on self-sufficiency embodied in the nation's welfare reform legislation, and in the expectations born of the changes in the Social Security Act's work incentives – that people were increasingly challenged to

provide entirely for themselves. How do counselors best respond to these opposing forces when face-to-face with the client?

Answers to these concerns were not available from existing research. Although there is a growing body of literature on employment for persons with serious mental illness, it focuses almost exclusively upon assessments of the effectiveness of the wide variety of vocational rehabilitation program models. While important, such information provides little information on the past careers of the clients they serve or the distant careers people can expect. To provide some light on those issues, I turned to the client.

## II. METHODOLOGY

*Leo Bruckner is a 21-year-old White man who appears to be a bundle of energy in a sleepy rural town ninety minutes south of Chicago. His first job “would be when I was ten years old and ran away from home to join the carnival: the owner had to send me back home after two months when he saw my picture on a milk carton, but I worked with the same carnival every summer after that for ten years.” Throughout his adolescence Leo was in and out of foster homes because of a difficult relationship with his mother. In his senior year in high school he had been placed in a training program installing insulation in the same company where his mother worked, but “I screwed up so bad they were going to fire me and my mother unless I got out of there.” He made his way a year ago to a psychosocial program, where he works five days a week as an expediter in the assembly workshop, but the program has been encouraging him to enter a welder training program he’s not all that interested in. His short-term plan is to drive a truck, which he has done in the past despite the fact that he doesn’t have the necessary license, or to own and operate another carnival. In any case, he plans on working because “. . . I really don’t want to be dependent on SSA.”*

*JG is a 50-year-old African American man working in the same workshop where Leo is the expediter. Asked about his past career, JG says, “there really isn’t much to tell: after I graduated from college, I worked for two years at an art gallery selling prints, and then for the next 25 years – from 1969 to 1993 – I was a partner in a real estate property management firm in South Chicago.” When the real estate market changed there, JG’s business collapsed, and he spent the next two years living on savings and having increasing emotional difficulties, which led to his seeing a psychiatrist. It was his psychiatrist who suggested that JG could “get away from the stresses of his life” by applying for eligibility to Social Security, moving into a group home in a rural community, and working in the local psychosocial rehabilitation program’s assembly workshop. Although the program has encouraged JG to seek other jobs, he is stymied, he says, by either a lack of transportation, the fear that earning a substantial income will force him out of his group home, or problems with his back. He expects to remain in the workshop for another ten years or so, noting that “. . . I’m not very strongly motivated about work.”*

### **A Qualitative Research Initiative**

The study reported on here attempts to capture the experiences of 38 very different people as they each struggled to balance their mental illness with their work aspirations. In framing a research effort that provided a portrait of past work experiences and future work hopes, it was increasingly clear that a quantitative initiative might not suffice: it seems inadequate to report on the average experiences of people as different as Leo and JG. Although they see each other every day, they are separated by 30 years of life experience, race, education, energy levels and – perhaps most importantly – dreams. A qualitative research initiative seemed far more likely to be able to capture both their differences and their similarities – and those of the 36 other people whose stories are the basis of this report – than a purely quantitative effort.

Although the economic and time restraints implicit in the one-year Switzer Fellowship grant from the National Institute on Disability and Rehabilitation Research that provided support for this effort also suggested a qualitative approach, it is increasingly clear to researchers in both the mental health and vocational rehabilitation fields that some of the most interesting research questions are the most complex: even the most rigorous of quantitative analyses often suggests multiple factors that account for various career patterns. Qualitative research seemed a better way to enhance our understanding about the complexity of these human experiences in the workforce.

## **The Methodological Approach**

This report is based on extensive interviews with 38 people with serious mental illness and an intensive analysis of the transcripts of those interviews, followed by a review of preliminary findings with both human service professionals and other consumers of mental health services. In particular:

- . A number of psychosocial rehabilitation agencies throughout the Eastern and Mid-Western sections of the country were contacted and asked to recommend clients who would be interested in participating in the interviews. Each agency was sent a one-page written summary of the research objectives to share with potential interviewees, and after agency counselors had identified a number of people who were interested in both the research topic and the \$25 fee offered, appointments were scheduled at mutually convenient times. Recruitment of participants also included contact with consumer-operated programs (where the same procedures were followed), and a presentation to a local (Philadelphia) Depressive and Manic-Depressive self-help meeting, where two additional interviewees were identified for later interviews. No one who volunteered to be interviewed through this process was eliminated from the study.

- . Interviews were scheduled in New York (NY), Albany (NY), Chicago (IL), St. Anne (IL), St. Louis (MO), Minneapolis (MN), Washington (DC), Bethesda (MD), Philadelphia (PA) and two suburban Philadelphia sites, in Lansdowne and Plymouth Meeting, so that urban, suburban, and rural settings were each represented. The cooperating psychosocial rehabilitation agencies were both small programs serving a geographically compact area and large agencies serving, in several sites, major metropolitan communities. Although I had long-standing relationships with many of the agency personnel who agreed to cooperate with the study, in general I minimized my contacts and conversations with them on site, focusing my time and energies on the interviews.

- . In most of the settings I met interviewees at their psychosocial rehabilitation program, although in half-a-dozen cases I met with people in restaurants or homes. I typically spent about 15 minutes at the beginning of the meeting introducing myself and explaining the survey's focus, purposes, funding, and procedures to each interviewee, basically reviewing the information they had already received in the course of the staff's initial contact. In every case the interview was conducted in a private room with neither other clients nor staff present.

. Each person was asked at that point to sign an ‘informed consent’ form, which reiterated the major points of the previous discussion. However, as part of the consent form process, I also asked each interviewee whether or not I had permission to tape record the session, which served as the basis for the transcripts and subsequent analyses. Each interviewee was also asked to indicate on the consent form whether or not I had permission to use his or her real name in any subsequent reports or articles based on these interviews, and most people (30 of 38) readily agreed to have their names included: for the 8 others who decided they would rather remain anonymous in case families were embarrassed or employers were made wary, I have used initials in this report.

. The interviews lasted from 90 to 120 minutes: although I explained to each interviewee that if they found any particular question or general line of discussion upsetting, they could either take a break or cancel the rest of the interview (without forfeiting their fee), this never happened. In general, interviewees seemed quite pleased to contribute to the research initiative, and the interviews generally proceeded for as long as the interviewee felt he or she had something to say.

. The interviews roughly followed the same format: each interview began with some very basic demographic questions (age, residential circumstances, family relationships, ethnicity, etc.) about the interviewee; interviewees were then asked to talk about their general attitudes toward work and its meaning for them; the bulk of the interview time was spent asking interviewees to talk about their first work experience and each subsequent job they had held, with questions about each job title, hours, duration, performance, and reasons for leaving; with a final set of questions focused on the interviewees’ plans and hopes for the future. This general format was frequently modified to give the interviewees time to expand on the way in which their psychiatric disability did (or did not) impact on their work performance, their assessment of their co-workers, and their involvement with a psychosocial rehabilitation agency’s vocational programming. The interviews, with only a semi-structured format, resembled a conversation more than a formal interview, and succeeded very often in putting interviewees at ease.

. I took extensive notes in each session, as a backup to the transcription process and as a way to identify particularly interesting points in the interview. Following each interview, however, I generally took a few moments to note any particularly striking items in the interview itself, any suggestions for further pattern analysis, and any thoughts on alternative or new questions to be asked of other interviewees that occurred to me. Each taped interview was later transcribed in full.

. The transcriptions were transferred to The Ethnographer program, a well-tested format for qualitative analysis, and working with the transcriptions I noted major and minor themes, repeated patterns, and significant differences. As the major themes of the analysis emerged for the group of interviewees as a whole, I used The Ethnographer program to explore further themes that would distinguish between men and women, among interviewees from different socio-economic or educational backgrounds, or among those from different ethnic groups. Although a few such differences did emerge and are noted in this report, these were relatively rare.

. A 'Preliminary Report' was developed soon after the final interview, and this was shared with a number of individual mental health or vocational rehabilitation professionals and consumers for their responses. The Preliminary Report, developed prior to the detailed qualitative analysis described above, highlighted a number of quantitative findings: the number of jobs held; the average job tenure; the most frequent reasons for 'job leavings,' etc., and these too are a part of this report. A focus group of consumers from the Philadelphia area also reviewed the 'Preliminary Report' and made major contributions to the interpretation of the data. The 'Preliminary Report' was also mailed to each of the interviewees for their comments.

## **Notes on the Methodology**

While the overall methodology of the study proceeded much as planned, there were several significant shifts in the research process and perspective as the project went forward, as is both likely in and important to qualitative research initiatives.

First, before undertaking the formal interviews, I asked a close friend of mine who had struggled with mental illness for his entire adult life to allow me to 'pilot test' the process and the questions in a trial interview with him. One of the most important findings from the pilot test was the degree to which I became aware that discussions of the past careers of people with mental illness will inevitably surface raw and uncomfortable feelings, particularly with regard to the degree to which individuals may feel that they have failed to meet their work potential. I re-examined the assumptions underlying my questions, and revised both the questions and probes in a way that sought to obtain the same information but within a less judgmental framework, so that interviews with those who were disappointed in their careers would be less likely to dwell on or conclude on their failures.

Second, after the first half-dozen interviews I became concerned that the cooperating psychosocial agencies may well have been referring to me those clients who they thought I would find most interesting: those with substantial past careers and exciting vocational plans, those who were most articulate or analytic; those with more than enough personality to sustain the 90 minute interview. In my future requests to the agencies, I specifically requested a broader variety of people – working and not working, motivated or not motivated, articulate or reticent – to help insure that I was getting a more complete view of the world from a wider variety of clients. Agencies responded to this request quite readily.

Third, unlike many qualitative interview surveys in the literature, many of those who participated in these interviews were unwilling to speculate on the broader social issues that affected them or to provide an in-depth analysis of their experiences. Although in the earliest interviews I had been asking such questions as 'what do you feel was most helpful to you in seeking work' or 'what are the major barriers to your finding suitable employment in the future,' I found I had better success asking clients simply to tell me the story of their past careers in a relatively linear fashion, to talk about how they felt their mental illness had impacted on their work performance at each job, and to imagine their immediate and distant work futures. There was little in their discussion of an analysis of the systems that served them, the effectiveness of the programs they

were in, or the broad social forces arrayed against them: there was, however, incredible richness and poignancy in their individual stories.

Fourth, about midway through the interview process I began to recognize a recurring theme: many interviewees felt not only that they had often performed quite well in this or that job, but also that they had performed as well as, or better than, their non-disabled coworkers. Although I had not initially thought to ask them this kind of comparative question, I did begin to ask interviewees I talked to later in the process about their coworkers, and I began to read much more extensively in the literature on ‘normative work experiences’ about how people without significant disabilities fared in the same types of jobs held by the interviewees. This comparative analysis has become a major theme of the study.

Fifth, I was deeply surprised and disappointed by my own prejudices. I generally met the interviewee at a psychosocial rehabilitation agency’s lounge, and found myself quickly assessing the client on the basis of his or her clothing, his or her graciousness and articulateness in greeting me, or his or her overall ‘presentation.’ My heart frequently sank upon saying hello to a disheveled young man, or a woman whose manic gestures and frantic speech were barely under control, or the slow talking and glazed-eyed older fellow who could hardly seem to acknowledge my presence, or the fast-talking con artist. How, I wondered, was I going to get through the interview without becoming bored or frustrated? I would then spend the next 90 minutes relearning how easy it is to be misled by appearances: almost invariably, I would find myself charmed or fascinated or deeply sympathetic as the interviewee willingly and frankly talked intelligently and passionately about work. I did get bored twice, but then I was infatuated much more often: like so many others, I had let surface features cloud my view of the vital person behind the mask of mental illness.

Sixth, then, I concluded the interview process with a deep sense of debt and gratitude to those who were willing to share their stories with me. People were patient while I fumbled with my notes or the tape recorder, gracious as they went over, again, the sequence of jobs because I had misunderstood something five minutes earlier, and startlingly frank about both their successes and their shortcomings at work. In part, this was the nature of the interview process, in which people happily responded to the request to tell a part of their life story to an interviewer who seemed really quite interested. In part, this was the natural generosity of people who know what it is like to need help now and then. I had a wonderful time, and my thanks to the interviewees are heartfelt.

### **Challenges to the Integrity of the Data**

Challenges to the integrity of the data reported on here are important to acknowledge, for there are inevitable questions about the degree to which interviewees accurately reported their past careers and honestly talked about their future ambitions. I believe they were essentially both accurate and honest, for a wide range of reasons.

On the one hand, I was impressed with the clarity with which people remembered jobs – some of which they had held over 30 years ago – and the circumstances that led to their leaving those

jobs. While people readily acknowledged that they may not have been able to account for every single job and weren't exactly sure of the month they started this position and left that post, they were able to talk about the types of jobs they had held in some detail, to remember their supervisors and coworkers, and to talk about what they liked or didn't like about particular jobs.

On the other hand, they were able to talk without embarrassment or defensiveness about the problems they had had on some jobs – about problems with concentration or consistency, about coming in late or missing days because of depression or drinking, about their attitude problems or the paranoia that quickly led to hospitalization – and did so in a way that lent credence to their more positive estimations of their performance at other times in other jobs. Further, the interviewees were, for the most part, disinclined to view 'job endings' – whether they quit or were fired – as someone else's fault: while there were the usual stories about unpleasant bosses or nasty co-workers (that is, the sorts of stories one hears about any workplace), these were only infrequently referred to as the reason someone was fired or decided to quit.

Indeed, there is some confirmation in the literature (Cook, 1992) that the self reports of clients with psychiatric disabilities about their employment experiences are relatively reliable: in one study, Cook and colleagues compared self reports with independently gathered information from employers and counselors and found no significant discrepancies. It is interesting to note, as well, that when reviewing the data in the 'Preliminary Findings' paper with a focus group of mental health consumers, the participants in the focus group were mildly annoyed by my asking whether they thought I could trust self reports, asserting that people with serious mental illness were no more likely to purposely misrepresent or defensively misinterpret their work experiences than the non-disabled worker.

At the same time, a number of other questions about the validity of these responses might be asked. Were the people who participated in the interviews reasonably representative of the widest range of experiences? Thirty-eight people is not a large number, by either quantitative or qualitative standards, but there were so many common themes and consistent perspectives that emerged from these thirty-eight interviews that it is hard to discount the unanimity of opinion in several key areas. Although the characteristics of the interviewees are discussed in the following chapter, it can be noted here both that the process sought out people from reasonably diverse geographic and demographic backgrounds, and that each time there seemed to be a preponderance of interviewees with similar characteristics, efforts were made to seek out people with quite different characteristics: e.g., when most people in the initial interviews turned out to be currently employed, new interviews were scheduled with those who were not working, and when most people seemed to have a strong middle-class family background, interviews were scheduled with those from more economically constrained or dysfunctional family settings.

How broadly do these interviews represent the past careers and future prospects of people with serious mental illness? To be scrupulous, the applicability of the findings is somewhat limited by the process, described above, for selecting interviewees: they were almost exclusively being served by public mental health systems, had all been involved with local psychosocial rehabilitation agencies, community mental health centers, or consumer self-help groups, and had all been involved, with varying degrees of success, in some type of work-oriented rehabilitation program.

This suggests, at the very least, that the findings may not apply to people whose economic advantages or symptomatic problems have allowed them to avoid the public mental health system. It is also true that the findings may have little relevance to the most seriously disabled clients, those who remain actively psychotic, institutionalized, or unwilling to participate in a community-based psychosocial program. At best, the findings may be understood to represent the experiences and hopes of a broad range of persons with serious mental illness in public mental health systems who have also received services from psychosocial rehabilitation agencies, without shedding much light on the experiences of either the least or most disabled of clients. It is this broad middle range of clients, however, to whom public mental health policy and current rehabilitation practice must address itself.

If the data do accurately reflect the experiences of this middle range of clients in public mental health systems, the interviews raise some profound questions about our preconceptions about both the past careers of people with serious mental illness and the future prospects for them in the competitive labor market. The data provide considerable insight about the way in which mental illness does or does not impact on job performance, and the way in which the nature of the labor market plays as important a role in their career as their illness. That insight can be critical in re-examining both the public policies and professional practices that need to change if we are to meet their needs for a long-term engagement in the labor market. At the very least, the data suggest that the field needs to re-examine a number of its assumptions about the answer to the question – “where have these folks been and where are they going” – that is at the core of this qualitative inquiry.

### III. THE INTERVIEWEES

*Norma Maxwell is a cheerful 31-year-old African American woman living in New York City. Although she currently works as an administrative assistant for a mental health housing program, where she also resides, her ambitions are to make a living as an artist, with either her drawing or her singing. Born in upstate New York, Norma was raised in a family that emphasized education, employment and independence, and she feels that her problems have set her apart from her more successful siblings. After one year at Howard University, where she had worked part-time as both a waitress and in telephone sales, Norma dropped out because of poor grades, some financial problems, and emotional difficulties. Returning home, she worked at a number of different jobs – hotel clerk, nurse’s aide, library staff, housekeeping – that were mostly seasonal in nature or foreshortened by one of twelve different hospitalizations. Some years ago she moved to New York City to pursue the life of an artist, but shortly found herself homeless and then hospitalized, eventually making her way toward a major mental health housing provider, who provided a home and then a part-time and now full-time job as an administrative assistant. Norma dreams of making it as an artist, but keeps working as an administrative assistant for the sake of the stability it provides.*

*Chris Macaluso is an Italian-American from South Philadelphia. He is 26, lives at home, and works 32 hours a week as an usher in a local movie house, a job he enjoys, he says frankly, because “. . . I like the girls.” He had worked in local grocery stores most summers throughout his adolescence, but after high school he ran away from home. He was picked up by the police – who found him confused and convinced that he was actually Michael Jackson – and returned home. After a year or two of idleness, eligibility for SSA, and repeated hospitalizations, Chris was referred to a local psychosocial rehabilitation program, where he spent four years in various day activities until they helped him to land the movie usher’s job. On the one hand, Chris is intent on living the ‘American Dream’ and looks forward to marrying, owning a car, and raising a family in a home in the suburbs. On the other hand, Chris is not sure about what job to move to next: “To tell you the truth, I do want a better job – with better pay and better benefits – but I’m not sure that I want to move from the job and benefits I have now, but I do want a better job eventually.”*

#### **The Demographic Characteristics of the Interviewees**

In many ways the interviewees resembled those served by the public mental health system in community settings. Of the 38 persons interviewed:

##### *Setting*

- . 71% were from urban settings (n=27);
- . 16% were from suburban settings (n=6); and
- . 13% were from rural settings (n=5).

### *Ethnicity*

- . 66% were White (n=25);
- . 26% were African-American (n=10);
- . 5% were Latino (n=2); and
- . 3% were Asian-American (n=1).

### *Gender*

- . 66% were men (n=25); and
- . 34% were women (n=13).

### *Education*

- . 8% had not finished high school (n=3);
- . 45% had graduated from high school (n=17);
- . 21% had some college (n=8);
- . 21% had completed a four year college education (n=8); and
- . 5% had a post-graduate degree (n=2).

### *Age*

- . 3% were teenagers (n=1);
- . 16% were in their twenties (n=6);
- . 16% were in their thirties (n=6);
- . 50% were in their forties (n=19);
- . 10% were in their fifties (n=4); and
- . 5% were in their sixties (n=2).

### *Secondary Handicaps*

- . 18% had secondary handicaps (n=7), including mental retardation, brain injury, blindness, missing limbs, etc.

### *Employment Status at the Time of the Interview*

- . 52% were working (n=20); and
- . 48% were not working (n=18).

The interviewee group was somewhat over-representative of African Americans and somewhat under-representative of women. Educationally, the interviewees as a group seemed much like the US population as a whole, with about 50% without any college experience and 50% with at least some college (Pigeon, 1999). It should be noted as well that the age range of the group – particularly when combined with their educational achievements – suggests that if these individuals had not been disadvantaged by serious mental illness we would expect to find both a wide range of vocational experiences and many people well along in their careers. This, as we shall see, is not the case.

## Personal Lives: An Overview

In the course of the interviews, sometimes in response to a direct question and sometimes in relationship to the explanation of a particular work-related experience, I learned a good deal about the personal lives – beyond the demographics – of the interviewees. Several aspects of their lives struck me as particularly important in the context of studying past and future careers.

First, almost everyone was living in very constrained economic circumstances, and the majority lived at or near the poverty line. Their individual economic circumstances differed only in regard to the degree of financial support they received from family members – mostly parents – and the type of services support (housing, recreational activities, etc.) they received from their psychosocial rehabilitation agencies. It was not surprising to find that fully 85% (n=32) of those interviewed had received support from the Social Security Administration in the past, but it was telling that most (79% / n=35) were still receiving either SSI or SSDI at the time of the interview, even though more than half of the group (53% / n=20) were currently working. Only one person owned a house (which she had inherited from her mother), and only four or five people owned an automobile. Vacations, as several participants pointed out, were more often taken at the State Hospital than in faraway resorts. These were people at some considerable remove from ‘The American Dream.’

Second, the people I interviewed were often quite personally isolated. More than half of the group (58%) lived by themselves, either in their own apartments (n=12) or in some form of supported single-person housing (n=10), with another four persons in group homes and six persons living with their parents. Only two people were living with other adults of their own choosing. These residential arrangements also reflected the complete absence of married relationships: 71% of the group had never married (n=27) and 29% were currently divorced (n=11), although two or three people did indicate they were living in a romantic relationship with someone. I was greatly surprised as well by the relative rarity of children in the lives of those I interviewed: only 7 people (18%) had children, but most (86%) of the fourteen children of the group were either adults now on their own or were living with grandparents or the ex-wife or ex-husband of the interviewee. Although many of those I talked to maintained healthy and very supportive relationships with parents, siblings, nephews, and nieces, they also talked often about the degree to which their ‘aleness’ was viewed by themselves and their families as one key aspect of the ‘failure’ of their lives.

From the employment perspective, however, I wondered – but did not ask about – the career implications of their personal circumstances. On the one hand, most of the interviewees had no one to talk to at the end of either a long, frustrating day or a successful, exciting day – no one to share the experience with, no one to provide a new perspective on problems at work, and no one to strategize with before catching the bus in the morning. On the other hand, I wondered how much the absence of dependents – of spouses with expectations or children with normal needs – impacted on the motivation of the interviewees to fully participate in the labor market: does living on one’s own without family responsibilities lead toward a more casual attitude about the importance of work on a day-to-day basis? While these are questions for another study, they are worth considering in light of the actual work experiences and ambitions to be reported below.

## **Mental Health: Onset, Diagnoses, and Symptoms**

*Onset.* These interviewees' description of the onset of their emotional problems validates much of what one reads in the professional literature: while a few people were aware of and received professional treatment for mental illness in their childhood, for most people the real onslaught of problems began when they were older teens or young adults.

*I had a lot of problems as a child. There were a number of suicide attempts – at least five – while I was a young teenager, and I had a lot of problems as an adolescent. (Ron Berman)*

*After high school I had a girl friend, and it just wasn't working out, and I now can see that I was beginning to get sick then. I wasn't aware of it, though. But I was always worried, and that was leading into delusions, and that went on for a couple of years before I got help, when I was 22. (VIDS)*

*I can look back on the fact that I was mentally ill and go back with my history and say this is mental illness and this is not, and that goes back to my youth as a matter of fact. But where it really got serious was in my senior year at college: I had about six months before I graduated, and it became a serious problem. (Steve Counts)*

*Well, after a while at a junior college I started going almost full time to Northeastern University: I was there for three and a half years, doing pretty well . . . but I left without a degree because I had my first nervous breakdown. Now, I always thought that my breakdown was caused by my parents' divorce, but I was also drinking a lot, and then I became totally self-conscious about personal hygiene problems. (MM)*

*By the time I was in high school I was having a lot of problems with Obsessive Compulsive checking behavior, although I didn't get help with it because my family was totally focused on the much more serious problems my brother was having. I was hospitalized in 1982 when it got so bad no one could ignore it anymore, and of course it then was a problem for me in college, so bad that I had to come home after a year and finish my degree closer to home. (DW)*

In most instances the first episode of serious mental illness – whether it led only to a visit to a psychiatrist or resulted in a brief psychiatric hospitalization – did not immediately alter the individual's overall plans, nor the hopes of their families. Many people responded to their first seriously psychotic episode with a relatively rapid recovery and a return to their usual activities: people who had been in high school went back to class, people who were working almost immediately set out to find a new job, and those in college returned to school in one way or another. People picked up the thread of their lives with an expectation that this incident had been an aberration and was now behind them. Although new problems and repeated hospitalizations often awaited them, it was often years before some people lost their faith in their ability to complete their education or find a job that realized their potential.

*Diagnosis.* The survey did not directly ask the interviewees about their diagnoses, and it is interesting to note that without an expression of interest on the interviewer's part the people in the study rarely raised diagnostic issues themselves. Diagnoses appeared to have very little meaning to the interviewees. Several people commented wryly on their diagnostic labels:

*The diagnosis I have now is of a bi-polar disorder, which I think is the right one, but before that I was seen to have schizophrenia, and then depression only, and this and that diagnosis over the years. (Ron Berman)*

and others seemed not to know very much about their diagnosis and its implications:

*All I know is that I have been on medication for a long time. I can't remember what my diagnosis was: it may have been depression or something. (Armenta Taylor)*

and they rarely thought about or mentioned the relevance of their diagnosis to their working careers. Diagnoses were of interest to mental health professionals, but of limited utility, it seemed, to the clients they saw.

*Symptoms.* On the other hand, the interviewees were much more concerned about their symptoms, the impact of symptoms on their capacity to work, and the degree to which symptoms could or could not be controlled with medications. Symptoms, and not diagnoses, were seen as a major source of their problems (in relationships, in coping, and in work), and it was the symptoms of their illness that led to hospitalizations and all the consequences of hospitalization.

The symptoms were quite varied and often quite frightening, and most people were able to reel off a list of half-a-dozen different symptoms they had experienced in the past or that they were still attempting to cope with in their daily lives:

- . anger
- . disorganized thinking
- . visual hallucinations
- . depression
- . lost time
- . preoccupations
- . low tolerance for stress
- . compulsivity
- . auditory hallucinations
- . mania
- . paranoia
- . anxiety

*I had a temper and didn't know how to control it. Nobody ever knew I had a temper: I used to take it out on myself, but I was constantly under stress. (Steve Markind)*

*For a month I started hearing voices. I heard a lot of them, and they caught me by surprise. I knew some people that heard voices, and they know what to expect, but I didn't know what to make of them the first times. What you have to do is not pay attention to them: you can't believe them at all, the things they say to you, whether it's good or bad. (Lou Deardon)*

*I think too much, and I focus on myself and my inadequacies. (GD)*

*I have manic depression and I tend to get agitated and verbally abusive, or very irritable (particularly when I'm very manic and stop sleeping at night) and then I wind up in the hospital. Of course every time I wind up in the hospital I lose my job because I don't show up for work. (Cindy Emerald)*

*I was hearing things, and I felt like I was losing my mind, and I was finally going crazy. I was very depressed, I remember, and sort of becoming unconnected with the people around me, and then everybody was trying to hang onto me but I was getting worse all the time. I couldn't sleep at night at all, and the nights I did sleep I was having nightmares, which continue to this day. They're different from the one twenty years ago, but they're still nightmares. (Myria Manfred)*

*Just these ups and downs. There was no one thing. I think loneliness was a big part because I didn't make any friends at my new job. And I just got to where I didn't want to live anymore. I do believe that I have a choice about my actions, but at that point I knew nothing about mental illness and knew nothing about why I was feeling the way I was feeling. (Monica Zachoe)*

There was less awareness, but some mention, of the 'negative' symptoms of mental illness – such as social withdrawal and shyness, or a lack of motivation or lethargy – that also impacted on both relationships and employment.

Moreover, it is important to note that people had been struggling with symptoms of mental illness for many years. Those in their 30s and 40s and 50s had first experienced symptoms in their late teens and early twenties, had lived with these symptoms for most of their adult lives, and did not expect their symptoms to vanish any time soon. There was considerable appreciation for the increasing effectiveness of medications in helping to alleviate the most disruptive aspects of their symptoms, but so many problems remained that many seemed resigned to the continuing presence in their lives – even if on an intermittent basis – of the symptoms that were now so familiar to them. They had watched helplessly as their symptoms destroyed relationships, dragged them toward hospitalizations, and made work difficult and sometimes impossible for them to sustain, and it was their sense – as we shall see – that these symptoms would continue to disrupt their lives.

## **Vocational Identity**

In reviewing the transcripts of the interviews, one of the most significant issues to emerge was the consistent *absence* of interviewees who spoke of themselves in terms of their 'vocational identity.' They talked readily and frankly about various aspects of their lives – age, marital status, living circumstances, diagnosis and symptoms – but they rarely talked about themselves in terms of their vocational status, as most other people do. No one described themselves as a waiter or handyman, teacher or accountant, although these were some of the jobs they had held in the past. Even those people who were working never suggested that I could get to know them by learning what they were doing for a living. Several people were working as consumer advocates or as leaders in consumer-run drop-in centers, for instance, but they too failed to

describe themselves in those terms, either because it was too new to them or because they didn't have much hope that they could continue in that career for very long.

One might compare this to the way in which many people in Studs Terkel's remarkable book on the lives of working Americans – *Working* – chose to describe themselves. Terkel's 1972 book gives voice to several hundred people who were interviewed about their working lives, and frequently the interviewees described themselves as stonemasons, waitresses, actors, or taxi-cab drivers, etc. Even those who hated or were embarrassed by their jobs defined themselves within the working context. Those who loved their work and were proud of their accomplishments – people who built bridges or buildings, or who served as social workers or teachers – readily saw one core aspect of their identity as wrapped up in their work.

Little of that emerged here. People did not have a firm sense of vocational identity, neither in their past nor their future. They often had worked quite a lot, and yet there was no sense that a career of any kind had emerged around which to frame a sense of their role in the broader productive society. This failure to establish a vocational identity – like the failure to establish a family of their own – was part of their sense that they were so very far behind their contemporaries. The working Americans that Terkel interviewed were often disappointed in themselves and bitter about their careers but, unlike the interviewees in this study, they took considerable pride in their ability to survive, to function independently, and to make a contribution to the broader community within their 'career.' The implications of this divide are enormous. A generation ago, it was hospitalization that marked you as somehow 'different' from your neighbors; today, a failure to thrive at work has begun to fill that function.

#### IV. PREPARING FOR WORK

*John Meyer is a pleasant, quiet White man, 47 years old, living in the Washington, DC, area. After a series of fast food jobs in high school, he went away to college but found he had ‘problems with people’ and returned home to finish his degree locally. He went through a series of both blue collar and white collar jobs – stock boy, landscaper, computer programmer, etc. – over the next several years. He left or lost those jobs either because of hospitalizations or boredom, and followed the same pattern both when his Dad and he moved to Boston and then when they returned to the DC area. He has worked – with interruptions for hospitalizations – as a clerk, computer programmer, and landscaper in the last few years, sometimes through Transitional Employment services. He recognizes that his problems with concentration and social interactions affect his work. Currently he is working one day a week at a local hardware store. He is ambivalent about the future: he is interested in becoming a teacher, but realizes that he “. . . is not very cooperative with other people, and I’ve tended in the past to be very immature and inappropriate.” He is abundantly aware of the wide gap between his academic/intellectual abilities and his achievements at work.*

*MH is a very straightforward African-American woman, aged 42, who has worked most of her life. “I look forward to working, and I’ve always worked in spite of my illness, and I’ve always pushed myself to work because when I don’t work then I feel like I’m not moving forward anymore.” Her first job, when she came up from Georgia to Washington, DC, was as a salesperson at one of the major department stores downtown. After several years she developed serious emotional problems, she divorced, and she was hospitalized. After leaving the hospital she returned to the South, worked at a variety of short-term jobs there, and then returned to DC to work at small clothing stores, then at another chain, and finally back at the department store where she had started, where she was quickly promoted to a supervisory position. Subsequent hospitalizations meant that she lost each of those jobs, but eventually found her way to one of DC’s psychosocial rehabilitation programs, which placed her as a receptionist or clerk at varied transitional employment slots in the community. At the time of the interview, MH was working part-time in a TE position on the weekends so that she could attend college during the day, and is looking forward to graduating with a business management degree and potentially starting her own clothing store.*

#### **Attitudes Toward Work**

One of the most frequent complaints about people with serious mental illness is that they are ‘unmotivated’ with regard to work. Clinicians, case managers, social workers, and rehabilitation counselors frequently argue that those with the most serious mental illness are reluctant to enter rehabilitation and placement programs, are likely to sabotage their own success either before they move into competitive employment or soon after they have taken a job, and are frightened to move toward the economic independence that will set them adrift from the financial and medical supports of the Social Security Administration. Such arguments may be said to ‘blame the victim,’ yet there appears to be considerable ‘case wisdom’ to support it. Nonetheless, the

data that emerge from this study force one to challenge it as an incomplete portrait of prevailing attitudes toward work.

This research offered two separate opportunities for people to talk about their attitudes toward employment: first, there was an early question about their general interest in work and its value; and, second, interviewees were later asked to share their specific plans with regard to their own work goals. Two different kinds of responses emerged: people were generally quite positive about work and its potential meaning in their lives, but more than a little ambivalent about returning to the competitive marketplace in the near term. This ambivalence – a clear understanding of the value of work and yet a reluctance to fully commit themselves to financial independence in the competitive marketplace – reflected their grasp of the barriers that exist between the ideal and the real.

There was a very deep and varied understanding of the importance of work in their lives. Some focused on specific advantages. Keith Robinson's position was unambiguous: "I'm working now and I love to work. I like the money." Joe Demaro liked both the money and the self esteem that earning it provided: "It makes you feel good about yourself to have to earn your money: to go cash a check and pay your own bills. It makes you feel a little bit a part of society when you bring your check in to cash it, and it makes you feel a lot better than waiting a whole month for some SSI money." GD wanted to work primarily to provide for and prove something to her children: "The only thing I think about a job is that I want to work. It gives me self esteem: My kids sometimes ask 'are you going to work' or 'when are you going to go to work,' and I just know this is what I need to do. I feel it's important, and it shows my children that things don't just come to you, that you have to work for them."

Quite a few people talked about the role that work plays in distracting them from their problems and alleviating the symptoms that would otherwise overwhelm them. Many agreed with Kayce Mendez:

*I find right now that I want to start working because I don't like staying at home. Being in the house and not doing anything, it really drives you down. It keeps you depressed, staying in the house and not having anything to do and not being a part of anything. It's like a waste. A part of my life is going by. I like to stay occupied. Once I start working I still have these problems where I can't concentrate, but I'm trying to stay focused on my assignment.*

Others were simply socially uncomfortable being unemployed. Lou Deardon spelled it out pretty clearly:

*It's terrible when you don't work, especially being a male, I guess. A lot of people are always asking what are you doing for a living, and I have to say I'm unemployed, which is kind of embarrassing sometimes, I say it so much. After a long period of time people wonder what you are doing with yourself."*

Lou's comments were echoed in Dave Pezick's:

*I do want to work because I notice that people on the outside have more respect for people who are working than they do for people who collect a government check, like SSI or SSDI. While the check does provide money to spend, I get a better attitude from people when I'm working.*

But many of the interviewees were aware that work provided a host of advantages, and this made work an even more important life goal for them. Cindy Emerald was succinct: “Actually, I enjoy working. I like meeting people, I like making money, and I like not getting bored, because work keeps me occupied when I’m having symptoms.” Lucy Kim, however, had a more complex assessment of the role of work in people’s lives:

*For a lot of people it's not just about the money. When you're not working, you are in 'the other class' of people, you are a mooch. It helps if you have worked before to realize you can work again, and people with really positive prior work experiences are much less afraid that they will ultimately screw up on the job, that they will fail. The connection between work and self-esteem is difficult to explain to people, it's a little obscure. Once you get used to being on the receiving end, you find yourself stuck there.*

Claudia Thomas-Frazier similarly had numerous reasons for her repeated forays into the labor market:

*I like to work. I feel proud when I do, I feel important, and I like to be able to say that I have a job and I'm off SSA, and I want to make my children happy and give them a house and a car. Some people are satisfied just to get their check, but maybe they never had a job or a good work experience like I have had, so they don't know how good it feels. I believe that God made us to 'go and do our best' and that's what I've tried to do in all of my 13 or 14 jobs.*

In fact, then, the general attitudes toward work held by most people with serious mental illness is predominantly positive. It is not lost on them that work provides income and self-esteem, or that work provides a valued place for people in the community as well as a way to keep from obsessing about or surrendering to one’s symptoms. People are well aware that it is generally wonderful to meet new people at work and make new friends, and they want to provide for their families if they can. Even those who saw themselves as likely to be dependent upon SSA support for the rest of their lives wanted to work at least somewhat, for the same mix of financial, self-esteem, social status, and clinical reasons as the others.

In an extensive series of interviews with minority workers in fast food restaurants in New York City, Katherine S. Newman found a similarly positive orientation toward work. Her book – *No Shame in My Game* – explored in depth whether the ghetto workers she interviewed were ‘unmotivated’ to work, and found no significant “value divide between these workers and the rest of the society: work remained central to their understanding of how to provide for themselves at both the financial and psychological level, and how to move forward in the broader society.” Here too, there is no ‘value divide’ or ‘amotivational state’ for people with serious mental illness that significantly separates them from the rest of us: Black or White, male or female, lower, middle or working class – they want to work.

The interviewees were well aware, however, of the many barriers to work for them to overcome, and thus their attitudes toward getting a competitive job – and particularly working toward full economic independence – are far more ambivalent. Lucy Kim and Claudia Thomas-Frazier both hinted in their comments, above, that people who had not worked before or who had not worked successfully were likely to be more than a little reluctant to jump into the workforce again, and that reluctance has several aspects. People talked about how they had to be careful to avoid anything that was going to be too stressful and likely to exacerbate symptoms, and they were worried that they didn't want to be stuck in boring jobs they couldn't stand for very long:

*I have a friend with a telemarketing job: boring, boring. I could not do that job. I could get it, but that's a very boring job where you sit on the telephone and you talk to people you don't see and they tell you to get lost. I don't need aggravation like that. (Steve Counts)*

Others were clearly concerned about the economic implications of a return to full-time work. Part-time work was fine with VIDS, if it supplemented his SSA check:

*I don't know how I'd survive if I just got Social Security, without working a couple of hours a week. No, I wouldn't be able to survive if I didn't work. I like to go out and eat a couple of times a week, and I like coffee. I smoke cigarettes, which are expensive, although I don't drink beer. I haven't in a long time, because just coffee and cigarettes where I spend my extra money. I make about \$40 or \$50 a week, that's about it, but it helps.*

But more extensive work that threatened SSA ineligibility was clearly a difficult decision for most of the interviewees. JG, for one, was very worried about losing his place in his group home, which required SSA eligibility, and others were concerned that if they went to work and lost SSA's support they would be truly stranded if they lost their job for one reason or another. Chris Macaluso, for one, wasn't sure whether he was ready yet: "To tell you the truth, I do want to work, but I'm not sure if I do want to do it now."

Later in this report we discuss more fully the way in which the interviewees' assessment of their economic prospects limit their ambitions. For now, however, it is important to note that however clearly most people understood the value of work in their lives, most were – for good reasons and bad – clearly ambivalent about their own immediate economic independence.

## **Encouraging Employment**

How much, in light of the ambivalence discussed above, had people been encouraged over the years to seek and sustain employment? Not much. Indeed, that work continues to be a primary goal for so many individuals is remarkable in light of the failure, as the interviewees reported it, of both the mental health and vocational rehabilitation systems to encourage people to consider work. There was some encouragement – from family members, the occasional clinician or counselor, and a few of the nation's psychosocial rehabilitation agencies – but the picture that

emerges from these conversations with clients is that such encouragement is far more the exception than the rule.

On the positive side, several of the interviewees identified their families as the source of their continuing interest in work. Families played a key role in several ways: first, there was a sense that hard-working parents established a model for adult life that their children valued; second, interviewees reported that parents continued to directly encourage employment – a polite way of saying that any number of parents were persistent naggers, a nagging that became more persistent as parents aged and they began to worry about how their son or daughter would manage without them; and third, several people talked about the standards set by their siblings, and how humiliating it was to be the only unemployed or unsuccessful sister or brother.

MH was particularly grateful to her brother, who both consistently encouraged her to work and was always interested in her progress once she was working. RB was aware of his mother's anxieties when he was not working steadily:

*I guess my mom tired of me sitting around doing nothing. I'm getting old, you know, and my mom's 64 and she's not going to live forever, and my Dad's in a nursing home. She wants me to get kind of independent, so she did most of the work finding me jobs or rehabilitation programs.*

Norma Maxwell felt both encouraged a little intimidated by her family's overall emphasis on work:

*What encouraged me is that my mother and all her other children consider it very important for people to be successful. That's both encouraging and discouraging. They talk a lot about the importance of education and getting a good job, and they've all been very successful. They expect me to do everything myself. You know, to be out there and be a go-getter – and sometimes I can be very shy around people I don't know – makes it kind of hard for me.*

Myria Manfred looked back with some regret on her lack of response to her father's importuning: "I'm sure my dad tried: he was always saying something like 'if you could just find something, even if you don't like to do it, even just a couple of hours a day, that would be good for you. But I didn't.'" Surprisingly, no one suggested that their parents had discouraged employment: despite all the 'case wisdom' about how parents, worried about the emotional instability of the client or concerned about the financial implications of SSA ineligibility, tend to directly or indirectly undermine vocational rehabilitation efforts, there was no evidence of this among these interviewees.

Asked whether mental health workers – clinicians, counselors, case managers, etc. – had encouraged employment, the answer was unhesitatingly and consistently, 'no.' Although there were a few reports of clinical staff who encouraged work (e.g., DW's psychiatrist told him that if he was going to be obsessive compulsive about anything, it might just as well be a job) and a few other clinicians referred clients to their state vocational rehabilitation systems or to local work-oriented psychosocial rehabilitation programs, for the most part clinicians and case managers

seemed to the interviewees to be disinterested in work, if not downright hostile. Listen, for instance, to Ron Berman, who had worked extensively in his early years:

*I thought that the partial program that I was referred to by the psychiatrist would eventually lead me back to work, but it didn't, in part because the doctor there kept saying that I wasn't ready for work. No one really encouraged me to go back to work: I can't remember anyone even talking to me about work. I was once referred to DVR, but I found that pretty useless: they did a lot of testing, which I found difficult, and then never called me back. One psychiatrist mentioned work to me maybe once, but there was no follow-up.*

Cheri Clodi liked her doctors, but while “the doctors helped me to cope a lot, it was always in the area of symptom management, and not much about a job or a career.” Steve Markind, who had worked as a bank auditor, felt that the psychiatrists he saw after he became ill “never made any connection between me and the world of work, but I'd have been better off if they did.” Claudia Thomas-Frazier, with a similarly extensive work history, says that her “psychiatrist says I'm not really ready to work.” Lou Deardon applied for a job with the airlines, but when his drug tests came back positive because of the Prozac he was taking, the airlines contacted his psychiatrist, who refused to say that Lou was capable of working. One of the more critical comments came from Sarkis Tashjian, who had worked for many years in a wide range of demanding jobs, which were frequently ended when his problems with manic behavior and/or drugs got out of control:

*If you want my opinion about both the mental health and drug and alcohol programs I've been to, neither one of them pay much attention to your interests in work. Not from my experience. They are there to treat you for – what's the word I want – for 'acute' symptoms, but past that, no, no. . . . Without a doubt, if you could put someone on the road to acquiring some skills, that would be a blessing, because a lot of people's self esteem is based on what they do. Why not give them a better opportunity in life, or at least point them in the right direction? There's nothing mentioned.*

Even psychosocial rehabilitation programs came in for a fair share of the criticism, with many people agreeing that it was possible to attend PSR programs for years – and many had – without either working or feeling especially pressured to be involved in transitional or supported employment programs. Others felt that while their PSR programs had in fact encouraged their engagement in on-site work crews, off-site transitional employment programs, and agency-operated or consumer-run businesses, few pushed people beyond that level into the competitive labor market unless the consumer was fairly well motivated on his or her own. Indeed, many planned to spend the next several years in and out of their PSR agency's TE or SE programs, primarily for both the extra income and the symptom distraction they offered.

Ellen Fabian (June, 1999) offers an interesting discussion about the failure of the mental health system to address the employment needs of people with serious mental illness, suggesting that there is an abundance of evidence (Noble et. al., 1997, Anthony & Blanch, 1987; Connors, Graham, & Pulso, 1987) that “. . . vocational issues and work have not been historically featured in the development and implementation of community-based rehabilitation programs for individuals with serious mental disability.” This tendency, as Fabian puts it, “to separate work

from other life domains” is one that is not unnoticed by clients. The question, then, might be to question more closely who exactly – staff or client – is unmotivated with regard to work.

## **Rehabilitation and Training**

A less clear picture emerges from the interviews with regard to the job training these people received as part of the effort to prepare them for competitive employment. Many of the individuals in this sample had some sort of specific skill training earlier in their lives: participating in a bricklaying apprenticeship program, attending secretarial school, completing an electrician’s licensing program, graduating from a nurse’s aid preparatory course. Others had attended college and concentrated on career-oriented courses (e.g., in accounting, teaching, counseling, or business administration). Much of this skill-oriented training was undertaken either prior to the development of the individual’s significant emotional problems, or between the initial hospitalization and the growing realization that a long-term mental illness would have to be faced. It is worth noting, sadly, that interviewees were rarely in the careers that made use of their prior training.

It was also true that only a few interviewees mentioned that their state Office of Vocational Rehabilitation (OVR) had paid for them to go to a training program of one kind or another (an automobile mechanics course, for instance), most of which turned out to have little impact on the individual’s subsequent career. A few people found the state/federal vocational rehabilitation program of little real or lasting value to their developing careers.

*So I go to downtown Manhattan to the vocational office, and like all day they take all these tests, and they called me back with the results a couple of weeks later and basically they said, ‘well, you’re not good at office work’ and they ended up again saying, ‘well, what do you want to do?’ They said I was good putting the pegs in with my right and my left hand, but when I had to use both hands I wasn’t so good with that, so maybe I should go and get some neurological testing. I don’t have time for this. At this point in my life, I don’t have time to find out why my brain isn’t working. I’m interested in working with people, helping other people, and so the counselor there started going through the computer and the names of some programs were coming up, and that’s how they referred me to the Howie T. Harp Center (a consumer-run vocational training and placement service in New York City), and I came by on my own and they offered me an application to this day care worker training program, and I start next week. (GD)*

Very few of those who participated in the Transitional or Supported Employment programs of their psychosocial rehabilitation agency were aware that OVR may have supported their engagement there as well, and so there were few kind words for the state/federal vocational rehabilitation system in these interviews. MM “tried the (state vocational rehabilitation) program a couple of times, but that never seemed to help,” and this was a common experience. But then, MM didn’t find her local psychosocial rehabilitation program very helpful either. Similarly, Mark Davis wasn’t impressed with his PSR experience: “I felt like it was a baby sitting program at the time, and I strongly feel that I was well enough at that time to take a job and manage it by myself.”

It should be noted that, for most clients, entry into the rehabilitation world came years following their first entry into the general mental health community. People had typically spent years struggling with mental illness, had experienced multiple hospitalizations, months and months of community mental health services, homelessness and idleness and a general drift in their vocational lives until, often by chance, they were referred to a local office of the state/federal vocational rehabilitation system or to a psychosocial rehabilitation program. It was apparent that there was no consistent effort, on the part either of individual clinicians or of public mental health systems – nor welfare offices nor the Social Security Administration – to insure that clients were referred to employment-oriented programs early in their mental health careers.

Many others were very grateful to the psychosocial programs that served them: the agency was a place to go, it offered an accepting atmosphere whatever the type or level of symptomatic behavior they were exhibiting, and it was one of the few entities that made work possible for them, through a range of transitional and supported employment program models.

What emerged from the interviews, however, was how often these transitional and supported employment programs – in which about half of the people interviewed were participating – were used by the interviewees as ends in themselves: that is, those on in-house janitorial work crews or out on TE/SE assignments in restaurants, hotels, secretarial pools, or loading docks, as well as those working in consumer-run drop-in centers or as case management or residential service aides saw their jobs less as training opportunities preparing them for fully competitive employment and more as one of a series of jobs that provided them with the income and activity they enjoyed while not seriously challenging their eligibility for SSA benefits.

It was not clear whether the agencies had failed to convey that these positions were preparatory in nature rather than merely part of a chain of readily available jobs, but few interviewees articulated that these were training opportunities preparing one for a more competitive future. Indeed, many of the TE/SE jobs held by clients in psychosocial programs bore a marked resemblance to the jobs that clients had previously obtained on their own.

## **Job Finding**

In general, people had very little difficulty finding jobs on their own when they wanted them. Particularly in the early stages of their careers they used the same avenues for job finding that most people find effective: family contacts, friends who had a small business, newspaper ads, and the ‘word of mouth’ that continues to dominate the labor market. It should quickly be noted, however, that the ready availability of jobs may be related to the types of jobs that most clients were able to find for themselves – often part-time, entry-level, low-wage, poor-benefit positions that offered little opportunity for either longevity or advancement. Even as the years went by, however, and the relatively inconsistent work patterns of many clients became obvious, these types of jobs were frequently quite easy for people to obtain. Most interviewees expressed little frustration about being unable to find the type of work they could most easily handle. This was one of the reasons, however, that the interviewees were unlikely to make a major distinction

between the jobs they found for themselves and the jobs that were offered to them through Transitional and Supported Employment programs.

Further, few clients were aware of any particular discrimination against themselves in the hiring process: few felt that employer attitudes constituted a major barrier to their employment. This was particularly the case since they had acquired most of the jobs they described to me on their own, without revealing to the employer that they were dealing with a major mental illness and without demonstrating such bizarre behavior in the job interview that the employer could figure this out on his or her own. Indeed, as in other surveys of consumer attitudes toward disclosure of their mental illness in the employment setting (Granger, 1998), most respondents in this research effort were happiest when the employer did not know about their psychiatric background.

This job-finding pattern, however, leaves unaddressed the discrimination that this group of people with serious mental illness might have faced had they seriously pursued more 'mainstream' employment: that is, more demanding jobs with better pay, regular schedules and decent benefits may also employ more extensive interviews, a closer reading of a resume, and much greater caution about bringing onto the worksite people with even minor personality idiosyncracies.

The dominant themes that emerged from these discussions about the degree to which people were encouraged both to pursue work and to prepare for work in the competitive labor market suggest a gap between consumer needs and system responses. On the one hand, these mental health consumers held many of the same attitudes toward employment as their non-disabled peers, and yet, on the other hand, the mental health and vocational rehabilitation systems they frequently relied upon neither encouraged them to work nor provided substantial assistance to them in reaching their work goals. These mental health consumers were frequently able to find jobs on their own, but what kinds of jobs were these?

## V. THE JOBS

*Mark Davis is a 41-year-old White man with a manic depressive illness, an HIV+ diagnosis, and a history of substance abuse. For the past several years he has developed a national reputation as an articulate spokesperson for the consumer empowerment movement, and is currently employed by the Philadelphia City Office of Mental Health as a coordinator for HIV/AIDS policies. Mark was raised in Ohio, where he worked in a variety of 'Dairy Queen' type jobs throughout high school, and as a residence counselor in college. Although he had some emotional problems in his undergraduate years, he only became seriously ill while in graduate school. After getting his Master's Degree in Counseling, Mark was unsure that he could work professionally, and so took a job in a furniture store, moved to Florida to help his sister in her shoe store, and then found himself homeless or hospitalized on several occasions. He moved to Philadelphia at the invitation of a family member, but again experienced difficulties and wound up in a group home and dependent on SSA. Dissatisfied with the types of entry-level jobs his vocational counselors recommended, he applied on his own for a residential counselor position with a mental retardation program, where he quickly found himself in a supervisory position. After a few years he went to work for the then-fledgling consumer movement in Philadelphia coordinating consumer self-help programs. Mark helped to found the Pennsylvania Mental Health Consumer Association and has received many awards for his advocacy work. Social Security is currently asking him to return over \$26,000 in benefits he received while ill and unemployed, and the case is currently in dispute.*

*Joe Demaro is a 43-year-old African-American man, also living on his own in Philadelphia. Born and raised in Georgia, he graduated from high school after a number of school-sponsored apprenticeships in electrical engineering, masonry, and maintenance work. After a few years of jobs in these areas, Joe joined the Marines, but left after a year when two of his brothers were killed at home, and he returned to Georgia and his family to grieve. After one year he went back to trade schools, seeking to avoid dependency on SSA. He wound up pumping gas and working as a mechanic (where he was robbed), and then moved to live with relatives in Philadelphia. He continued to work at a number of now familiar jobs – on a construction crew, as a car mechanic, and in maintenance jobs – but he also began to attend a local community psychosocial rehabilitation program, and wound up on SSA. His jobs – often part-time and short-term (in order to remain SSA eligible) – ended when he either quit out of frustration with bosses or co-workers or was fired for problems related to his drinking and drug difficulties. His plans for the future are to somehow find and hold on to a full-time job with benefits so that he can have “a house, a car, and a bank account,” earning enough, he hopes, to be able to escape long-term dependency on the Social Security Administration.*

### **The Types and Characteristics of 285 Jobs**

The 38 people interviewed in this initiative could clearly recall 285 different jobs they had held after leaving high school: each person, on average, had held 7.5 jobs during his or her adult life. Many people acknowledged that there may have been some other jobs that slipped their memory

during the interview, and these were likely to have been summer jobs or seasonal work or the types of jobs that they left after a very brief stay. The total number of jobs held, then, may have been as much as 20% higher, but the focus here is on the 285 jobs that people were able to recall with some clarity. Some people had been in only two or three jobs, and several had held quite a few more jobs, with older interviewees more likely to have held down more jobs as the years had gone by.

The average length of stay at these jobs was approximately 14 months: again, many jobs only lasted a day or a week or a month or two while another small set of jobs had lasted six to ten years, or, in JG's instance, 25 years. Most of the jobs, however, had lasted for six to eighteen months, with the reasons for 'job leavings' – as we shall see in the next chapter – quite varied. Full-time employment – accounting for 47% of the jobs reported on here (n=133) – was more common for interviewees in the periods immediately before and immediately after the first recognition of serious psychiatric symptoms. Part-time employment – accounting for 53% of the jobs (n= 152) was more common as the years went on, and, in fact, among those clients currently working at the time of the interview almost everyone had a part-time job. Whether the later preponderance of part-time work reflected client capacity or Social Security limitations can only be a matter of conjecture at this point.

What kinds of jobs were they? They were most often the kinds of jobs that are characterized as 'entry-level,' requiring only unskilled or semi-skilled capacities, paying poorly and offering few if any benefits. The chart on the next page provides an accounting of the 100 types of jobs people reported that they had held. The range of jobs was quite broad, although some categories – pumping gas, fast food worker, receptionist, file clerk, store clerk, deliveries, maintenance worker and dishwasher – recurred most often and the more white collar jobs (in education, accounting, or the growing consumer empowerment and self-help movement) were more rare.

What is there to learn from these accounts of jobs? First, it is important to recognize that the clients served by vocational rehabilitation programs are neither inexperienced nor unfamiliar with the world of work. They have worked in a wide range of jobs (a wider range than many of the young job coaches assisting them), and they have a fairly well developed sense of the demands of the average workplace. The numbers of jobs they have held indicate that for the most part they know how to obtain employment if they want it, and their average tenure indicates that they may not need as much introduction to 'the world of work' as rehabilitation programs assume: they know they have to get to work on time and use their time there productively; they know they need to dress appropriately for the job and interact civilly with coworkers and supervisors; and they know that stress is an inherent part of the job and that they had better find a way to cope with it. They have worked – and worked a lot (the average interviewee had worked over 100 months) – and it is a bit odd that we don't recognize their overall level of experience.

Whether or not they can or want to accommodate to the demands of the workplace is another matter, but that is one that programs can best resolve by placing clients relatively rapidly in real work situations rather than through education and off-site practice. That is, the work histories of the clients give some credence to the growing recognition in the field that effective programs do not need to hold clients in long preparatory stages – in sheltered workshops or in-house

**THE JOBS**  
**(past job titles held by thirty-eight interviewees)**

gassing airplanes	treating lumber	car repair
meat packing	Woolworth's salesman	teacher's aide
busboy	pizza delivery	computer data entry
stock boy	computer salesman	gas station attendant
carnival worker	insulation installation	farm truck driver
factory expediter	messenger	teacher
daycare worker	receptionist	cleaning zoo cages
mowing laws	fast food clerk	mail room worker
printer's assistant	grocery clerk	office clerk
assistant manager	dishwasher	taxi driver
accounting assistant	college house parent	group home supervisor
furniture store clerk	shoe store clerk	consumer advocate
paper boy	camp counselor	security guard
landscaping	construction	trash man
parcel dispatcher	factory work	electronic repair
maintenance worker	Marine Corps	carpet cleaning
bicycle rental	delicatessen clerk	furniture delivery
cook	truck loading	Navy
army private	dietary aide	telephone operator
real estate management	art gallery salesperson	car wash
toy store salesperson	mh housing counselor	payroll clerk
store supervisor	beauty salon	legal filing
patient aide	administrative assistant	waitress
temp worker	clothing sales	media assistant
hospital clerk	apartment cleaning	movie usher
art teacher	teaching	bartending
cashier	stock examiner	comptroller
selling cell phones	market researcher	clown
assembly work	auto detailing	mail house worker
hardware store clerk	packaging	locksmith
hair care product sales	punch press operator	folding machine operator
wiring pin ball machines	trimmer	go go dancer
nanny	chef	substitute teaching
consumer center staff		

(from *The Career Patterns of People with Serious Mental Illness: A Qualitative Inquiry*,  
Richard C. Baron, April 2000.)

psychosocial work crews – before introducing clients to the demands of real jobs. They’ve been there before, and in many cases they have coped successfully with the demands of the workplace well enough to hang onto their jobs for quite a while.

Second, however, the preponderance of jobs are at the lower end of standard occupational listings (Botterbusch, 1999). There are a large number of unskilled jobs (pumping gas, stockboy, grocery clerk, dishwasher, usher, kitchen helper) and a similar concentration of jobs in the semi-skilled arena (truck driver, salesperson, cashier). A smaller number of jobs fall into the skilled category (accounting, property management) and very few in the semi-professional and technical category (nurse’s aide, teacher), with almost none in the professional and managerial category (administrator, clergy, attorney, business owner).

The critical point to be made in relation to this clustering of jobs at the bottom on the occupational listings ladder is that the preponderance of jobs in entry-level positions does have enormous *economic* meaning for the interviewees. People in these jobs even on a full-time basis earn very little, and people in these jobs on a part-time or intermittent basis earn still less. The health care and vacation and related benefits associated with skilled and semi-professional jobs are generally not attached to these jobs, and the opportunities for advancement into ‘better’ jobs in supervisory and management positions in the same field are often cut off by the individual’s lack of educational achievement. Joe Demaro is unlikely, even if he continues to work successfully in the unskilled and semi-skilled arena for the next twenty years, to obtain the “house, car, and bank account” that are his goal.

Third, it is worth considering for a moment what many of these jobs are like. It has been commonplace in the mental health field both to concentrate job placements in the entry-level unskilled and semi-skilled categories and then to poke fun at those jobs. “Flowers, food, and filth” is the ungracious way in which I have frequently referred to these types of jobs in the past – as though such jobs were beneath both myself and the clients I served. It ought to be an article of faith within the rehabilitation community that any necessary job that is reasonably well done has an essential nobility about it, and that the people who do those jobs ought to be as well respected as anyone else who is working for a living. But this does not mean that we need to overlook some of the distressing characteristics of those jobs, for they are often quite physically taxing, mind-numbing, repetitious, and poorly-paid.

In Studs Terkel’s *Working*, his conversations with people without disabilities in those same kinds of jobs reveals a level of disappointment and despair that is distressing to anyone who hasn’t been trapped at that level of daily work. Surely these are as well the responses of people with mental illness in similar jobs. While some of Terkel’s sample actually liked their jobs, discontent was the more frequent response, and one might expect people with mental illness to have the same range and intensity of responses. Such responses are particularly poignant for those individuals whose emotional difficulties have kept them in jobs at great variance from their intellectual and educational qualifications: even those interviewees who had successfully completed college or graduate school and whose first jobs had been in skilled and professional roles often now found themselves working part-time in grocery stores and temporary agencies. Even Mark Davis worries about how long he can sustain the professional role he has acquired – and lent some distinction to – in the face of his multiple health problems.

Fourth, the preponderance of unskilled and semi-skilled jobs raises a question about the future: how long will such jobs be available? Plentiful now, will they continue to be readily available to our clients? Some labor force projections (Cook, 2000) note that 70% of the jobs in the fastest growing occupational categories in the US over the next two decades will require advanced degrees – that is, not just four years of college (rare enough among people with serious mental illness) but graduate training as well. In looking forward, entry-level jobs may be in shorter supply, and more competitively sought by others without disabilities who are similarly without the educational qualifications for economic success in the new economy.

This represents a considerable challenge to the nation's network of vocational rehabilitation agencies – including the psychosocial rehabilitation agencies that offer transitional and supported employment programs. Their ability to move their clients into better paying – i.e., more skilled – jobs is currently considerably limited, and the limits are in part a result of the past educational levels and vocational achievements of the clients they currently serve. That is, as has already been noted, the jobs that TE and SE and other vocational programs assist many clients to obtain are not really much different from the jobs they have been able to obtain in the past on their own.

## **Job Satisfaction**

Very few clear themes emerged from an analysis of interviewees' comments about whether or not they liked their jobs. Given the substantial number of jobs many people had held, it was not surprising that most people liked some jobs and disliked others. Given the range of individuals in the sample, it was similarly not unusual to find that some kinds of jobs were liked by some and disliked by others. Even a few comments give a sense of the variety of opinion about job satisfaction:

*I feel like I'm a little older than most of the people who work in the store, and I feel like an idiot working with teenagers and getting the same pay. It makes me angry. (RB)*

*The staff at the psychosocial agency where I now work as a receptionist talks to everyone about things that are really interesting, like mental illness. I'm interested in various aspects of mental illness, and I ask them questions from time to time, and they provide an answer. I'm not supposed to be listening to their conversations, but I do, and it's really very stimulating to work there, and I feel that I have a very important job. Another job I enjoyed was working at a fast food place. It started part-time and ended up full-time, and the longer you stayed the more you got paid. I enjoyed it. I got responsibility. It was hard work, and I stood on my feet a lot longer than I ever had, but so what? And then, once, when Social Security said I wasn't qualified to work, my PSR agency in Virginia Beach got me a job at a hospital, where they loved my work, which only encouraged me even more, so I did a really good job. (Steve Counts)*

*The job with the Sanitation Department as a trash man was all right. That's a hard job. I learned how hard that was. Very tedious, very repetitious – just emptying trash all day and walking a lot. They did it at a fast pace, and that's another thing you really don't*

*notice, that they do work at a fast pace. Another time I was only pushing carts outside a supermarket. I thought I was over-qualified for that, plus they were short-handed on weekends and it was very busy and crazy, and I didn't like that at all. (Lou Deardon)*

*I liked it when I was a floor technician, because all I did is just floors and operate machines like six or eight hours non stop. I'd be so tired when I got off work in the morning that I couldn't even get my keys together to get into the house. But I thought, 'this is sweet, because I'm making a lot of money, even if it is a lot of work.' (VIDS)*

*At one point, I couldn't find anything I liked. I looked for part-time work, and had a lot of short-term jobs over about five years. I didn't have very good experiences with these jobs. Either I hated them and left or they didn't like me and I got fired, particularly the kind of jobs I got with temporary agencies. (Aussie Humphrey)*

*The restaurant jobs I can do, and the funny thing is, that's the only thing I can seem to get these days. I don't like the work, but I can do it and before I couldn't. I used to always be awkward at cooking burgers, and now I can do it pretty good and I can't stand it. (Paul Lapira)*

*What you have to do, being only a high school graduate, is a lot of physical labor, like bussing tables, washing dishes, load weighing, and cleaning floors and bathrooms – jobs I don't really like, and that are especially physically demanding if you're on medication. (Jack Motta)*

The only consistent pattern that emerged was that the 'atmosphere' of the work environment was a major determinant of job satisfaction: if the interviewees got along with supervisors and co-workers, most people seemed happy enough, despite the type of job and the rate of pay. Making friends on the job, finding people who could be supportive, or even just being able to joke their way through the day made even depressing jobs bearable. But if the work environment was unpleasant – if people made fun of the interviewee or even just left them socially isolated, if one began to believe that coworkers were gossiping behind one's back or undermining one's success – then the work itself became unbearable.

It was interesting, as well, that hardly anyone in these interviews mentioned discrimination. There were very few comments about discrimination in the interview or hiring process, as previously noted, and still fewer with regard to supervisory or coworker harassment. There were one or two cases in which someone talked at length about how employers in general were disinclined to hire people with serious mental illness, but no personal stories of having been disadvantaged in this way. There were a few instances in which interviewees complained about the way in which they were treated on the job by coworkers, in which people made fun of them or turned away from the possibilities of even casual friendship, but the interviewees attributed this on-the-job cruelty to their own peculiar behaviors or social awkwardness rather than outright discrimination.

A few people counseled others to avoid mentioning their mental illness to supervisors or co-workers if this was at all possible, a widespread opinion that has been noted in other research

(Granger, 1996). Because so many of the jobs we talked about in these interviews were those that people had found on their own – without the benefit of a mental health or vocational rehabilitation program – interviewees had mostly experienced work from the perspective of people with an undisclosed mental illness, and were far more comfortable in that environment than when they had been ‘placed,’ ‘supported,’ and ‘monitored’ in ways that made their psychiatric histories prominent aspects of their work persona. While Steve Counts felt that “if they knew I was mentally ill, they might be inclined to treat me more kindly, and because I have not experienced any discrimination, I’m not reluctant to talk about it,” most others felt more wary:

*It’s hard to explain the gap, and that’s it. Telling them you’re a mental patient doesn’t look good. They don’t understand it. It has to be explained to them that you’re a good worker, the same as anybody else, but so much stigma is involved it doesn’t really help. The stigma involved is mostly preconceptions: like you’ll be freaking out on the job and shooting everyone. One employer actually asked me that. (Lou Deardon)*

*On my next job I won’t disclose my mental illness to anyone. I didn’t like the way my boss treated me when he knew, and I wouldn’t want to go through that again. He treated me as though I was stupid and incompetent, and I hated it. I might disclose to someone like a boss or a co-worker after I had been on the job for a while and had proven myself, but people just don’t believe someone like me, with a serious mental illness, can work. But then, a lot of people with mental illness don’t believe they can work either, and don’t know what kinds of jobs they can do. (Cindy Emerald)*

## **Opinions about Coworkers**

While the interviewees had only mild concern about the attitudes of their non-disabled co-workers about them, they had no shortage of opinions about their coworkers, and it was not particularly flattering. On the one hand, there was a lot of concern – particularly in the unskilled jobs categories – that other people on the job didn’t work very hard. Joe Demaro complained to the supervisor in one job that he was doing “all the stripping and waxing of the floors, and stuff, and it makes no sense for me to be bringing those floors up and I’m doing all the work and the other guys don’t do no work.” Norma Maxwell had been in a job where she felt she did pretty well for a while, but then “got involved with some ladies that worked there that would sit and watch soap operas, so I got into that and my boss didn’t like that one bit.” DW was very disillusioned about the workplace:

*For a while I had mostly short-term jobs, for no more than two to four months: dishwasher, factory worker, working in a hair salon for a friend. Usually I got bored: the jobs would get old after a while, and the factory jobs were often chaotic – assembly work and janitorial work mostly – where there was hardly any supervision and most of the regular guys just goofed off and didn’t take any responsibility for their work.*

There was also a sense in these entry-level jobs that people with mental illness tended to stay at them for longer periods of time than their non-disabled co-workers, and this was sometimes a

source of pride and sometimes a source of embarrassment. RB felt that “people who work in the stockroom for too long are thought of as suckers. You spend too many years there at any job and you’ll be taken advantage of. People leave all the time: managers leave to see if they can get a better job. I don’t know why I stay.” Dave Pezick had the same experience:

*Yeah, a lot of the people I started with left the job. They couldn’t take it. It was hard work and a lot of them left. I guess some of them found other jobs. I’m sure they did. When I had been there a year, because it was just so unbelievable because the work is really hard, and it’s a lot of night work too, people who came back were just amazed.*

### **Job Patterns: An Initial Analysis**

The job pattern that begins to emerge from these interviews is relatively consistent, with several key points:

- . most interviewees worked before graduating from high school (after school and during summers), and those who go on to college may have some similar collegiate work experiences;
- . most people begin working at age-appropriate and education-appropriate roles, and continue in similar jobs in the years immediately before and after the first serious signs of emotional difficulties and/or hospitalizations;
- . a pattern begins to develop thereafter of entry-level jobs, held for one or two years, with intervening periods (of varying length) caused by symptom exacerbation, hospitalizations and insecurity about one’s own work capacity;
- . consumers alternate between jobs of this type that they find for themselves and similar jobs made available to them through TE and SE and other similar rehabilitation programs; and
- . a later entry onto the Social Security roles for financial and medical support encourages a long-term commitment to part-time employment in entry-level positions, with little concerted movement toward full-time work and financial independence.

Two key issues should be noted in this regard. First, there is an all-too-clear lack of *movement* from one level of employment to another. Most of those interviewed – and these were largely middle-aged individuals – were still at the entry-level of employment and had not advanced very far up the economic ladder. One might expect to find within this age range of non-disabled individuals a significant number of people who had made meaningful vocational progress: people who had begun to establish increasing tenure in their jobs, others who had become supervisors or managers, some who had found a way toward economic independence. Such progress, however, was largely absent for these interviewees. Even those who were working within the consumer empowerment movement, where both better-paying and more intellectually-challenging jobs were available, were either just getting by on their salaries or combining their just-better-than-minimum-wage salaries for part-time work with their continuing Social Security payments.

For most of these people, then, their ‘careers’ consisted mainly of repeated efforts to start over. To look at this within a positive framework, it does suggest that there are a great many people with serious mental illness who have both a rather substantial work history and a dogged willingness to return to the labor market whenever and however they can. But a more dour economic analysis suggests that even those with work experience and work motivation make little progress toward the kinds of jobs that offer the opportunity to establish economic independence or – far harder – to manage any substantial realization of the American Dream.

Second, it is useful to stop for a moment and wonder how different this job pattern is from the job patterns of persons in similar jobs who do not have disabilities: that is, how do the careers of persons with serious mental illness differ from the ‘normative’ patterns of their coworkers without disabilities?

In fact, a significant number of people without disabilities work in jobs similar to the unskilled and semi-skilled jobs that dominated the work histories of these interviewees. Economists capture information about those workers in two major categories. First, those who are *contingent* workers are in jobs that are not really designed to be long term, including seasonal workers, people on temporary assignments, and independent contractors. In an October 1996 analysis of data from the Current Population Survey (Polivka, 1996), economists estimate that as many as 6 million people hold such jobs, with as many as 40% of them in unskilled or semi-skilled roles. Second, there is a growing *secondary labor market* composed of people holding similar jobs (with low wages and minimal benefits) but with an expectation that their jobs can be permanent: 42% of those who hold minimum wage jobs, for instance, are adults in the 25 – 65 age range (Haugen & Mellor, 1990), and some estimate that one out of every fifteen Americans has worked in this kind of job within the fast food industry alone.

For people without disabilities who work in the contingent and secondary labor markets, then, traditional career patterns may be unusual. The services sector of the economy – comprised of those people who work in fast food restaurants, on landscaping crews, in gas stations, or at hotels, etc. – is thought to generate remarkably high rates of job turnover, sometimes as much as 300%, and episodic employment is a remarkably familiar pattern in the nation’s inner cities and isolated rural communities (Newman, 1999). Although there is very little definitive normative data, what is suggested here is that more research needs to be done to assess the degree to which the employment patterns of people with serious mental illness – careers frequently composed of an intermittent series of entry-level jobs – are similar to or different from those of their non-disabled coworkers in similar jobs. If the work patterns of people with mental illness are not substantially different from those of their non-disabled coworkers, then research needs to look more closely at the work experience itself. It may well be that the individual’s mental illness plays only a small role in the unsatisfactory career patterns that seem so ubiquitous: the structures of those jobs or the nature of the labor market itself might also contribute substantially to the static careers reported here for people with serious mental illness.

## VI. THE JOB EXPERIENCE

*Steve Counts is a 49-year-old White man with a Bachelor's Degree in Political Science who is working at a psychosocial rehabilitation program in Washington, DC, as a part-time receptionist and accounting assistant. He first began to have emotional problems at the age of 23, while in college, but didn't seek professional help until two years later, when he responded to a television public service announcement and sought out a community mental health center. Work is important to him, in part because of the models his parents set and their encouraging attitude toward his career throughout his life. In high school he had many part-time and summer-time jobs (lawn mowing, baby sitting, etc.) and after high school he worked in a fast food restaurant for a year and a half, but quit after a fight with his boss. He then worked for a printing company for a year, but left to attend college. After college he worked as a clerk in a fast food restaurant, but quit after a while and didn't work at all for the next year. His next job, as an assistant to the general manager of a beer distributorship, ended when he became paranoid, lost time on the job, and was fired. After five more years of unemployment – with only part-time jobs in between hospitalizations – he faced a choice: he could either accept Social Security or get a job through a psychosocial program. He took the job, and worked as a management trainee in a restaurant for a year until the company went bankrupt. He then drove a taxi for better than two years, worked for a newspaper for two years, and then went back to driving the taxi for another two years. After some financial problems, he wound up in the Washington, DC, area, broke and homeless. Contacting a psychosocial program there proved very helpful, including finding a home, getting a part-time job with the agency, and then reluctantly accepting SSDI eligibility.*

*Ron Berman, a 55 year old White man living on his own in Philadelphia, has a similarly rich work history. He was aware of his emotional problems throughout his childhood, and after some suicide attempts and neurosurgery, dropped out of school in the tenth grade. He worked for three years for the neurosurgeon who had operated on him, gassing airplanes, but left for a better paying job at a lumber treating plant, where he had an accident after about a year that forced him off the job. The state Office of Vocational Rehabilitation sent Ron to an automobile mechanics course, and for the next four years he worked at a car dealership, winning several awards for his work. The job ended when a General Motors strike forced large layoffs locally. He went to work then for a meat packing plant where his father worked: after a year he was in a serious accident on the job in which he lost one arm, but went back to work at the plant later for another ten years, driving a truck for the company. Despite the fact that Ron never felt that his emotional problems were a problem on his job, they were affecting his home life: after his wife left him, however, he began to have more problems coping on the job. He is still unclear whether he was legitimately laid off from his last job or was in reality fired, but he has never worked again, particularly after becoming eligible for SSDI in 1984. He believes that he has a very high intolerance for stress that makes competitive employment impossible: although Ron is very active in consumer self-help programming in his community, he says that he cannot manage more than six hours of meetings in three days without exacerbating his manic-depressive illness. Nonetheless, Ron is surprised that “no one has encouraged me to work since 1984,” although he freely admits that to consider working full-time he would have to be assured that he'd “never need to go on SSDI again.”*

## Work Performance

Steve Counts and Ron Berman were but two of the people interviewed for this study who had both extensive work histories and several positive on-the-job experiences, but who were currently either unemployed or underemployed. What happened? This chapter looks at several characteristics of their careers: their performance on the job; their impression of the impact that their mental illness had on their job performance; the reasons for leaving their jobs; and the alternating patterns of employment and unemployment that characterize their careers. To some degree, all of these aspects of work serve to set them apart from their coworkers, but perhaps not as significantly as it is often assumed.

Work performance is a useful starting point for understanding the careers of people with serious mental illness. What happens on the job? How well do such individuals perform? The answer is rather mixed: at most of their jobs, the interviewees felt, they did either very well or at least as well as their coworkers, but they understood clearly those instances in which their work performance simply didn't measure up. Indeed, most people had had both types of experiences.

Lou Deardon felt not only that his work performance was good, but also that other people with mental illness also did well on the job:

*Mostly I did good work. . . . I think that most people like me put their best foot forward when they're on the job, and if they have any crazy thoughts they let them go when they're off the job. They try to look good on the job.*

VIDS was actually surprised that despite the problems he has with memory and stamina, his boss always says "you're doing a good job. He has told me that twice since I've been there: when I leave every day he says thank you, which I guess means that he's pleased with my work." Jose Perez felt that he had found a number of jobs where he performed well: at one early job as an electrician, "I had always been very good with my hands in high school, so I fell in love with that at the time and I excelled in it. Just like I'm falling in love with the legal services for the disabled that I'm doing now, and doing really well at." GS had done well, she thought, at a wide variety of Transitional Employment positions:

*I do really well in those six-month TE positions, before I have to move on to another assignment. I work well with the other people, and they almost always say they are sorry to see me go, but that's the way the program works.*

Even in those instances in which the job may have ended badly, most people thought they had done a good job for most of the time they had worked. Claudia Thomas-Frazier had a history of nurse's assistant or day care jobs, one after the other over the years, but still felt that her work performance was generally pretty good:

*I was a nurse's aide again for a year, and I liked helping older people, but I got a reputation in the end as a troublemaker. For four months then I worked in a day care center for kids, but it was too cold that winter to go to work every day, and I quit. So*

*that's the pattern. I do real good on a job at first, but after a while I start 'second thinking,' and wonder whether I should be there or not, or worry that I'm going to be fired. Maybe I would have done better on these jobs if I had stayed with the medication, but what usually happens is I get depressed or angry and then quit. I lose my hold on reality. They always tell me that I'm a good worker and they can't understand why I leave, but it seems to always happen pretty much the same way: I quit.*

Like Claudia, everyone was aware that there were two important aspects to every job: getting the work done and getting along with other people. Most people felt that they were adept at both challenges: indeed, as we shall see later on, Claudia's pattern of quitting was far more common than firing.

People were also aware of their more pronounced on-the-job deficits. VIDS knew in one job that "they were never satisfied with me," and Paul Lapira understood that sometimes he was so preoccupied with his emotional problems that "I would have to take breaks – long breaks – and they didn't like that." MM's situation was typical of a number of stories I heard, where people were aware that their on-the-job performance was inadequate, but not so inadequate that they lost their job:

*So I worked in an office on weekends, for Standard Oil, while I continued in school. I didn't do too well there: they said I talked too much. Even though I got a promotion and a raise, I didn't do all that well: my attendance was a little erratic, and I disturbed others with my talking and they were always complaining about me, and my typing was getting pretty inaccurate. I worked there for two or three years, however.*

Kayce Mendez would lose jobs, he knew, because he just couldn't keep up cognitively. "I found a lot of jobs complicated. I was forgetful, had problems remembering things, like the steps I was supposed to follow, even in jobs flipping hamburgers, where there are certain steps to follow," and he knew that people had a difficult time with him because "I pretty much keep to myself. I don't have problems with anyone, it's just that I'm a quiet person . . . and if I'm in a room where people are having a conversation, I would probably just read a book." John Meyer had the same combination of cognitive and relationship problems:

*They had the old stock cash registers, the mechanical kind. I had a lot of trouble with the keys on the cash register, and it was very frustrating for the customers because there were lines of people. I liked working there, but I think I could have been a little more approachable, but I was kind of isolated . . . . The thing I remember about that job was that I was not cooperative in dealing with people, and I was very immature. My interactions with people were inappropriate, and I couldn't follow their directions, so they let me go.*

Often enough the interviewees' work experiences started off positively, but then something – an exacerbation of symptoms, a change in job assignments, or a serious error on the worker's part – became problematic. GD was working as a secretary at a university and was feeling pretty good about the job:

*. . . because I always felt like I was doing something in there. I was typing or doing the budget, or working on reports. . . . I felt like I was doing a lot of stuff . . . and everyone got along with me, everyone liked me, like the professors and the students. But, then, I starting stealing petty cash, and although I'd return the money, because I knew they needed the money, I was always nervous, and when they found out of course they fired me.*

It is useful to keep in mind, however, that these reports of work performance – of mostly good but occasionally poor efforts to meet production standards and get along with everyone on the job – were predominantly in unskilled and semi-skilled jobs, by definition those jobs that make very minimal demands on the intellectual capacities of workers, and where even interpersonal skills need not be as highly developed as in many other skilled or professional positions. All the same, two key points emerged repeatedly: first, that many of the work experiences of the interviewees had been quite positive, where they had done good work in both the productivity and interpersonal dimensions of the job; and, second, that people were very aware – and remarkably undefensive – about those instances in which they had not been able to manage.

The interviewees' perspectives on their job performance dispelled a number of my expectations about how the past work histories impacted on future work goals. On the one hand, not only had people worked a good deal, they believed they had often worked quite successfully, and therefore could readily imagine a future, with appropriate supports, where they could work successfully again. On the other hand, there was little complaining about discriminating bosses and harassing coworkers: most people had a realistic sense of when and where they had had some problems – for whatever reason – and had few wildly unrealistic expectations about their capacity for their next entry into the labor market. This pattern – of meeting employer expectations early on and then failing later on when they became sick again – fed interviewee concerns, it should be noted, about their ability to leave SSA support permanently behind.

### **The Impact of Mental Illness on Employment**

While there was no question in the responses of the interviewees that mental illness had had a major impact on their careers, they were careful to draw a distinction between the overall impact of mental illness in their lives and the impact of their illness on their on-the-job performance. On the whole, interviewees felt they had performed satisfactorily – and sometimes with considerable distinction – while they were at work, but that their symptoms often kept them from going to work or induced their quitting. In talking about the 285 jobs that had been held, there were only two stories of people who had lost their jobs directly because of bizarre or unacceptable behaviors while at work: Steve Markind reported a manic episode during a staff meeting in which he suggested his accounting firm could expand dramatically, and was fired that afternoon; and GD has stolen some money in a desperate need for cash to deal with her drug addiction. Otherwise, the impact of mental illness on the career patterns of these people was often far more subtle.

Many people talked about some of the performance-related impacts of their illness: early in his career, Joseph Ciupa had lost several jobs in ways that he thought were unrelated to his incipient

mental illness, but more recently he felt that his cognitive problems – “I can’t remember eight things or keep the assignments I have in order, and I have difficulty with the rules of most workplaces, like no drinking, no flirting, no stealing, and no absences” – were related to his underlying illness; Mark Davis understood that his depressions had been a work problem, but more recently finds that “the thing that most disturbs me, because it affects my work, are the problems I have with my memory, which is partly a result of shock treatments and partially just a general problem I have related to my illness;” and several people commented on the impact of medication on their work capacity, and on their stamina in particular.

More often, however, people talked about the importance of keeping their illness off the work site. Ron Berman was not the only person to make this distinction:

*I was always dealing with my problems with anger, the occasional episode of violence on my part, the depression which swept over me, and the problems of having lots of manic energy. But I want to make clear that none of these problems ever affected me on the job, and people at work almost never saw the depression or the energy or the mania in a way that upset the workplace.*

MM “never had any sort of symptoms on the job.” Monica Zachoe had worked as a teacher for many years, and through several hospitalizations, but felt that:

*I was a very good teacher, that I know. And the reason I say that is because not many teachers get letters from their students after they leave a school to say that “you’re the best teacher.” And my mental illness never had much impact on my teaching, because I was real steady emotionally when I was teaching. I was doing something that I liked, and because I wouldn’t allow my mood to show to the kids. I’m not saying I didn’t have the moods, especially the depression, but I would not let the kids see that. And I was able to control it for many years.*

Norma Maxwell felt very similarly. Although she heard voices all the time:

*. . . the only time I experienced difficulties on the job is if somebody found out, and then I felt like they would treat me differently. I don’t know if it was just my paranoia, or what it was, but I felt like once they knew, it was always a different situation. . . . My mental illness is my problem, it’s my own personal ordeal. When I’m with my friends I don’t act crazy, but when I’m alone what I do is my business.*

Lucy Kim, on the other hand, had a very balanced perspective: she could recognize the problems that her emotional difficulties created on the job, but felt that for the most part she had developed a series of strategies and supports that allowed her to work successfully nonetheless:

*Initially, I just couldn’t cope on the job. After dropping out of college I just moved around a lot, got into drugs, and took whatever sorts of jobs I could find to keep going: I was a waitress, did office work for a temporary agency, was a clerk in a couple of clothing stores – with none of the jobs lasting more than six months. I was pretty unstable, but I certainly didn’t see myself as having emotional problems, just being a*

*little flaky. And this went on for several years. But, to tell you the truth, this was the kind of life a lot of my friends were leading then.*

*I manage pretty well at the moment, though. I occasionally start to feel confused, but then I can usually get the medication raised and that helps. I have also gotten more adept at using my supervisor for support when I know I'm beginning to have problems, and since it is an agency where everyone is familiar with mental health issues, this works out pretty well for me. I was always sort of hiding this secret before, and I'm much more comfortable now.*

*But I'm always afraid the illness will cycle back. I have big problems with concentration and organization of my work, and I think a lot of people with mental illness have the same issues. Sometimes I just don't want to go to work, in part because I still feel different from everyone else. And sometimes I just am so anxious or nervous that I can't sit still. I'm still always waiting for 'the big one' – the onset of some psychiatric problem that leads to job loss, where my judgement deteriorates and then I'm back on drugs or drinking, and then my friends abandon me, and then I'm homeless and crazy again. So you can see why taking a job is scary for a lot of people.*

There were two areas where interviewees felt the strongest connection between their emotional problems and their work performance: first, alcohol and substance abuse; and, second, a low tolerance for stress. Both Lucy Kim and GD talked at length about how their problems with drinking and drugging cost them jobs that they really liked: in several instances lunchtime drinking led to pronounced 'attitude' problems back on the job in the afternoon, but inevitably led as well to the more serious problems of being unable to get up in the morning or simply neglecting to come back to the office after lunchtime. Joe Demaro recognized his substance abuse problems as directly related to failures in his career: "that's the whole history of 23 years of addiction. That's why I know why I couldn't maintain jobs, and still can't. I know how I was."

Indeed, over a third of the interviewees identified themselves as substance abusers. A few people discovered the seriousness of their substance abuse while in the military:

*At one point I was living with one sister and decided to join the Navy and make it a career, planning to retire in my 40s. What I didn't realize was how my addiction was already in full swing, so to speak. I made boot camp, had two weeks of apprenticeships and school, and I was busted for smoking reefers. I was discharged after two years, the discharge papers say, because my alcoholism 'was a burden to command.'" (GD)*

*My problems really started over in Germany with the Army, because I started drinking most weekends, and things sort of went downhill from there, and in the end I got a dishonorable discharge from the service, which was too bad because I really liked my job as a prep cook. (Cindy Emerald)*

Aussie Humphrey lost several jobs because she got involved in drinking, and Paul Lapira, who was "using drugs, mainly marijuana, and drinking lots of coffee and staying up throughout the

night all the time” was confronted by his boss, denied having a problem, but then thought that Howard Stern, on the radio, was talking directly about him and broke down. Jose Perez lost his job with the electrical company for the same reason: “I didn’t like my job, but the alcohol and drug abuse at that time magnified or augmented the underlying problems.” One interviewee, who as a teenager had begun dealing drugs on the street and living very well with the profits, had been in and out of drug treatment programs since he began using drugs at the age of 12, and became a serious cocaine addict at 17.

One of the most frequent explanations people offered with regard to the way in which their mental illness impacted on their careers, however, was the low tolerance for stress that many interviewees believed was a characteristic of their illness. Ron Berman finds that the Lithium he takes controls his mania but that the ‘depressions are pretty debilitating’ and leave him without the capacity to cope with pressure. VIDS thinks of work as “inward stress every day, every hour, on every job. There are demands on a job you have to perform, and if you don’t perform, they get rid of you.” JG believes “more emphasis has to be placed on helping people to deal with stress more productively, so that they can work.”

Stress, however, is notoriously difficult to define and more difficult still to measure: nonetheless, many of the interviewees believed that the fundamental characteristics of most decent jobs – full-time work, the demand to show up every day, week in and week out, the pressure to perform consistently, and the presence of so many other people to contend with – all represented very real challenges to their emotional stability. There was little sense that these could be the kinds of stressors that ‘reasonable accommodations’ under the ADA or strong support from a vocational program could help people to cope with more successfully, and there was little faith, in any case, that such accommodations or supports were likely to be available in the workplace. Many interviewees knew that they could *get* a job and that they initially could perform reasonably well on the job, but they were concerned that a long-term commitment to the marketplace could not be sustained because of the stresses implied by this commitment. Indeed, many clients had had the experience of leaving jobs in the past when they felt that the stress of the position – of performance demands, of interpersonal relationships, of balancing the demands of one’s private life with the demands of the workplace – had become insupportable.

## **Leaving the Job**

To better understand the career patterns of people with serious mental illness, then, it becomes important to look more closely at the reasons that people leave the jobs they have. The initial outlines of the ‘careers’ of these people – a series of entry-level positions that they hold for varying periods of time – only provides a partial portrait. This study sought more information on the reasons people gave for ‘job leavings’ – whether voluntary or not – and the degree to which the patterns of ‘job leavings’ experienced by people with serious mental illness were or were not similar to patterns of job leavings among their non-disabled coworkers. Cook (1992) had already explored some of these questions in her examination of job leavings among youth with mental illness, in which she found that “it appears from these data that the labor force behavior of youth with psychiatric disabilities is somewhat like that of their non-disabled counterparts, at least as reported in the research literature.” However, the interviewees reported upon here are a

more mature middle-aged group: how did their patterns of job leavings compare to their non-disabled counterparts?

At the broadest level of analysis, there was tremendous variety in the reasons provided for job leavings, both across the sample as a whole and within individual cases. Almost everyone reported some mixture of layoffs, firings, precipitous quitings, and thoughtful resignations to seek better paying jobs or more education. Three broad patterns emerged among the 260 job leavings the interviewees discussed: a) job leavings unrelated to mental illness; b) job leavings directly related to mental illness; and c) job leavings that fell into a broad middle ground in which both the interviewee and the interviewer were unsure of the role of the individual's mental illness in the decisions that led to unemployment. No one pattern, however, overwhelmed the others.

*Job Leavings Unrelated to Mental Illness.* One major group of the job leavings appeared to have nothing at all to do with the mental illness of the individual: that is, neither symptomatic behavior on the part of the interviewee nor prejudice on the part of the employer or coworkers forced a job leaving. Some people left their jobs for the best of all reasons: they either found a better job or had decided to return to school. Ron Berman, Steve Counts, Aussie Humphrey and Lucy Kim all left full-time jobs at some point in their careers to go to jobs that offered more pay, better benefits, and an interesting change, and they were not unusual. MM was not alone in leaving her entry-level job to return to school, and one interviewee left her job after a year as a go-go dancer "to concentrate on getting my GED."

But other people were forced out of their jobs by economic circumstances: restaurants, car dealerships, publishers, printers and factories closed down; some people were out of work when Kmart moved out of town, a private school closed its doors, or a company moved out of the country; and the layoffs, downsizings and buyouts of the past twenty years of economic turbulence pushed more than a few of the interviewees into unemployment. Leo Bruckner lost his job when his fellow carnival workers had a dispute with the owners, and Ron Berman was out of work at the car dealership when GM went on strike.

Several people lost jobs due to accidents: Ron Berman lost an arm on the job, Keith Robinson left his favorite job when he was electrocuted working on wiring out on a building site, Steve Markind made a serious accounting mistake when he was a bank teller, and Dave Pezick stepped on a conveyor belt at the wrong time and was fired because of it. Joe Demaro left his job at a gas station after a series of robberies. Health issues, family crises, and social violence forced withdrawal from jobs in several cases: VIDS almost lost his arm in an accident, Armenta Taylor left one job to have her first child, Paul Lapira was too physically sick to show up on the first day of a job he had been looking forward to, and Keith Robinson left the military to return home after two of his brothers had been killed. More tragically, one of the interviewees had been raped in the parking lot outside her office one evening after work, and another had been sexually abused by the father of the family where she was working as a nanny. One woman had been hospitalized for depression following the break-up of her marriage, and found that the religious school where she taught felt both of these events made her somehow morally unfit to continue teaching once she had returned to her job; they subsequently asked her to resign.

None of these events had much to do with the emotional problems of the individual who was then unemployed, and it is important to remember that the reasons they lost their jobs are not different from the wide range of reasons one would hear from their non-disabled coworkers about their own ‘job leavings.’ In a still volatile economic era, it can be anticipated that layoffs and downsizings and closures will continue, and that accidents and health crises and incidents of violence will have the same impact on people with serious mental illness as on those without psychiatric disabilities. It is a warning, as well, to vocational rehabilitation programs to ensure that their programs are able to help people in these post-placement circumstances: Granger (1999) has made the point that rehabilitation programs have to be able not only to assist some people in finding jobs over the course of their careers, but also to provide people the skills they need to independently ‘pick themselves up and start all over again,’ as the Cole Porter song phrased it.

*Job Leavings Directly Caused by Mental Illness.* Just as frequently as they talked about job leavings unrelated to their mental illness, however, people talked about the jobs they lost specifically because of their symptomatic behaviors. As noted earlier, there was very little discussion on the part of the interviewees about how they resented employer intolerance of their disability-related behaviors, of how they might have continued had some kind of ‘reasonable accommodations’ been available to them at the time, or at what point they considered filing an employment discrimination case under the ADA to rectify matters. For the most part, people either withdrew from a job because they felt they were too ill to work (which often meant that they had been hospitalized), or were fired because they just stopped showing up on a regular basis and the employer – often after weeks or months of difficulties – finally had had enough.

Hospitalization was perhaps the most frequently cited single reason for job loss. Lou Deardon, VIDS, Cindy Emerald, MH, and Bernice Scarborough had all lost several jobs due to hospitalizations. For Gail Slick, hospitalizations were particularly disruptive:

*For the next five or six years after that first hospitalization it was always the same pattern: I’d work in the winter while living at home – and also drinking and drugging a lot – and then I’d get sick in the summer and have to be hospitalized. . . . By the time I was in my late twenties, I had been hospitalized maybe a dozen times.*

Job leavings due to hospitalization raised a number of interesting questions in the interviews. It was clear that most people quit following hospitalization, or were out of touch with the employer and lost the job by simply disappearing. Almost no one said that they had contacted their employer following hospitalization to say they were sick but would be ready to return to work as soon as they were released. Neither family members nor clinical personnel – in the hospital or in the interviewee’s community mental health center – nor vocational counselors took this step on their behalf either. There were several explanations for this: first, many interviewees felt that the return of such serious symptoms confirmed earlier concerns that they couldn’t really expect to work; second, other interviewees assumed that their treatment, whether in the hospital or in community settings, would be too extensive to permit a return to the job; and, third, most were simply too embarrassed to return to the work site, where they would feel compelled to explain what had happened to them.

Much the same was true for people whose job leavings were precipitated by substance abuse problems. Jose Perez felt he had been dismissed because of his ‘bad attitude’ at work, due to his drinking, even though they called it a layoff. GD had worked at a series of secretarial positions over the years, but they frequently ended badly too:

*Basically, I lost a lot of these jobs because of my bad attitude, and I know it had to do with my drinking at the time. I had, like, an ‘I don’t care’ attitude and was very defensive. If I was corrected for something, I took it like this person was trying to hurt me and I was always making excuses for the things I would do which were wrong. . . . . I had problems with supervisors on some jobs, and in other jobs I was just bored: I hated sitting all day filing papers, and used to throw them in the garbage. . . . I was just so bored, and I found myself going to lunch, drinking, and coming back and being nasty to coworkers.*

Sarkis Tashjian’s substance abuse problems were of another type: he had difficulty getting to the job:

*Sometimes I worked 50-plus hours a week, but sometimes I was struggling to get to work on time, or at all. I often missed three days in a row, but I was such a good employee while I was there that they kind of persevered with me for a long time. I was there about a year and a half. They’d call me at home and my mother used to cover for me, back in the beginning. It was bad. They finally let me go, because I basically forced them to. They had said they’d give me one more chance, but then I didn’t show up and they had to fire me.*

Indeed, almost everyone had at least one story in which their failure to show up for work – to be consistently late, to disappear for one day or several days, to stretch out breaks or be noticeably late returning from lunch, or to leave earlier and earlier each day – was the major problem. In some instances, as noted above, this was due to psychiatric hospitalization or substance abuse, but more often it was a result, as the interviewees understood it, of their symptoms. Several people spoke of the paralyzing depression that overwhelmed them before they had even gotten out of bed in the morning, while others talked about the manic episodes that found them on an outing with friends or across town on some seemingly critical errand, or in another state heading for the beach or the casinos or the girls, before they realized they were due at work, or that they had the only keys to the building, or that this had been their last chance. It was not uncommon for employers to put up with this type of behavior for a while, and then lose their patience.

Other symptoms played a role as well. Ron Berman was driving the company truck one day when he became convinced that ‘the Secret Service was following me, and I took the van and parked on the interstate and I was thinking I should jump in front of a truck. I was gone for four hours and when I got back they fired me.’ It was not uncommon for interviewees to come to believe that everyone in the office was talking about them and plotting to make life difficult for them. And others were well aware that their social inhibitions led to tensions for them that resulted in a decision to quit. Quite a few felt that some of the less bearable symptoms of mental illness – visual and auditory hallucinations, anxiety attacks and obsessive-compulsive behaviors – distracted them from work and led to firings due to ‘failure to perform’ prescribed tasks.

A fourth recurring theme was the degree to which an intolerance for stress was the decisive factor in the interviewees' decision to quit. Many interviewees felt that an inability to manage normal levels of work stress was an inherent part of their disability, and indeed several felt that their eligibility for Social Security SSI and/or SSDI payments was based on their low tolerance for stressful situations. Aussie Humphrey told a story that was repeated often by others:

*The psychosocial agency had gotten me a variety of transitional employment jobs – at a factory, filling balloons at a toy store, and as a dishwasher at the university dining hall, for six months each. After a while I got my own job waiting and bussing tables at a restaurant on weekends, but left after a few weeks there too because I got a full-time job at a restaurant down the street. But I left there after three weeks because I just couldn't handle either the physical demands of that much work or the stress of that much work.*

Kacey Mendez found it stressful to work at McDonald's: "I ended up leaving because the people got to me and I was not following directions too well. I get fatigued a lot when I work full time: I kind of get burned out, stressed out, and everything." Jack Motta left in the middle of the evening when the restaurant owner for whom he worked "gave me all these chores to do, cleaning up and everything, and putting everything outside, and I just kind of called my dad and said I've had enough stress here." Dave Pezick left a part-time job when they wanted him to switch to full-time: "I just couldn't handle it." Such job leavings were also particularly damaging to the future vocational ambitions of the interviewees: stress-related quitings served to reinforce more than anything else the notion that they were simply not able to work.

*The Middle Ground.* Between those job leavings that had nothing to do with the individual's mental illness and those that were directly a result of debilitating symptoms or stress intolerance was a broad middle ground in which it was difficult for both interviewee and interviewer to assess the role that mental illness had played. In the great majority of these cases the interviewee had quit, but in an economic age in which "take this job and shove it" has become a national anthem and the abundance of jobs encourages rapid job mobility, it is difficult to assess the degree to which these types of job leavings are symptomatic. Indeed, many of the reasons offered for leaving a job were familiar to those given by others in the broader society who work in the secondary labor market.

Several people left their jobs because "it was too damn cold that winter to work outside" or because they had difficulty finding transportation to the job, and several other people were fired because they were found sleeping through the night shift or argued repeatedly with coworkers. A few people had gotten into either verbal or physical fights with their supervisors:

*I went to work for the Philadelphia Stock Exchange for several years, when I examined the books and records of brokerage houses all over the country. . . . It just got to a point, from the first day, when I was rubbing my boss the wrong way and he rubbed me the wrong way, and after a couple of years we just agreed to part. (Steve Markind)*

*For four years I had a job at Denny's, where I started on the day shift and then did night shift work, mostly cleaning up, and I worked there pretty much full time, with good*

*benefits, and it was working out pretty well. I had a number of bosses over that time, but after a while I had one supervisor I didn't get along with at all, and I wound up having a fist fight with him about the length of a break I was on, and I was fired. That was very upsetting, but I immediately found another dishwasher job, full-time, and got along really well with everyone there. I had that job for seven years, until I got into another argument with my supervisor, and was going to quit, but they fired me first. (DW)*

Others were told by their supervisors that they were just too slow-moving or too slow-thinking to be worth their salary. The interviewees, for their part, didn't dispute these negative estimations of their work, but neither did they feel that the issues raised by such job leavings were fundamentally based in their mental illness.

A few people lost jobs because of their dishonesty in handling money: they borrowed cash from the till that they intended to pay back; they took someone else's tips off a table; they didn't pay back a short-term loan; they stole lottery tickets; they spent themselves into bankruptcy without telling their partner in a small business; etc. These are not particularly unusual stories in today's world, it should be noted, nor are they at all uncommon among people living on the very limited incomes most of the interviewees reported; it is far from clear, however, that such actions (as well as other on-the-job lapses of judgment) were based in the individual's mental illness.

Similarly, the interviews were full of stories about people who quit their jobs – after a few days but more commonly after a few months or year or two – because they were bored. Some who found their jobs boring were like the college-educated and intellectually-oriented John Meyer who left an entry-level routine job because “it was extremely boring: there was nothing to do, and they wouldn't let you wander around, and they didn't like you to leave your desk.” But there were also those like high-school graduate Cindy Emerald, who had worked as a cook for a while, but then left a later job as a telephone operator “after three months because it was really boring.” None of the interviewees thought that leaving what they thought of as boring jobs – as store clerks or salespeople or lawn mowers or factory workers or restaurant staff – was symptomatic of their underlying psychiatric illness. The question remains, however, whether a repeated pattern of leaving boring jobs does suggest some underlying incapacity to cope, or whether many people without psychiatric disabilities would respond in much the same way.

And it is similarly hard to know how to evaluate the repeated instances in which interviewees left their jobs because they felt the pay was too low. It was not just those whose educations or experiences might ordinarily have given them access to better paying jobs. Joe Demaro and Paul Lapira, whose qualifications were relatively limited, were not alone in deciding to leave the maintenance jobs where they were making \$5 or \$6 an hour, part-time, without any real benefits. Myria Manfred had had similar experiences:

*I worked in a grocery store, I worked in a restaurant, and I worked in a hotel, and I was paid like \$3 an hour, and after a while I quit because it just wasn't worth it. . . . I worked a whole winter at a supermarket for almost nothing. I was desperate when I quit. I'd rather walk the streets for days than work for \$3 an hour doing cleaning jobs.*

The wide variety of reasons given for job leavings in this broad ‘middle ground’ – the inconvenience of some jobs, the conflicts with coworkers and supervisors that made the work site an uncomfortable setting, the boring nature of most entry-level jobs, and the low pay that is offered – raise the question of whether those in the mental health and vocational rehabilitation community have gone too far in ‘pathologizing’ job leaving behaviors that are in fact rather reasonable and rather like those of the non-disabled workforce in similar types of jobs.

## **Being Out of Work**

The final aspect of the job experience that needs to be explored here is the ‘out of work’ experience of the interviewees, which is the subtext for their decisions (when it was their decision) to leave jobs. Almost everyone in the sample had been unemployed for significant periods of time during their working lives, and this is as important a part of understanding the career patterns of people with serious mental illness as any other.

Several themes emerged slowly in the interviews. First, hospitalizations often resulted in the longest periods of unemployment. Whether it was the seriousness of the symptoms that led to hospitalization that made it difficult for people to quickly re-engage in the labor market after discharge (and, indeed, many clinicians are especially wary of a return to work in the immediate post-hospital months) or the way in which hospitalization seems to confirm for the mental health consumer, family members, clinicians and case workers alike that work may be too challenging to reconsider, many people withdrew from the marketplace for months and frequently for years following a significant (longer-term) hospitalization. This tended to be less true in the early years of an individual’s struggle with mental illness, when they were more likely to want to leave the psychiatric experience behind them and rapidly demonstrate that they were fully ready to participate in the mainstream of community life, but it was more typically the case in later years.

Second, the growing recognition on the part of the interviewees that theirs was likely to be a continuing disability, to one degree or another, seemed to result in a search for an acceptable but alternative lifestyle. Many people continued to live at home with their parents, in part for emotional support, but in part as well for the financial support they could expect if they were not going to be working. Families were often caught in a bind: realizing the psychiatric problems of their children, they wanted to offer all the support they could, but they were also frequently reported to be the only voice in the client’s life suggesting work. Immediately after his first hospitalization, Steve Counts found himself having “trouble getting a job. I laid around the house for a while, and then my father gave me an ultimatum to get out and find a job;” however, Steve was so paranoid that he “couldn’t even go out to get food, couldn’t go out to do anything,” until he reached a community mental health program and asked for help. After JG’s business of 25 years had collapsed, “I couldn’t find any other similar job, lived off of my savings for about two years until they were all gone, and then was really nervous all the time about money.”

Quite a number of people have wandered in and out of human service systems without really re-engaging in the labor market, and homelessness was not at all uncommon among this group. A number of women followed boyfriends from community to community, while many men found shelters an acceptable alternative between jobs. Lots of people supplemented their Social

Security payments with short-term entry-level part-time jobs, but others withdrew from work entirely. For most of the interviewees, contact with a psychosocial rehabilitation program, or, indeed, any kind of comprehensive community based mental health and rehabilitation service system, came rather late in the course of their struggle with mental illness, but people were in and out of psychosocial programs – and in and out of the Transitional and Supported Employment jobs they offered – with the same casualness with which they approached the general competitive labor market.

Others found solace in private projects. Myria Manfred devoted a number of years to writing:

*Well, I wrote this 400 page book about my life, and I don't know if it was my doctor who asked me to do it, or whether I just started out writing, and I put out 400 pages and I gave it to him as a manuscript. I don't know whether he read it or not.*

John Meyer appeared to find solace in reading, widely, and spending many hours in the years when he wasn't working at the library. RB dreams of an opportunity to develop his energy-system plans, and has done a good deal of research in that direction. But many of the interviewees simply do not know where the time went when they weren't working. They were not overly engaged in clinical treatment, nor actively volunteering in community life, nor playing homemaker roles within their families. They were out of work – for months and years at a time – with no real alternative engagement, and the longer they were out of work the more they feared that they would never be able to work again.

Finally, one of the major inducements to long-term unemployment appeared to be the availability of financial support and medical assistance from the Social Security Administration, to be discussed in greater detail in the next chapter of this report. It did seem that the repeated efforts of the interviewees to re-enter the labor market slowed considerably when they at last began receiving SSI and/or SSDI checks. Many had struggled with mental illness along with the demand to earn a living – or part of a living, if they had family members to assist them – for much of their early years of psychiatric difficulties. The reluctant acceptance of financial dependence upon social transfer payments, however, seemed indistinctly to make their periods of unemployment less problematic and their efforts to rejoin the labor force less vigorous.

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These career patterns, then, must be understood within the context of the types of jobs most interviewees had been able to obtain in the past: entry-level unskilled or semi-skilled positions, sometimes on a full-time basis but more often on a part-time schedule, with low pay and meager benefits. Within that context, these people with serious mental illness may have been working, with regard to both productivity and interpersonal relations, at or near the level of their non-disabled coworkers. Indeed, most interviewees reported that their emotional problems did not have a significant impact on their on-the-job behaviors, although their symptoms may have kept them away from the job to a degree that forced either quitting or firing.

We can turn to some of the other literature in the field to assess the validity of several aspects of the above assertion. Cook (1992) found roughly similar patterns of job performance, job tenure,

and reasons for job leavings among both youth and adults with serious psychiatric disabilities, and Botterbush (1999) found similar results among adults with psychiatric disabilities who were working in white collar roles, with even fewer job leavings attributed to psychiatric disability than in this study. Newman (1999) reports on the reasons inner-city residents on welfare report for leaving their jobs, and their reasons provide a strong parallel to the reasons provided here. It is commonplace for employers to report difficulty in holding onto entry-level workers: in one study (Kruger, 1991), estimates for the annual turnover rates in the fast food industry hovered around 300%, and many major employers are finding it necessary to moderate the demands they make on entry-level workers in order to hold onto to the ones who are most productive (Kiernan, 1999). The proliferation of employer-sponsored Employee Assistance Programs over the past twenty years is largely attributed to the explosion of drug related problems among employees as well as increases in emotional problems that impact on employee tenure.

One of the minor themes that emerged from the interviews, in fact, was how forgiving many employers turned out to be. It was not uncommon for people to note that they had repeated difficulty getting to work on time or controlling their negative attitudes toward coworkers, but that they were able to hold onto the job for one or two or three years anyway. It is comforting to think that employers recognized the emotional problems of these individuals and – without formally making ‘job accommodations’ under the ADA – cut them some slack, but it may be more likely that their on-the-job behaviors may not have been worse, or that much worse, than the performance of their non-disabled, or non-labeled, coworkers, and employers were overlooking everyone’s idiosyncracies just to make sure enough people showed up to work each morning.

However, two aspects of the career patterns described here provide some grounds for a more worrisome interpretation. First, there were substantial periods of unemployment in almost every interviewee’s history, with some of it due to extended periods of hospitalization and some of it due to either an inability or unwillingness to seek work while living in the community. This is a significant factor distinguishing this population from their non-disabled coworkers. Sometimes these interviewees moved to new jobs after leaving another one, but more often they took their time – often considerable time – regrouping and returning to the workplace, which is less true for non-disabled workers. Although these gaps in employment history did not appear to have a significantly negative impact on their ability to find new jobs, when they did go looking for them, in the entry-level labor market, they did create a substantially different career pattern for this population, one of repeatedly entering and leaving the labor market.

Second, what emerges most clearly from this data is that these interviewees made little or no *progress* in their careers: there is no evidence that over time this group moved to positions of greater responsibility or challenge; wage rates and benefit offerings are as low, relative to prevailing wage rates, at the point of the interviews as they were at the beginnings of their working careers ten or twenty or thirty years earlier; tenure on the job did not increase, in part because there seemed no clear improvement in people’s ability to manage the stresses of the work site; and there was little development, it seemed, in the formation of a clear work identity or a sense of the ‘arc’ of their careers.

Szymanski and Hershenson (1998), in their review of general career development theory and its relevance to people with disabilities, talk about the ‘arc’ of one’s working career, and that there is for many people a change over time – a dynamic in the process – as they develop their capacities. Super (1990) talks about a ‘life-career rainbow,’ with changes in one’s life parallel to changes in one’s career, with ‘exploration’ (from ages 15 to 24), ‘establishment’ (from ages 25 to 44), and ‘maintenance’ (from ages 44 to 65) the predominant model – bounded on one side by ‘development’ in childhood and on the other side by ‘decline’ in the retirement years. For the people studied here, however, such a maturational dynamic does not appear to be in play.

It is important to ask, however, whether this established career arc is universally applicable, and indeed there is some growing evidence (Pigeon, 1999) that for people on the lower end of the economic ladder such an arc may not be a common experience. One of the most profound impressions left by Studs Terkel’s *Working*, written nearly thirty years ago, was the number of people in traditionally working class unskilled and semi-skilled jobs who felt left behind by the general economy: waitresses who had held essentially the same job for thirty years, truck drivers with no greater responsibility at the end of their working lives than at the beginning, porters and maintenance men, welders and brick layers who were doing pretty much the same thing for their entire careers, and making very little economic headway in the process. A generation later, Newman is hearing the same thing from the inner-city residents whom she interviews, who work hard at the fast food jobs that were the focus of her study, but can only occasionally capture one of the few full-time jobs and are almost never able to move forward into the ranks of managers.

Similarly, the individuals interviewed here appear to be perpetually ‘starting over’ in their careers, making little progress over the years, with neither the labor market nor the rehabilitation community seemingly able to move them forward into more challenging jobs or more economically rewarding careers. A Boston University study of substantial numbers of people with serious mental illness in managerial roles throughout the economy provides initial evidence that this need not be the case for everyone (BU, 2000). Nonetheless, such career patterns may remain the norm for the majority of persons with serious mental illness today. Even the people interviewed in this study who were working in very responsible positions within the consumer empowerment and consumer self-help movements (e.g., Manfred, Slick, Perez, Berman) were mostly doing so on a part-time or volunteer basis, with little sense of where to go from there. Botterbush’s study of the Minnesota Mainstream program and its work helping people with serious mental illness re-enter the white collar fields that serious mental illness had forced them to leave behind reported what must be seen as very disappointing earnings data. We have made remarkably little progress in helping people move toward the economic mainstream of the country. We need a much greater understanding of why this is so, and whether this is an immutable fact – generated by the way that disability interacts with the labor market – or one that individuals and rehabilitation providers and policies can impact upon.

But, certainly, no understanding of this can move forward without taking into account the way in which Social Security benefits shape the vocational, economic, and medical lives of these interviewees, for no factor is more often cited as the basis for unemployment than the way in which the Social Security Administration’s SSI and SSDI regulations are seen to serve as a disincentive to employment.

## VII. THE IMPACT OF SOCIAL SECURITY BENEFITS

*Lucy Kim is thirty-six, Asian-American, born and raised on the West Coast, currently living in a supportive housing program in New York City, where she is also working full-time as an Administrative Assistant at a competitive salary with benefits. Asked about her attitudes toward work, Lucy begins talking about SSDI and the fact that she is no longer receiving a check and “it is really scary to move off of SSDI, since I feel as if I’m spending my very last poker chips.” After high school, Lucy dropped out of college and worked at a variety of short-term jobs – waitress, temporary secretary, saleswoman – until she wound up in a drug treatment program and on SSDI for the first time. The program put her to work within the agency, and then Lucy got herself a job as a ‘media assistant’ at an ad agency, full-time, where she did well (and left SSDI) until moving to another full-time job with another ad agency. When she transferred from the LA to the San Francisco office she didn’t like the people or the work, began to drink heavily again, and was ultimately fired for non-performance. Homeless and in treatment, she reentered SSDI, then moved to New York, where she was soon on her own and homeless again. Referral to a shelter and a treatment program eventually led to a rehabilitation housing and employment program, where she began volunteering as a receptionist, then took a part-time job as an administrative assistant: although she now works full-time, she is “still very fearful that I’ll wind up back in a shelter.”*

*Jose Perez is a 40 year old Latino man who is currently working part-time as a Benefits Specialist for a New York City advocacy project, where he provides counseling and assistance to people with disabilities with regard to the work incentive provisions of the Social Security Administration’s SSI and SSDI programs. Jose’s major emphasis with those he counsels is on ‘the false impression of fear’ that most people have about the SSA programs, “when in fact most people can find a way to work without losing their most critical benefits.” Jose’s work career began when he dropped out of high school to take a well-paid job as a maintenance man and locksmith, which he held for four years but lost due to substance abuse problems. He quickly found another very similar job and held that for five years, but was fired for the same reasons. In and out of hospitals for his substance abuse and mental health problems for a while, he later landed a job with the electric company in New York City, where he worked for another four or five years before his abuse problems led to another firing. His most serious problems on the job, however, came after his father died: after trying various entry-level jobs Jose wound up on SSDI four years ago. In the last two years, Jose has been working as a Peer Specialist and going to school to study both computer information and paralegal work on behalf of people with disabilities.*

### **Establishing Eligibility for SSA Benefits**

Of the 2.4 million people estimated to have a serious mental illness by the National Institute on Mental Health, about half – 1,154,754 – receive SSI or SSDI benefits (Kennedy and Manderscheid, 1992), yet almost all of these interviewees had received SSI and/or SSDI support in the past, and all but a few were still currently on the SSA roles. This is partially due to the

fact that the interviewees were drawn from within the community of those receiving public mental health treatment and rehabilitation benefits of various kinds, and so it was far more unlikely that they would be financially comfortable enough to escape SSA dependency. Within this community, however, SSA is ubiquitous.

There were two issues about establishing eligibility for SSA that emerged in the interviews. First, applying for eligibility was often a step taken both reluctantly and long after the first recognition of the severity of the disability. People did not receive a diagnosis of serious psychiatric impairment and immediately turn to the SSA system for financial support. Estroff (1997) makes the point that the factors that first lead to application for eligibility are a mix of ‘dysfunction, demoralization, and dependence,’ and it appears from the data collected in these interviews that people sought to function independently as long as they could, working when possible and/or relying upon family members when that was feasible. As noted earlier, if unemployment is the new marker of serious mental illness (replacing hospitalization), then entry onto the SSA roles is the clearest indicator that this is going to be a long-term issue. Lucy Kim captures a part of the way in which this happens:

*This is when I went on SSDI, which Synanon had arranged for me when I first came into the program. I didn't think I could do anything at the time. I was just totally defeated. So SSDI seemed like a good idea.*

Lucy's comment above captures the second major theme that emerged here: the decision to apply for SSA eligibility, while nominally that of the applicant himself or herself, is in fact more often that of others. Lucy applied for SSDI – or her application was ‘arranged for’ her – by the substance abuse program she entered, both in her own interests and, reasonably enough, to ensure that the program would be paid for its services. Shelter programs often assisted homeless individuals to apply, parents were often quite rigorous – once their hopes for ‘cure’ had faded and their finances were running thin – about making sure that the application process proceeded forward, and clinicians and rehabilitation counselors of all kinds were cited by the interviewees as the ones who took the initiative in applying for support. For GS:

*Once I got into the hospital they got me on welfare before I left so that I wouldn't have to go back to work right away, and then welfare got me to get onto SSI on account of my mental illness. But even then I went out and got another factory job part-time.*

Estroff's analysis of SSA entry (1992) captures this reluctant entry into the system as well. Her study explored intensively the process and reasons for application, and found that the process of “dysfunction, demoralization and dependence” not only took some time but required the participation of others:

Most study participants became involved in the disability income application process reluctantly, after repeated efforts to work and support themselves by other means, and with the substantial involvement of their families and mental health professionals. Seldom, if ever, were these decisions made primarily by the study participants alone, and equally rarely were the respondents the sole beneficiaries of receipt. We view the process as entangled with and reflective of the needs of service providers and members of

the respondents' social network, and in relation to the limited opportunities available to them.

### **Living with an SSA Dependency**

There was more than a little ambivalence in the interviewees' discussion of what it was like to be the recipient of an SSI and/or SSDI check. Most people were grateful for the check, for they relied upon it for their basic needs:

*I've had epilepsy and schizophrenia all my life, and I don't seem to be able to hold a job for very long, so the check comes through pretty regularly. At this point, I don't really think I can work more than four hours a day, so the check is pretty important to me, and was particularly important when I was raising my two younger sons. (Claudia Thomas-Frazier)*

*I'm only 31, but I don't really plan to work anymore in the 'real world' because even though the SSA check isn't much, it keeps you off the street in an apartment with enough food to eat. (Aussie Humphrey)*

Mark Davis, who was working, was aware that the only alternative for him in the past to make sure he got the counseling and medications he needed was the medical support that came with SSA eligibility, and he was aware that leaving or losing his current job, with its relatively reasonable medical benefits, might create a crisis for him. Ron Berman, who felt that his problems with stress would easily overwhelm him if he worked, appreciated SSA support and the opportunity it gave him to volunteer a major portion of his time to the consumer self-help movement. And all of those who were interviewed who were working part-time felt that they were thankful that their meager part-time earnings were supplemented by the SSI or the SSDI check and the access to comprehensive physical and mental health care that it provided.

There was, at the same time, some marked hostility toward this dependence, and toward the impoverishment it implied. Steve Markind very much wanted to leave SSA behind because he felt the whole system 'demeaned' him, and MM spoke a little contemptuously of the 'paltry amount of money that SSDI provides' as hardly the major factor that kept her from working. For Lucy Kim, entry onto the SSDI roles was a bit disturbing:

*I just want to say one thing about SSDI: being on SSDI was my first real experience of not having much of an 'id' or an identity beyond that of someone who was so sick she needed to depend entirely on SSDI for support.*

Sarkis Tashjian thought that most people viewed their dependency in a much more cavalier fashion:

*I see the problems with 'the check' to lie with the psychiatrists who tell people 'you know what, you qualify for SSI and you're severe enough that you need it,' so I think many people get complacent about it. That's what I see in people who want to go for this, and*

*they're all gung ho because they get that first big check and they don't need to work anymore, and they actually laugh about it. There's nothing to laugh about when you get \$500 a month: that's not much, and some people think it's some kind of gravy train. That's nothing. I don't know how anybody could live on that. It's sad. It's pathetic.*

Mark Davis echoed the frustration with the SSA system in discussing a now long-standing dispute between himself and SSA: he reported that SSA wanted him to return over \$26,000 in back payments that they said they should not have sent him in the first place, a story which was echoed, in less financially dramatic form, by several of the interviewees. For most people, then, SSA dependency was not an ego-enhancing aspect of their lives, but it was in many instances all they had by way of security. GS, whose entry onto the SSA roles had been managed by the welfare system, ultimately managed to leave SSI for a while, but “it felt like I was throwing away a crutch.” Such attitudes are worlds away from the attitudes of entitlement that most older Americans have about the Social Security retirement checks they feel they have earned.

## **Leaving SSA**

While a few of the interviewees did feel that they would be dependent upon SSA for the rest of their lives, most people hoped to be able to establish their financial independence at some point – usually a rather vague point – in the future. There was no question, however, that the prospect of leaving SSA's roles for self-reliance was the source of tremendous anxiety, one that almost everyone said had to be done with careful planning and lots of financial and programmatic assurances before it would be possible.

Those who did not believe it would ever be possible to end their dependency on the SSA check spoke about their prospects with a kind of hard-nosed realism that seemed to mask a basic sense of hopelessness. Mike O'Donnell, who struggled with both mental illness and blindness to hold a number of entry-level restaurant worker jobs, had little hope of independence: “Well, because of my disabilities I'll be receiving SSA for the rest of my life . . . unless things were to drastically change and I became very rich, which I don't foresee happening.” DW, with a degree in Political Science and a wandering career in part-time unskilled jobs that supplemented his check, was perhaps the most cynical about his prospects:

*Well, I might be an errand boy, but I really don't know what kind of work will be next. I think I like small-time, low-stress and part-time work, something temporary like in a restaurant. I don't really want a regular job, full-time, because even in a restaurant they require you to have speed, and I can't do that. Also, I want to stay part-time because I don't want to lose my SSDI. You know, I was hospitalized in 1993, for a long time, and it really frightened me about what would happen if I was off SSDI and needed this kind of care. I wondered whether work was really for me, and although the answer to that question is 'yes,' it is probably part-time work that I need. I've accepted the economic level that I'm going to be living at. I do some bartering, and I ask myself every time I want to buy something whether I really need it. I have difficulty managing the stress of jobs, so I think the next 20 years will be made up of SSDI checks and part-time work.*

Others articulated a greater hope for their departure from the SSA rolls, but on a very conditional basis. They wanted to establish their financial independence only *if*: *if* they could be assured of medical benefits; *if* they could be guaranteed a quick re-entry to the rolls when they lost their job and couldn't find another; *if* they were earning enough in their jobs to make it really worth their while; *if* they knew they wouldn't get terribly sick again, and so forth. While RB felt that "I wouldn't need (SSA) if I had a full time job," and Lucy Kim believed that "getting a full-time job is a little like gambling: you risk losing some of your benefits, its true, but if you win, the payoff is big," most people were far more cautious.

Indeed, most interviewees not only believed they had a long-term disability that would require continuing treatment, but that they were quite likely to be very sick again somewhere down the line, sick enough to lose their jobs, as they had in the past. Sarkis Tashjian felt as though he was in a 'Catch 22' in which if he worked he would lose the services that made it possible for him to work in the first place. VIDS expressed the fears of many when he said that:

*If I got a job they (SSA) would cut me off, and if I got sick again in a year or two, I don't know if I'd ever be able to get it (SSA) back, and that's the main reason that I don't even try full-time work. I've been working part-time for years.*

Cindy Emerald felt exactly the same way:

*While I wasn't sure I wanted to be on SSDI, once I got it, I didn't want to take the risk of losing it by working full-time, particularly if I thought that I'd get sick again. Which was just as well, because in the end I did get depressed and suicidal and had to quit the job. Now I'm pretty determined that I'm going to need to stay on SSDI for the rest of my life, particularly to make sure I can pay my medical bills, and so I am going to work only part-time.*

The loss of medical benefits was the most frightening of prospects for the interviewees, and this had a significant impact on the types of jobs – and the rates of pay – that most people thought would make it possible for them to leave the SSA rolls comfortably. Cheri Clodi wouldn't worry about losing her SSI benefits "if I could find a long-term job that paid me in the vicinity of \$30,000 a year." Aussie Humphrey took a very similar and pragmatic approach:

*To tell you the truth, getting the SSI check just about kills any motivation I have for staying on a job. At the same time, I do want to work. The PSR program here advises everyone to start slow with an easy entry-level part-time job, but I'd like to work full-time and get off of SSI, but that depends on being able to find a good paying job, but who's going to hire me for one of those if I don't have the education or experience?*

There were two patterns of thought among the interviewees with regard to their ongoing relationship to SSA: Joseph Ciupa expressed one of them when he noted that "I realized that if I earned much money on my own that would disqualify me from SSA, so I pretty much stayed away from work." Most of the others had accepted, at least in the short-term and until they felt they would not be likely to be so seriously ill again that they would lose their jobs and need SSA,

that they would continue carefully to work part-time, like Monica Zachoe, running a consumer drop-in center in Minnesota:

*My work is very important to me. I enjoy it, and, frankly, I wish I could afford to work full-time, but I can't, because my medication runs about \$500 a month. I've had to refuse two raises for that very reason . . . But the one thing about my work is, I work 32 or 33 hours over a two week period that I'm paid for, but probably volunteer 20 hours more over those same two weeks, so it's almost full time, even though I'm paid part-time.*

## **The Impact of SSA on Career Patterns**

Two closely related themes gradually emerged from the data. First, it became important to make a distinction, in assessing the past careers of these people with mental illness, to distinguish between 'failure' in the labor market and a 'failure' to move forward. In fact, many people with serious psychiatric disabilities were not failures on the job: their productivity and interpersonal relationships on the job seemed reasonably good enough, their tenure in unskilled and semi-skilled positions seemed not unlike those of their non-disabled coworkers, and their willingness to return to the competitive marketplace, albeit sometimes after months or years of unemployment, was commendable. As a group, however, they had failed to make *progress*, to increase the numbers of hours they worked, to diminish the length of no-work periods between jobs, to move toward supervisory or management positions, to earn more, and to become less dependent on social transfer payments for their basic financial and medical needs.

Second, a fair measure of that failure to move forward, if we listen to the voices in this report, is the way in which 'the check' impacts on their sense of themselves, their role in the competitive labor market, and their best interests. The Social Security system may not be such a significant disincentive to work, but it is a powerful disincentive to career advancement. That is, many of those interviewed had worked – extensively and successfully – in the past and planned to do so in the future, but on a part-time basis that would not threaten their benefits. Many balked, however, when the prospect of genuine economic independence reared its head. Although quite a few knew they could work full-time, they were not sure for how long, and whether the medical benefits they rely upon now would be available to them in the future.

Equally as important, the interviewees returned frequently to the theme of their inability to find and hold a job that would hoist them beyond the economic exigencies of 'the working poor.' They were not sure, given their limited educational and experiential backgrounds, whether the competitive labor market had a job with a respectable salary and the extensive medical benefits they need. The success of a few mentoring programs, the ambitious programs of a still small number of consumer-run placement services, and the placement of a small corps of consumers into the mental health services delivery field was not enough to convince most of these consumers that they could find full-time work that would keep them safe from economic and medical disaster.

## VIII. LOOKING AHEAD

*DW is a 43-year-old White man who has been living on his own for the past 15 years. DW attended several colleges over three years, earning a BA in Sociology, but has never worked in the field. Although he had entry-level restaurant jobs throughout high school and college, DW didn't work for a year or two after getting his BA. The symptoms of his obsessive-compulsive disorder, which had begun in high school, prompted several hospitalizations and, once he did begin to work, made him an over-exacting employee in most jobs. After a referral to a local psychosocial rehabilitation program, DW began a series of Transitional Employment placements, and then began to get a few part-time jobs on his own. A job at Denny's lasted for several years, but ended with a fist fight with his supervisor. Another quickly attained job as a dishwasher elsewhere lasted seven years, but ended similarly. DW does not feel that his mental illness was a factor in these incidents: he was "doing good work and living on his own, but had abusive supervisors." Until two years ago DW had avoided applying for SSA support, getting by, if very modestly, on his part-time earnings and family support, but at the suggestion of a social worker he did finally apply and begin receiving SSDI checks. He returned recently to the psychosocial rehabilitation program, combining the Transitional Employment placements, which he doesn't like, with part-time jobs that he gets on his own – mowing lawns, cleaning up at a hair salon run by a friend, etc. He views his prospects soberly: "I really want to take it easy, working a schedule that doesn't put too much stress on me."*

*Sarkis Tashjian is a 34-year-old White man, born and raised in Philadelphia, with a long history of manic-depressive behaviors and drug and alcohol abuse problems. He was recently in treatment again, and living with his parents. Sarkis was a very bright and active teenager, doing well at school, managing a part-time (20 hour a week) job at a delicatessen in the neighborhood, and selling drugs on the side. In the year between his graduation from high school and entering college, he was making \$2,000 a week working full-time at a deli and dealing drugs. He left college because of a growing drug dependency, and began selling ladies' shoes at a local department store, but was fired after the store accused him of stealing. Sarkis found a partner and opened an auto detailing business, but the drug addictions of both partners led to disaster within a year, and Sarkis began selling cars for an auto dealership, a job he lost when his drug problems and manic behavior wore out the patience of his employer. In and out of mental health programs and drug treatment centers over the years, Sarkis says that no one ever spoke to him about his problems at work. Recently, Sarkis has entered another drug treatment program, and feels that – now that he is a born again Christian – he is turning his life around. He is sober, on welfare (for the first time in his life), and planning to go to college for a degree in Environmental Science and Engineering so that he can work on environmental issues in the future.*

### **The Vocational Future**

This study sought interviewees' assessments of 'future employment prospects' through two means: for a general sense of the employment potential of people with serious mental illness, interviewees were asked how they saw the future for the other people with serious mental illness they had met in their journeys through their community mental health clinics, day hospital

programs, psychosocial rehabilitation agencies, and vocational training programs; for a more specific assessment of their own future, each interviewee was asked to imagine the next five or ten years for themselves.

In reviewing the data on interviewees' assessments of the career prospects of *other* people with serious mental illness, one cannot help but be struck by the gentleness and compassion of their responses. To be sure, there were repeated references to the fact that a lot of people are just too 'lazy' and 'complacent' to find jobs on their own or to cooperate with the vocational placement personnel available to them, but even this laziness was viewed more regretfully than angrily: what, many of the interviewees seemed to be saying, could people be thinking if they weren't at least minimally interested in some kind of a job?

For the most part, however, people readily understood the motivations of those who were reluctant to work, perhaps projecting their own ambivalent attitudes toward employment. They saw people avoiding the labor market for a wide range of now familiar reasons: fear of losing their eligibility for SSA support; anxiety about whether they could actually hold down a job without getting very sick again; the work incapacities that are inherent in the symptoms of illness itself or the lethargy induced by the medications taken to treat the illness; or the persistent discouragement of work that they had experienced. Lucy Kim captured a part of the problem:

*Well, there is this culture of unemployment, this 'culture of the patient,' that is pretty discouraging for people. . . . Once your spirit is broken, you accept a different level of existence. People are just too scared to get out there. It makes me angry that they won't try, that they don't want to try, because it's not an issue of functionality, it's an issue of fear.*

Cheri Clodi captured another issue, one that several other people mentioned, in talking about how difficult it is for people with serious mental illness to find the right kind of job, where they felt they could work within a supportive environment:

*First of all, there is a lot of fear of the world outside a mental health program, and a lot of people are looking for jobs in 'safe places,' where they will feel at home and not be made fun of or taken advantage of. We all know it's not quite right to 'live off the system' the way we do, but most people are so concerned about their day-to-day living, getting by on their check and getting the medications and treatments they need to keep going, that the idea of going out and getting a job and managing for themselves is very scary.*

However, there was a clear sense among the interviewees that the people with mental illness they had known *should, could, and would* work if the right kind of opportunity presented itself. GS noted not only that she likes to work, but also that:

*Most people here are thrilled to get a Transitional Employment Placement and have a chance, even though many of them have hygiene problems or really odd personalities. Most people say they just can't sit around and look at the wall: I did that for a year, and it was all I could take, so I got a job. You should see people around here when they learn they've gotten hired for a job: they're so excited. Partly it's because society says you*

*have to work, but partly it's because they are so bored without some daily structure in their lives.*

What then did the interviewees see for themselves? What future careers awaited them? Being asked this rather difficult question – at once mundane and profound – left most of the interviewees momentarily with little to say, as though a focus on a ‘career’ with a long-term future, rather than a more straightforward focus only on the next placement, was something that had not been broached with them before. While one might expect such a response from any sample of younger people, who are after all in the ‘exploration’ phase of their lives, it was a startling void for people in their middle years, and it was the only point in most interviews at which interviewees were noticeably uncomfortable. A few people, of course, had thought seriously ahead and were quick to sketch out their plans – for either long-term dependency or self-sufficiency – but most were ‘living in the present’ to such a degree that their more *distant* futures were fairly obscure. As they began to respond, however, three different projections of career patterns began to emerge: first, a permanent withdrawal from the labor market; second, a long-term combination of SSA support and part-time work; and, third, genuine financial independence in the labor market.

### **A Permanent Withdrawal from the Labor Market**

One clear theme that emerged from these interviews was the lure of never working again, particularly for those who thought their re-entry into the labor market, in any form, was extremely unwise or unlikely. Several interviewees clearly had no desire to work: frightened of losing SSA eligibility if they worked at all, concerned that work stress would exacerbate symptoms, or simply feeling comfortable with the economic and activity levels they had established without working, they planned no real careers for themselves for the remainder of their potential working lives – which ranged from 15 to 35 years.

Ron Berman provided an instructive example, for he had established a workable financial and social life for himself without employment:

*I rely on SSDI. It leaves me with very little money, to tell you the truth, but I don't really mind. I'm a little better off than just with welfare, and my parents have helped me out a great deal, such as buying me the condominium in the apartment where I live. . . .  
Actually, I don't believe I will ever be able to go back to work. Work just generates more anxiety for me, more frustration and depression. I've really given up, particularly when I consider my current capacity for work – running manic-depressive self-help groups as a volunteer – and compare it to the great work I used to do when I functioned at a totally manic level.*

VIDS was very concerned as well about the possibility that he would get sick again if he worked: “I don't really think about it that much, because I don't have any ambition. I live day-to-day. I don't have a car, but it doesn't bother me because I haven't had a car since 1980.” And JG, who says he would take the ‘right’ job for the ‘right’ pay also says that now that he is in his fifties he

wouldn't be unhappy spending the next decade in the assembly workshop in the psychosocial program that is his second home.

Disturbingly, all three of these men, like most of the others who expressed no real motivation to return to the competitive marketplace, had had substantially successful work experiences, and over many years. It is true that they all had substantial periods of unemployment as well, and that they clearly struggled with mental illness on a day-to-day basis, but their decision to avoid any further employment opportunities outside their agencies could not be explained in terms of their past failures, their inability to hold part-time jobs without losing benefits, or their complex social or volunteer obligations. They had simply decided to go no further. Cheri Clodi was a little more ambivalent, but seemed to be settling in to a kind of long-term dependency:

*Actually, I'm not sure I have any sort of well thought-out long-term goal where work is concerned. . . . I like the clubhouse program I'm in. I love working on the newsletter, and I do a lot of the writing that is produced here. I enjoy doing the work here, and they really don't push me too hard to get a job. I feel as though I fit in here very comfortably, with lots of friends, a place to live, and things to keep me occupied. I'm not sure about the need to find a job.*

This 'just say no' approach to work may have been sanctioned by the 'culture of unemployment' in which they lived or may have been the consequence of having the very modest but still workable financial support of the Social Security Administration to meet their basic needs. Alternatively, this may have been an accurate assessment of the way in which their mental illness limited their capacities.

What was certain, however, was that the decision not to work imposed a set of economic limitations on them with which they had come to terms. Any rehabilitation program designed to move them toward employment would have to deal with all of these complexly intertwined issues, and simultaneously at that. But those who said they didn't plan to work again were clearly in the minority here. Most people wanted to work, and held out greater or lesser ambitions for themselves.

### **Combining SSA Support with Part-Time and Intermittent Employment**

Substantially more people planned to remain on SSI and/or SSDI, probably permanently, but to supplement these financial supports with part-time and intermittent employment that did not threaten their SSA eligibility. Like those who chose to withdraw entirely from the workplace, people in this cluster feared losing the financial and medical support SSA provided and were concerned that if they took a job that forced them off SSA and then lost the job – due to either a return of symptoms or the vagaries of the economy – they would be economically stranded. Some couldn't imagine themselves with the stress tolerance, energy levels or intellectual capacity to survive independently. More than a few were aware that they didn't have the academic credentials or the work experience that would give them access to better jobs – with decent levels of pay and benefits – and didn't see themselves making much economic progress by pushing themselves into to full-time employment.

Several people saw themselves continuing to be active in the mental health movement, as volunteers or part-time personnel: this was interesting work, where a wide range of accommodations were readily available, and one in which an underlying set of emotional disabilities needn't be hidden all the time. But work within the mental health community was also work in which – perhaps most importantly – employers were often willing to bend the rules and requirements to make sure that people would not run afoul of the Social Security Administration.

It was interesting that few people bothered to make much of a distinction between the part-time jobs they acquired through Transitional and Supported Employment programs and the part-time jobs they were able to get on their own: the important issue, to them, was to have the chance to earn some extra money without the threat of SSA ineligibility. Few people in this cluster of respondents articulated that the TE/SE placements they had had in the past or would have in the future were designed to move them toward economic independence. No one took the time, in these interviews, to explain how one or a series of placements were designed to prepare them for full-time employment, to familiarize them with the demands of the marketplace, or to increase their vocational maturity. While this might indeed be happening, the people in the program were not aware of the process in which they were engaged, and did not appear to look much beyond the current placement and the one that would follow that one. Their engagement in these programs was, in effect, a lifestyle choice.

Again, one of the implications of this choice was the economic consequences of living within the very narrow confines of an SSA check and some extra income from part-time work. There were two different attitudes, within this cluster, toward these economic restraints. Some of the group – particularly those whose families of origin had not been particularly well-off to begin with – were comfortable with the lifestyles that a limited income dictated. Dave Pezick bridled a bit when questioned about how he felt living within a very restricted income:

*Actually, I don't think I am doing too badly. I have a little money in the bank, and I get by, without any real problems with money. Section 8 helps me with the rent, and I'm able to pay my bills. . . . And when you work full-time, you don't have much of an outside life. That's all you do, basically, when you work, so I'm just satisfied with my disability and my occasional part-time jobs. I'm satisfied just doing that.*

Others, however, resented the limitations but were determined to live within them to avoid the hazards of SSA scrutiny or the frustrations of independence in the labor market. It was noticeable, for instance, how many men, of all ages, talked about how much they wanted to be able to own a car, but realized that this would probably be permanently beyond their economic capacity: in fact, less than 10% of those interviewed owned a car, and in most instances car ownership was a result of parental indulgence. A few people, however, had established an almost Zen-like acceptance of 'doing without' in a consumer-oriented culture. DW, holding a BA in Sociology and working occasionally on landscaping crews and in a hair salon, captured this best:

*Actually, I've made my peace with my economic level: one learns to do without. A little bit of peace of mind is better than a lot of stress. I know that if I took a job I would press too hard to do it just right, and then I'd wind up in the hospital. I'd like to be able to work and to be financially independent, but I realize I have difficulty working with other people, particularly with those that are hard to deal with, so this is what my life is going to look like.*

### **Escaping Dependency: Full-Time Independent Employment**

Other people, however, articulated the hope that they would, sooner or later, escape their current dependency on the Social Security Administration, holding jobs that would provide them with a decent income, suitable benefits, and the opportunity to fully participate in the life of their community. Many of these hopes seemed reasonable and realistic, particularly where there was a strong correspondence between the individual's past and his or her projected future, but there were a few such hopes that were based on fantasies and conjectures that were clearly part of a story that people told themselves about themselves.

Most, however, made perfect sense. Leo Bruckner thought he might drive a truck or own a carnival, and indeed he had worked in such settings before. Cindy Emerald thought she might be able to get a steady job as a cook, a job she had succeeded at in the past in the military. MM wanted to return to retail sales, and MH wanted to do the same, and both had worked for years in the field when their illness was not overwhelming them. Myria Manfred and John Meyer both thought they might teach. Several people were either in school or talked about going back to school to develop the credentials they needed: Sarkis Tashjian was about to enter an Environmental Engineering program, and several others were already in college or technical schools.

A few people had unrealistic dreams. One man thought he might "make a famous discovery or something," and another man was still nursing an idea about an invention that would use 'compressed air to run a car' that he had first had when he was a teenager, and a few people who hadn't finished high school were interested in college programs and professional positions that seemed very unlikely. These were rare cases however, with most people at least thinking about the kinds of jobs they knew they could do that would lead them to self-sufficiency.

Two broader themes emerged, however, that sounded a note of caution. First, many of those with what ordinarily would have been realistic vocational ambitions for themselves had really no idea of how to get from their current circumstances to the full-time jobs that would establish their economic independence. There was, that is, no real plan in place for them to move from here to there, nor did they seem to be working closely with vocational counselors or job coaches or educational personnel to make their dreams a reality. In fact, most continued to dream of a more successful career without making substantial progress toward their goals.

Second, however, it was surprising how many people talked about the future in 'lifestyle' terms rather than 'vocational achievement' terms: that is, the interviewees frequently talked about their ambitions for living some portion of the American Dream – which was most commonly defined

as ‘a family, a house in a nice neighborhood, a car, and a chance to vacation now and then’ – rather than enjoying the non-monetary satisfactions of being a salesperson, teacher, social worker, or maintenance supervisor. Like many others in the service industry, the interviewees saw the job of their dreams as a means to an economic end, rather than an ‘identity’ or as a productive activity with its own intrinsic value. This was of particular concern because the careers that are most likely to be available to people in their circumstances may not provide the kind of financial security and lifestyle comforts that people so consistently said defined their goals. Indeed, for so many of the interviewees it seemed that even car ownership, that most commonplace possession in the standard American Dream, would remain well beyond their economic grasp.

What emerged most forcibly in these interviews was the gap between the demands of the US labor market and the work and lifestyle ambitions of people with serious mental illness. Even modest financial success in today’s economy depends upon some acquiescence to the way the vast majority of jobs are structured: employers want full-time workers with a long-term commitment to their jobs and a steady capacity to be productive. Other kinds of jobs are available, to be sure: part-time and full-time work, and temporary or short-term work, in the secondary labor market, as well as work in settings where the employer has made substantial accommodations to the disability of the individual. But these kinds of jobs are routinely poorly paid, with few benefits, and little long-term security. They do not provide real access to the American Dream to those who hold them, whether or not they have disabilities. It may be that many of these interviewees, despite our unwillingness to acknowledge it, will be entering the labor market in order to join the ranks – the growing ranks, it should be noted – of the working poor.

## IX. CHARACTERISTICS OF THE CAREER PATTERNS OF PEOPLE WITH SERIOUS MENTAL ILLNESS: SUMMARY OF FINDINGS

*RB is a 27-year-old White man who lives in the Philadelphia suburbs. After a series of part-time and summer jobs in high school and college – paper route, Woolworths counter man, teacher's aide, restaurant clean-up, pizza delivery, computer programming – RB dropped out of college just before graduating and returned home, where he has lived ever since. He had received counseling for his emotional problems both in high school and in college, and continues to work with a counselor. After leaving college he "didn't do much" for a while, working in gas stations and in similar secondary labor market jobs, as well as experiencing several brief hospitalizations for anxiety and depression. Two years ago he got a 20 hours/week job at a local office supply store near his home, where he works for \$6.75 an hour and few benefits. RB doesn't like the job, resents it that younger people and newer workers earn the same as he does, and worries that his education and intelligence have been wasted. He is interested in finding work in a lab so he can extend his college work in biology, but isn't sure how to proceed. While he is uncomfortable about his current job status, about his dependence (upon SSI, his mother and his part-time earnings), and about the demoralization he feels when comparing himself to his contemporaries, the future is rather obscure to him: "I really don't have any plans."*

*GD is a 41-year-old White woman, divorced and raising two children, ages 6 and 12, out of a one-bedroom apartment in the Bronx. GD, who is currently not working and is supported by welfare, wants a job in order to increase her self-esteem, set a better example for her kids, and distract herself from continual 'rumination' on her problems. Raised in a Catholic orphanage, GD was assigned a wide range of work tasks by the nuns, including summer assignments working with children in camp programs. After graduating from high school she worked in a series of secretarial jobs, but these usually ended after six months because of her growing problems with substance abuse. GD then joined the Navy with high hopes, but after two years was discharged, as a 'burden to command,' because of her substance abuse. She returned home, married a man who also abused drugs and alcohol, and again worked in a series of secretarial jobs – each for two or three years – before substance abuse led to her dismissal. After the birth of her second child, after which she stopped working and relied upon Welfare for support, GD and her husband divorced and she entered a Methadone program. Recently – over an extended period – she has been able to wean herself off Methadone as well. When her youngest child started school, GD began to wonder about returning to work, and was referred by the Methadone program to a training service at a consumer-operated mental health program, and was shortly about to start a six-week program to prepare her for work with children in day care centers.*

How, then, could we characterize the career patterns of these interviewees as they struggled with serious mental illness? To answer that question, it is important to note, first, the kind of people who talked with us about their past careers and future work ambitions. On the one hand, these were not people in the midst of psychotic episodes, or even those whose behaviors currently required either short-term or long-term hospitalization, although all had experienced those kinds of severe symptoms in the past. On the other hand, these were also not people who had

experienced only a single episode of psychiatric disturbance, or whose problems were not too disruptive of their domestic lives or employment patterns.

Each of the thirty-eight people spoken to in this study had a serious and long-term mental illness, but they lived in community settings, received treatment from community mental health centers or publicly-supported private psychiatrists and counselors, and they had been associated, to one degree or another (and for varying lengths of time) with the psychosocial rehabilitation, vocational counseling, or consumer-operated services from which they were recruited. They shared many of the same demographic characteristics and residential circumstances of others in these programs, and reported similar diagnostic and treatment histories, symptom problems and personal strengths.

In characterizing the career patterns of these interviewees it is also important to note that this was a qualitative research effort focusing on the themes that emerged from talking with people about both their past and their future. There has been some effort to quantify results, but this initiative primarily has searched for common themes among the thirty-eight transcripts of hour-long semi-structured interviews. The study was not designed to replicate or challenge past estimates (e.g., of the rate of unemployment among persons with mental illness, the percentages of those dependent on SSI and/or SSDI, or the three – or four or eight – most critical disincentives to employment that keep so many people from full participation in the competitive labor market. This study was, instead, an effort to listen closely to a group of individuals from a common, if broad, diagnostic and services background to learn more about their careers and to capture the ‘dynamic’ of their lives.

The study was also less concerned about capturing the somewhat static ‘point-in-time’ data – percentages working, average tenure in last placement, mean wages now earned, numbers who have left the SSA rolls in the last six months – that in the past have tended to dominate program outcome studies of these issues. It sought to answer the question of ‘where have these people been and where are they going’ within the context of their lifetimes, rather than simply in the context of their ‘entry into’ and ‘exit out of’ one or more human services delivery systems.

Ten tightly inter-related themes emerged from the analysis of these interviews. Certainly none of the statements below could be said to reflect the comments or feelings of *everyone* who was interviewed, but the issues and patterns that emerged repeatedly, however rich with personal detail and idiosyncratic interpretation, are important to note. They force us to re-examine some of the assumptions we make about current and future clients who are in public mental health systems, psychosocial rehabilitation centers, and vocational rehabilitation agencies, and may indeed suggest the importance of thinking through more closely our obligations to their *distant* vocational and economic lives.

*People wanted to work.* However tempting it may be to read this finding as a meaningless platitude that contradicts a great deal of case wisdom about the lack of motivation among people with serious mental illness, the data here provide strong evidence that the desire to work persists, and persists for broadly familiar – normative – reasons: to earn money, to establish one’s independence, to set an example for one’s children, to boost one’s ego, to avoid rumination, and to escape the boredom of a life lived without something meaningful to do. There is no great

‘values divide’ where employment is concerned. It is true, of course, that several interviewees had no intention of working in the future and that quite a few intended to work only to supplement their SSA check with cash from occasional odd jobs, but most people wanted either an ongoing and substantial part-time engagement in the competitive labor marketplace or a full-throated participation in the workforce that would lead toward economic independence. While there is tremendous anxiety about the leap from part-time to full-time employment, because this is often a leap as well from economic dependence to the multiple challenges of independence, people deeply resented the financial and medical threats to their survival that kept them from working.

People received very little encouragement to work from mental health and vocational rehabilitation personnel. It was surprising how quickly and surely interviewees, when asked about whether mental health or vocational rehabilitation staff had encouraged them to work, responded in the negative. They often noted how disconcerting it had been to have clinicians and case managers counsel them not to work (at least not yet) and thereafter remain oblivious to the work dimensions of their lives. It appears to have been very simple to escape the pressure of ‘getting a job’ by simply getting out of the house. Parents tended to encourage employment and nagged their children about becoming financially independent, but the three systems of care and support to which the interviewees turned – community mental health programs, the vocational rehabilitation system, and the Social Security Administration – had done little to actively promote employment for these interviewees. Even psychosocial rehabilitation programs and consumer-operated centers – both of which were viewed by the interviewees as much more likely to provide substantial assistance to clients who wanted to re-enter the labor market – still put little direct pressure on clients to work: with perhaps a too-fastidious approach to consumer empowerment, these ‘recovery’ oriented programs were reported to be less than assertive about the overall importance of employment outcomes.

People had worked a good deal in the past, and often had worked successfully. After-school and summer-time jobs were commonplace experiences, and those who went to college generally also worked in the evening and during semester breaks. More importantly, most people kept working for many years, sometimes intermittently, following their initial recognition of emotional problems and subsequent hospitalizations, repeatedly returning to the competitive labor force despite their diagnoses. Indeed, people reported that in many of their jobs they were as productive as their non-disabled coworkers and able to get along with them and their supervisors reasonably well. It is interesting to note that their tenure in many of the secondary labor market jobs they had held was comparable to that of their non-disabled coworkers. Employers, particularly those with substantial numbers of entry-level personnel, appeared to tolerate a wide range of idiosyncratic behaviors from everyone at the worksite.

Serious mental illness did not often affect on-the-job performance; instead, the symptoms of mental illness led to frequent absences from work, and these resulted in firing and quitings. The interviewees consistently reported that their on-the-job behaviors rarely gave employers grounds for complaint, and that their most serious symptoms of mental illness – voices, paranoia, anxiety, stress – rarely became problematic at the worksite. Much more common was the often gradual off-the-job escalation of symptoms (like paralyzing depression, hypermanic activities, paranoia about coworkers, or excessive alcohol and drug use) which made it increasingly difficult for the

interviewees to show up at work. Bizarre behaviors on the job were exceedingly rare, but a common experience was an unexpected inpatient hospitalization, at which point either the worker called in to resign or the employer, not having heard from the employee, was left with little option but to fire. Further, the interviewees reported very few instances in which discrimination or abuse, on the part of either supervisors or coworkers, impacted on job performance or tenure.

Most people had worked primarily in the secondary labor market, at entry-level jobs, often on a part-time basis, for little pay and few benefits, making little progress over time. The vast majority of jobs held by the interviewees were unskilled and semi-skilled jobs, where the requirements for the job are low, performance expectations are limited, and – as a result – pay is at or near the minimum wage, with benefits meager or non-existent. Even those people with the educational and experiential qualifications for more demanding and rewarding positions had either never held jobs in their field or had gradually sought refuge in the secondary labor market. Interviewees tended to move from job to job in this secondary labor market without making much progress with regard to salaries, benefits, responsibilities, social status, or satisfaction. Most people had never developed a strong ‘vocational identity’ for themselves that would either characterize their past experiences or future ambitions: indeed, many interviewees were continually ‘starting over’ at each new position.

The reasons for job leavings varied considerably, but about as many jobs were lost for reasons unrelated to mental illness as for reasons directly related to psychiatric pathology. Far more people quit their jobs than were fired. Many people lost their jobs for reasons unrelated to their mental illness (e.g., plant closings, store bankruptcies, family moves, the pursuit of additional education, transportation system inadequacies, better jobs, on-the-job accidents, health crises, etc.), but certainly many people also lost their jobs because of psychiatric hospitalizations or the chronic lateness or repeated use of sick leave caused by their mental illness. There was a broad middle ground of reasons for which people lost their jobs or quit – fights with supervisors, low pay, boring assignments, poor performance, etc. – in which it is hard to discern the role of the worker’s mental illness, suggesting a need for caution about interpreting every unplanned job leaving within a pathological framework.

There were frequent and long absences from the workforce for many people. One of the most distinguishing characteristics of the interviewees was the intermittent nature of their participation in the workforce. This did not appear to be a significant problem for most people in finding new jobs within the secondary labor market – where jobs continue to be plentiful and employer scrutiny somewhat casual – but it does suggest that people did not always aggressively seek to re-enter the workforce after psychiatric or employment crises. For many of the study’s participants, the salaries they received – from part-time employment in particular – only supplemented their basic financial assistance package: they were often able to comfortably withdraw from the workforce for short and long periods of time when they felt depleted by the hospitalization experience or demoralized by a failure or frustration at work.

While Social Security’s SSI and SSDI programs played a critical role in providing necessary financial and medical support to people, it also acted as a disincentive to vocational progress. Although the interviewees often succeeded at one job or another, they frequently failed to make

significant vocational progress: this failure to progress had much to do with the degree to which the interviewees were frightened of losing the financial support and medical benefits of SSA eligibility if they turned to long-term full-time employment. Although people typically turned to the SSA system for support years after their first diagnosis, and did so reluctantly, they then monitored their earnings closely, and preferred not to move forward vocationally without a wide range of guarantees – that they would be able to earn a decent salary, that available medical benefits would meet their mental health needs, or that the job they would take would offer a long-term assignment, etc. Interviewees were rarely willing to risk financial or medical abandonment.

*Most people planned to continue working in the future, but few had long-term plans.* Although a few of the interviewees had chosen to withdraw from the competitive labor market entirely – to rely on SSA or Welfare checks and family and charitable support – the great majority planned to continue working. Many hoped to continue working part-time, relying on SSA for fundamental support and supplementing that income with casual work in the secondary labor market and/or TE/SE placements. Many other people, however, hoped to return to full-time employment, eventually. There was considerable ambivalence about facing the challenge of financial independence and the escape from SSA dependency, and thus few people had well-developed plans for achieving such goals.

*The economic prospects for many of the interviewees are necessarily modest: most people, if they work, will remain in the ranks of the nation's 'working poor.'* Certainly those who have chosen to work part-time while relying on SSA for basic financial and medical support will remain only at or near the poverty level unless family and friends provide additional help. For those who look forward to full-time work, there are few jobs they can obtain, given their academic credentials and current capacities, that will give them access to the American Dream of economic prosperity. The demands of the labor market are such that those without a college education *and* without the capacity to work full-time, continuously, and at a very productive level are likely to find it difficult to find well-paid employment. It is possible that many clients will nonetheless find great satisfaction in working, enjoying the self-confidence, social involvement, and meaningfulness that many of their non-disabled coworkers find, but they may not find the financial success and genuine economic independence they believe awaits them.

## X. DISCUSSION AND RECOMMENDATIONS

*Cindy Emerald is a 41-year-old White woman, living in the District of Columbia suburbs. While she currently is not working, Cindy has spent 20 years in the food business because she “loves to work, because she is so bored with nothing to do.” After high school and a little time in community College, Cindy joined the Army, working as a ‘prep cook,’ – a job she enjoyed but lost when her escalating drinking problem led to a dishonorable discharge. Cindy’s marriage also ended. Back in the States, Cindy worked at various times as a dietary aide, a telephone operator, an electronics assembler, and a salesgirl in a flower store, all jobs she held for one or two years until she quit or was fired over drinking problems. After a particularly difficult period, including hospitalization for depression, Cindy applied for SSDI, and then began working part-time to supplement her check. Ten years ago she began attending a PSR program, which placed her in an entry-level part-time job for five years, until another hospitalization. For the past two years, however, she has not worked at all. She is hoping one day to leave SSDI for a full-time job in food services. “I know everyone has periods of success and misfortune, but I’d like to be making some progress over time.”*

*Monica Zachoe is a 61-year-old White woman working part-time in a small university town in Minnesota. Monica left college after three years to marry and start a family. When her three grown children had moved away and her husband had divorced her, she expanded her part-time teacher’s aide work to full-time teaching and then returned to college to earn her BA and then a Master’s degree. She taught on and off for the next 15 years, often in private Catholic School systems, leaving one job for a better offer elsewhere, losing another job when the school’s financial problems forced closure, and being forced out of another when a recent hospitalization for depression and suicide led to community and school disapproval, despite the affection and respect of her students. She moved from Minnesota to California to teach, and then back to Minnesota, where – unable to find much beyond short-term substitute teaching assignments – she entered the SSDI rolls following another hospitalization. After several years she entered a consumer self-help leadership training program, and for the past two years has worked part-time as the Regional Coordinator of a Consumer Program Network, although she would much rather be working full-time.*

With a more complete sense of their past careers and future ambitions before us, what could be done to enhance the work opportunities of these interviewees, as well as the many other people with serious mental illness in public mental health systems who are like them? What implications, that is, do the findings of this study have for the counseling practices, rehabilitation programs, and social policies that shape our human services systems for people with significant psychiatric disabilities? Although there may be many others, six broad issues are discussed here.

### **Recognizing the Past Work Experience of People with Serious Mental Illness**

It is useful for the field to take note of those people with serious mental illness who have in fact had repeated and successful work experiences, even though they have not had traditional careers. To assume that most people with serious mental illness have had only a minimal exposure to the

work world, or to presume that most of their jobs have ended prematurely because of the clients' own symptomatic behaviors, may be to misread the experiences that many consumers bring to the rehabilitation setting. Part of the problem, of course, lies in the casual way with which most clinical programs in the public sector gather vocational information on clients at intake: "have you worked in the past two years" being an all-too-common assessment of the new client's vocational past. Part of the problem as well is the often limited exploration of past job leavings: sometimes it's the economy that closes down a job opportunity, and sometimes it is the work environment that is indeed intolerable. What can the field do, however, to recognize those consumers with some degree of past success at work in a way that enhances the client's opportunities for meaningful recovery?

First, these interviewees would have benefited from someone in the mental health or vocational rehabilitation systems talking to them about work early and often. This is especially important for clinical personnel in psychiatric hospitals and community mental health centers, but also for case managers and day hospital staff. The interviewees' reports that they only made their way to vocational programs or psychosocial rehabilitation centers years after a diagnosis or inpatient hospitalization suggests either that the 'work' aspects of their lives were overlooked or that old clinical taboos about the dangers of work to clinical stability are still firmly in place. While there is a good deal of wisdom in refraining from pushing people back into the stress of work life immediately following a psychotic break or a difficult hospitalization, there is also more than enough evidence that the longer the reluctance persists to engage the client in a meaningful dialogue about their next job, the less likely it is that the client will ever re-develop a sense of himself or herself as a worker and a vision of the future as encompassing a long-term engagement in the labor market. This is hardly recovery.

Second, it would have been appropriate for service providers to go beyond merely 'offering' rehabilitation services to these interviewees and to take a more assertive and directive stance with regard to the importance of work in their next 20 or 30 years. While it is always unwise and generally counter-productive to force clients to return to the world of work, *strongly* urging clients to do so would have been less an 'imposition of one's own values on the client' and more a reinforcement of the client's own values with regard to the importance of work in their lives. Certainly the issues of SSA eligibility need to be discussed, but far too many people have assumed that no work or only occasional work is possible, when in fact the old Work Incentive regulations made regular part-time work very possible and the newly enacted SSA Work Incentives Legislation now makes full-time work eminently feasible for many.

Third, so many of these interviewees (and those like them) had worked in the competitive labor force before entering rehabilitation programs that there appears strong justification for one of the fundamental tenets of Transitional Employment and Supported Employment: indeed, moving clients back onto 'real' jobs as quickly as possible and eschewing long-term placements in sheltered workshops or psychosocial rehabilitation work crews seems eminently reasonable. These interviewees were well aware of the demands employers make on the job: they've been there before, and have as good a sense as anyone of the employer's preferences with regard to promptness, appropriate dress, responsiveness to supervision, and collegiality with coworkers. They may have had some difficulty with some of these issues – as do many of their non-disabled colleagues – but it is hard to argue that extensive prevocational programs in segregated settings

can do much to improve Cindy Emerald's or Monica Zachoe's on-the-job performance when they next move out to the competitive marketplace.

### **The Impact of Interrupted Careers**

The surprisingly rich past work careers of these interviewees should not blind us to the way in which many of their careers have been characterized by interruptions in work that occur again and again, forcing them into unemployment for both brief and quite extended periods of time. Such interruptions were devastating to morale and motivation, significantly impacting on the individual's sense of a vocational identity. The problem with 'gaps' in their work history would not appear to have been the suspiciousness of employers and their reluctance to hire, for this is a very minor issue in the secondary labor market that most interviewees sought out. The problem that emerged was that these individuals saw themselves less in terms of their work roles and more in terms of their patient status. What can be done to limit those interruptions and minimize their impact?

First, it is clear that many of these interviewees could have made good use of additional assistance in holding on to their jobs. The current fiscal practices in the rehabilitation community of rewarding agencies with outstanding placement rates but overlooking longer-term outcomes represents a short-changing of these interviewees' long-term potential. Programs need to have the resources they require to ensure they are able to track client tenure and provide support early and effectively before the client unnecessarily leaves a job or is fired.

Second, many programs need to develop the capacity to help people survive a psychiatric crisis without losing a job. Again, the problems to be resolved for these interviewees were not very often on-the-job problems of low productivity or disintegrating supervisor/employee relationships. The problems were most often ones in which the client began showing up late, taking longer breaks, calling in sick or not calling in at all, or resigning after a visit to a psychiatric emergency room or state hospital. These are the times when an effective counselor could have helped the client believe in his or her capacity to return to the job, to face the embarrassment many feel upon returning to work, and to negotiate for and use effectively whatever sick leave policies or job accommodation provisions are available.

Third, the tendency to help clients who quit or who were fired to 'take a break' from the workforce while re-assessing their performance was not so helpful: many of these interviewees could have been assisted in responding to a peremptory quitting or a demoralizing termination by getting back on the horse again and finding another job. A great many of the interviewees did just that when they found themselves out of work, for whatever reason, and job coaches and case managers ought to encourage that course of action whenever possible. Our practice, programs and policies don't need to reinforce the already prevalent but wrong-headed notion that the only people with mental illness who can work are those who never lose a job.

## **Establishing Normative Standards for Job Tenure: The Roseanne Syndrome**

Because so many of those interviewed in this study had worked, and often were still working, in the secondary labor market, it is useful to have some perspective on what the careers are like of people without disabilities who work in similar positions. This study did not explore in depth current information on the career patterns of non-disabled individuals in the secondary labor market, but the data that was immediately available, combined with anecdotal information from employers, suggests that in many respects the people interviewed, despite their psychiatric disabilities, may not have been doing that much worse than their non-disabled co-workers. This, in turn, would argue for helping those who were interviewed to see their past careers as far closer to 'normal' than they have presumed, as well as argue for re-orienting the performance standards of the rehabilitation programs that serve them.

For want of a better and more descriptive phrase to describe those 'normative' career patterns in the secondary labor market, let us refer to it as *The Roseanne Syndrome*, named here after Roseanne Barr's eponymous TV series about a working-class couple and their three children in the 1980s and '90s. The show, which was often praised as providing an unusually realistic portrayal of working-class life, was rare in its depiction of a family's economic struggle to get by. In the course of the eight years or so the show was being produced, Roseanne held down about five jobs: factory worker; telephone solicitor; hair salon maid; waitress; and owner of a mildly successful roadside restaurant. Dan, her husband, held about as many jobs: running his own home repair business; supervisor of a county automotive maintenance crew; owner/operator of his own motorcycle shop; and then back to home repair as an independent contractor.

Their work performance was not particularly outstanding: Roseanne was frequently at odds with her employers, frustrated and exhausted by the jobs, and often embarrassed by the more menial aspects of her work. Dan's home repair business dried up in the recession and his motorcycle shop business failed. There were emotionally trying periods of unemployment, real economic limitations in their lives, and no shortage of disappointment in what they had managed – or, really, not managed – to make of themselves. However, in no sense was this pattern of largely secondary labor market jobs, several of which were part-time in nature and relatively short-term in tenure (and few of which provided the basis for economic progress) ever portrayed as pathological in nature. These were people without college educations struggling at the end of the twentieth century to make ends meet as best they could.

This may be, of course, the career pattern today of many people who are without a college education or who, for one disabling or disadvantaging reason or another, cannot meet the normative standard of full-time, consistent, and highly productive work that is rewarded with middle-class salaries and benefits. There is an abundance of evidence that, indeed, this is the work pattern for many people without disabilities, and that, even as the rest of the economy surges forward, they are left behind. What we hear from employers is that, for this workforce, job performance is at best satisfactory, attendance is often erratic, and job tenure problems challenge the employer's best effort to create a coherent workforce. These are the problems that also can be heard as the 'welfare-to-work' juggernaut moves forward. While it may be unclear for the moment whether the problem is based in the incapacity of the workforce or the nature of secondary labor market jobs, it is important, nonetheless, that clients' careers and our program

successes are assessed with these normative patterns in mind. For those who hold secondary labor market jobs, where the pay, benefits, and other advantages of the job are decidedly low, job performance – productivity, attendance, loyalty, tenure – is likely to be low as well. How can the rehabilitation community respond best to these issues?

First, while it is certainly true that rehabilitation programs place far too many people into the secondary labor market because ‘that’s where the jobs are,’ it is critical to acknowledge that in fact many people are appropriately being directed to secondary labor market jobs, given their education, their intellectual capacity, their disability, or their work interests. Many of those interviewed in this survey either preferred these kinds of jobs or recognized their own limited capacity to move up the jobs ladder. It would have been better had their families and friends *and* their rehabilitation counselors and coaches found more explicit ways to honor those clients who can succeed in the secondary labor market, even while recognizing that job attendance may be somewhat more erratic and job tenure far less extended than what is anticipated (and, indeed, required) in more white collar positions. These too are careers, and although they may not be middle-class careers with middle-class rewards, those who struggle with their mental illness to maintain them are no less deserving of our respect and regard.

Second, it is absolutely critical that the field not pathologize every ‘job leaving’ as though it is rooted in mental illness, remembering that almost everyone has real difficulty with a supervisor and smoldering resentment about coworkers at least once, and that many people make rational decisions to leave their jobs because their work is boring or poorly paid. These are not mental health issues, any more than are those job leavings that result from business failures or physical health problems or family crises. What may be difficult is sorting out that wide range of job leavings that may or may not have mental illness in their origins, but – at least on the testimony of these interviewees – even repeated job leavings in the secondary labor market often may have had little to do with the individual’s psychiatric disabilities.

Third, however, the problem of on-and-off career patterns of these interviewees is less readily normalized, for the vast majority of people without disabilities, even those who change jobs frequently, usually quickly find their way back into the labor market. This has generally been true in good economic times: after the pain of being laid off and the shock of recognizing that one’s old job doesn’t exist anymore, most people make adjustments and return to work in one capacity or another. It is worth remembering, however, the daily stories of stress and tragedy that accompanied the widespread plant closings and company downsizings of the early 1980s and the difficulties that many people – without a college education often, but without disabilities as well – had in finding new careers in a recessionary economy. In this respect, then, the interviewees were not alone, yet far more needed to be done to help them return to the labor market as soon after they were unemployed as possible.

### **Poverty: A Central Aspect of the Lives of those with Serious Mental Illness**

It is hard, in reviewing the transcripts of these interviews, to escape the fact that most of this group of people with serious mental illness lived at or near the poverty level. They were well aware of the ways in which their lifestyle fell short of the American Dream, and particularly of

the lives of their siblings and their schoolmates and the images of a prosperous populace that fills their television and movie screens. They knew they were socially isolated and often without either families of their own or close friends they could call upon in an emergency, but they also knew that they couldn't afford to eat out very often, to wear nice clothes, to buy and operate a car, or to own a home. And this was true for almost everyone in the group, and particularly for those who did not have family members to supplement their lifestyle in one way or another. Yet, this relatively impoverished state – an almost inescapable fact of their lives – is the one thing that often is not discussed, either in treatment settings or in vocational planning. How can the field respond to this?

First, those few who have determined not to work except in the most casual and occasional of jobs, depending almost entirely upon SSI and/or SSDI (or welfare), had quite impoverished lives. It may be true that a variety of food and housing and recreational subsidies made life sustainable, but it was a meager existence nonetheless, and one that many clinicians and case managers could only barely imagine and thus found very painful to discuss. The mental health rehabilitation community generally opted to encourage this population to work as a way to relieve at least some of the stress of this level of deprivation, but it also chose to avoid making this impoverishment itself a focus of discussions with clients about their lives and their feelings about themselves. These interviewees, and others like them, could have benefited from a more sensitive exploration of what it means to them to be so poor.

Second, however, for those who had chosen to remain dependent upon SSA but to supplement their check with regular or intermittent part-time work, there should certainly have been a more forthright discussion of the economic implications of this choice, and a re-visiting of the topic every so often as circumstances changed. It is difficult to specify how counselors could have pushed people forward – to have assertively encouraged steady progress toward full-time independent employment – while validating and acknowledging the very real strengths it had already taken for some to manage their illness and a part-time job. Nonetheless, these interviewees might have made more progress if their clinicians, counselors, case managers and job coaches had consistently helped them to focus simultaneously both on the current job and the better jobs they might have been able to attain in the future.

Third, a still more perplexing issue emerges if rehabilitation workers begin to acknowledge that many of those interviewed in this study who wanted to leave SSA behind for full-time work might nonetheless have continued to face economic deprivation. It is certainly true that a greater number of these consumers could have been helped to seek and sustain more middle-class careers – with salary and benefit levels that would have provided a more substantial lifestyle – but many more were likely to remain in the secondary labor market, for a wide variety of reasons, and the field has to find a way to encourage independent employment, to honor it and support it, even while recognizing that for many people the decision to work only moves them into the ranks of the working poor. Such a concern does raise the question of how much the rehabilitation community really ‘values’ work for its non-monetary benefits.

## **Moving Beyond the Secondary Labor Market: The Prerequisites of Prosperity**

How, then, could the rehabilitation field have moved more of these interviewees into economic prosperity? It is valuable to remember that economic prosperity remains at the heart of many of their dreams of the future: a family, a house, and a car, and so much else that is currently beyond their grasp. Neither these interviews nor the predictive capacities of current testing programs can readily tell us which people would be most likely to have careers entirely in the secondary labor market, which people would do well to re-enter the labor market by starting off in entry-level jobs and then moving forward, and which could avoid the secondary labor market completely by moving directly into – and often back into – white collar roles. We do know, however, that there are too few programs available to assist those who want to reach for real economic success. On the one hand, there are few rehabilitation programs that offer real opportunities for consumers who are working successfully, part-time or full-time, in the secondary labor market to move on. On the other hand, there is almost a complete absence of programs to help people establish themselves in white collar careers or re-establish themselves in long-lost professions. The rehabilitation community must begin to frame – and study – programs that are more aggressive in this regard.

First, there needs to be much greater emphasis on education and training for careers that go beyond the secondary labor market. Supported education programs can play a critical role here, encouraging people to complete their high school education to be sure, but, more critically, helping people to complete their abandoned college careers or graduate programs: only with the credentials they need can they go forward economically. It is true, it should be noted, that two alternative approaches show promise: funding for ‘consumer operated programs’ provide opportunities for decent salaries at interesting jobs (jobs that didn’t exist a decade ago), and ‘entrepreneurial training’ offers the challenge of self-employment as a way to proceed. But these programs cannot be of use to more than a handful of those in the mental health system today: not everyone is cut out for the human services despite their experiences as recipients of services, and far too many self-employment schemes of those without disabilities fail all too quickly for this to be a productive avenue for many. While further development in these areas is important to pursue, the field needs as well to develop educational and training opportunities that move people toward the well-paid careers of the mainstream.

Second, it is also time to turn to the employer community to ask for help in examining and redefining the requirements of jobs with substantial salaries. Few people who work part-time have access to the salaries and benefits they require for a ‘beyond impoverishment’ existence, and few of those needing substantial on-the-job accommodations do well enough to live entirely independently. Employers may have a better notion than human service workers about how to reconfigure jobs so that people with psychiatric disabilities have the opportunity not only to perform well but also to earn adequately.

Third, and much more far reaching, is the need for advocates to address the growing wage inequality in this country. Most economists now agree that the wage gap between those with and without a college education is widening, and that the current economic expansion is not really ‘raising all boats.’ This is true for those entering the labor market under ‘welfare-to-work’ policies, who are rarely finding the types of jobs that are capable, however hard and well they

work at them, to lift them out of poverty. It was also true for these interviewees as well: several noted the frustration of trying to find a job they could manage that paid well enough to tempt them to part with their SSA check. These last two issues – redefining job structures and arguing for greater wage equality are difficult for human services personnel to undertake, but it is in challenging these kinds of broad social issues that advocates for those with mental illness will have the opportunity to link arms with representatives of other disability and disadvantaged groups.

### **Talking to Clients About Their Vocational Futures**

An apology for such gloomy prognostications seems in order here, and yet is beside the point. The most difficult of questions, for practitioners in particular, is when to raise and how to resolve these issues with consumers. Talking to people like these interviewees about their relative impoverishment – about the implications of not working at all, about the lifestyle that a reliance upon ‘the check’ and part-time employment brings, or about working full-time only to enter the ranks of the working poor – offers a profound challenge, for it requires one to be startlingly honest and encouraging at the same time. It is this challenge that has persuaded so many counselors to sidestep the question, to avoid discussions about the *distant* working lives of the clients they serve and the financial implications of their clients’ and the economy’s current circumstances.

Several factors argue for grappling with these issues directly. In the first place, these interviewees clearly recognized that work has a value far beyond the monetary. People knew that work was good for their mental health: it distracted them from symptoms, provided a fine alternative to thinking of themselves in symptomatic and negative terms, ended the boredom of their lives, and strengthened social skills and self concepts in ways that overwhelmed the advantages of a salary. In the second place, a great many of the interviewees had gotten by with a great deal less financially than their counselors for quite a while, and were able to talk about the problems of their limited funds fairly directly in these interviews: many had come to terms with their economic status, and were simply looking, as Cindy Emerald puts it “to make a little progress.”

Such discussions need not dwell on what is impossible, either in a general or specific sense. The counselor’s role is not to offer the individual with a serious mental illness a hard and fast prediction of his or her future work potential: we haven’t the tools for accurate prediction in any case. What makes more sense is to talk honestly with clients about how people throughout the society, with or without disabilities, follow different careers paths, with different economic implications, and to stress that no one path has a monopoly on virtue. We have to find a way to validate the ways in which many people live, giving working class life the sense of purpose and pride it held only a generation ago, while leaving open the possible door to greater prosperity.

For people with serious psychiatric disabilities, as for the rest of us, career patterns are unpredictable. The best thing most of us can do is to assess our own capabilities and interests, pursue the educational and training opportunities we think move us toward desirable goals, and then simply get started to see how it turns out in the end. Any of a variety of endings are

acceptable – indeed, honorable – if they represent a fair approximation of the individual’s potential. However, if mainstream career counseling is in part designed to help people come to grips with the economic implications of the choices they make, shouldn’t the rehabilitation community be doing similar counseling for people with serious psychiatric disabilities as they move to realize their potential?

More than anything, these interviews reinforced how great that potential remains. However unrealized at present, there is a wealth of experience and competence that is being largely wasted. We are in danger, if we don’t act on that potential, of watching yet another generation of people with serious mental illness lost to idleness and poverty rather than reaching their individual capacity, and that would be, both for the people in these interviews and so many like them, a tragic failure.

## CITATIONS

Anthony W A & Blanch A (1987) *Supported employment for persons who are psychiatrically disabled: An historical and conceptual perspective*. Psychosocial Rehabilitation Journal, Volume 2.

Anthony W, Howell J & Danley K (1984) The vocational rehabilitation of the psychiatrically disabled. In M. Mirabi (Ed.) *The chronically mentally ill: Research and services*. Jamaica, NY: SP Medical and Scientific Books.

Baron R, Rutman I & Hadley T *Rehabilitation Services for People with Long-Term Mental Illness in the Managed Behavioral Health Care System: Stepchild Again?* Psychiatric Rehabilitation Journal, Volume 20, Number 2, Fall, 1996.

Blankertz L, Cook J, Rogers S & Hughes R (1997) Choosing Client Level Outcome Measures for Individuals with Severe and Persistent Mental Illness. *Behavioral Healthcare Tomorrow*, Fall Edition.

Bond G R & McDonel E C (1991) *Vocational rehabilitation outcomes for persons with psychiatric disabilities*. Journal of Vocational Rehabilitation, Volume 1, Number 3.

Botterbusch K F (1999) *Outcomes and career achievements of persons with professional qualifications who have severe psychiatric disabilities: The Minnesota Mainstream experience* Rehabilitation Research and Training Center on Community Rehabilitation Programs, University of Wisconsin – Stout, Menomonie, WI.

Cohn R M (1978) *The effect of employment status change on self attitudes*. Social Psychology, Volume 41.

Connors K A, Graham R S & Pulso R (1987) *Playing store: Where is the vocational in psychiatric rehabilitation*. Psychiatric Rehabilitation Journal, Volume 10.

Cook, J A (1992) *Job ending among youth and adults with severe mental illness*. The Journal of Mental Health Administration, Volume 19, Number 2, Summer.

Estroff S E, Patrick D L, Zimmer C R & Lachicotte W S (1997) *Pathways to disability income among persons with severe persistent psychiatric disorders*. The Millbank Quarterly, Volume 75, Number 4, The Millbank Memorial Fund, Malden, MA.

Fabian E S (June, 1999) *Rethinking work: The example of consumers with serious mental health disorders*. Rehabilitation Counseling bulletin, Volume 42, Number 4.

Feather N T & Davenport P R (1981) *Unemployment and depressive affect: A motivational and attributional analysis*. Journal of Personality and Social Psychology, Volume 41.

Freud S (1953) Civilization and its discontents. In J. Strachey (Ed). *The standard edition of the complete psychological works of Sigmund Freud (Vol 21. Pp 64 – 145)*. (Original work published 1930).

Granger B & Baron R (1996) *A final report on a national survey on job accommodations for people with psychiatric disabilities*. Matrix Research Institute, Philadelphia, PA.

Granger B (1995) *Final report on a national survey of agency-sponsored entrepreneurial businesses employing individuals with long-term mental illness*. Matrix Research Institute, Philadelphia PA.

Harding C M, Strauss J S, Hafez H & Lieberman P B *Work and mental illness: Toward an Integration of the Rehabilitation Process*. The Journal of Nervous and Mental Disease, Volume 175, Number 6, June 1987.

Haugen S E & Mellor E F (1994) *A profile of the working poor*. Report 869, Bureau of Labor Statistics.

Kennedy C & Manderscheid R W (1992) *SSI and SSDI disability beneficiaries with mental disorders*. In “Mental Health, United States, 1992.” Department of Health and Human Services, Washington, DC.

Kiernan W E, Marrone J & Butterworth J (June 1999) *Beyond demographics: Strategic responses to a changing workforce*. Institute for Community Inclusion, Boston Children’s Hospital, Boston, MA.

Krueger A B (February, 1991) *Ownership, agency, and wages: An examination of franchising in the fast food industry*. Quarterly Journal of Economics.

Mallinckrodt B & Fretz B R (1988) *Social support and the impact of job loss on older professionals*. Journal of Counseling Psychology, Volume 35.

Marrone J & Golowka *If work makes people with mental illness sick, what do unemployment, poverty and social isolation cause?* Psychiatric Rehabilitation Journal, Volume 23, Number 2, Fall, 1999.

National Institute on Disability and Rehabilitation Research (1992) *Strategies to secure and maintain employment for people with long-term mental illness*. Washington, DC: Author.

Newman K S (1999) *No shame in my game: The working poor in the inner city*. Alfred A. Knopf and The Russell Sage Foundation, New York, NY.

Noble J, Honberg, R, Hall L L 7 Flynn L M (1997) *A legacy of failure: The inability of the federal-state vocational rehabilitation system to serve people with severe mental illness*. National Alliance for the Mentally Ill, Washington, DC.

Pigeon M-A & Wray L R (1998) *Did the Clinton rising tide raise all boats?* The Jerome Levy Economics Institute of Bard College, Public Policy Brief, Number 45: Annandale-on-Hudson, NY.

Polivka A E (October, 1996) *A profile of contingent workers*. Monthly Labor Review.

Rogers S, Danley K & Anthony W (1992) *Survey of client preferences for vocational and educational services*. Unpublished manuscript. Boston: Center for Psychiatric Rehabilitation.

Rutman I D (1994) *How psychiatric disability expressed itself as a barrier to employment*. Psychosocial Rehabilitation Journal, Volume 17, Number 3.

Strauss, MB (ED) (1968) *Familiar medical quotations* (p.663). Boston: Little, Brown.

Super D E (1990) *A life-span, life-space approach to career development*. In D Brown, L. Brooks, & Associates, "Career Choice and Development: Applying Contemporary Theories to Practice (2<sup>nd</sup> ed) San Francisco, Jossey-Bass.

Szymanski E M & Hershenson D (1998) Career development of people with disabilities: An ecological model. In R M Parker & E M Szymanski (Eds) *Rehabilitation counseling: Basics and beyond* (3<sup>rd</sup> edition), pp. 327 – 378. Austin, TX: Po-Ed.

Terkel, S. (1974) *Working*. The New Press, New York, NY.

Van Dongen C *Quality of life and self-esteem in working and non-working people with mental illness*. Community Mental Health Journal, Volume 32, Number 6, Spring 1996.