Facilitators and barriers to employment: The perspectives of people with psychiatric disabilities and employment service providers

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Abstract. This study examined the perspectives of people with psychiatric disabilities and employment service providers regarding factors that most directly help or hinder consumer efforts to obtain and maintain employment. Forty-four adults with serious mental illness (SMI) (consumers) and 30 providers participated in 12 focus groups across Massachusetts. We began both consumer and provider groups by posing two broad questions: 1) what factors most help people with SMI get and keep jobs (facilitators), and 2) what factors most prevent people with SMI from getting and keeping jobs (barriers)? Data were analyzed qualitatively and both person and environmental factors were highlighted. Among facilitators, participants agreed that quality consumer-provider relationships and individualized employment services are most instrumental in helping consumers achieve employment goals. Participants identified a range of environmental barriers, including issues related to the service system, entitlement programs, non-human resources, and social stigma. Implications for services are discussed.

1. Introduction

As many as five million adults in the United States have a serious mental illness (SMI) [38,52]. Data from multiple sources suggest that only 15\% of adults with SMI are employed at any one time [21,44]. Furthermore, persons with “mental impairments,” including SMI, comprise the fastest growing and most enduring group of people receiving Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) benefits [26]. Yet despite these statistics, many individuals with SMI express a desire for work and authors have begun to elucidate its meaning and role in the recovery process [6,21,44,48,51]. For these reasons, employment services are increasingly considered a critical component of the mental health service system [3, 13].

Although specific approaches vary to some extent, supported employment (SE) services for people with SMI generally help people obtain integrated prevailing-wage jobs of their choosing and provide on-going supports as needed [40,44]. SE is now considered an evidence-based practice for people with SMI [12,17]. Across several studies, research shows that when people with SMI are enrolled in specific employment-focused services, they achieve employment outcomes that are superior to those achieved by people receiving standard services, such as day treatment [12,13].
though such findings are encouraging and clearly show that people with SMI can work, data from even the most successful SE programs point toward high dropout rates and job placements that are typically part-time, low-skilled, and minimum wage, lasting 6–9 months on average [13,32].

Thus, despite innovations in services, people with SMI continue to encounter significant barriers to achieving continuous, skilled employment beyond the entry-level. What accounts for this substantial work disability among people with SMI? Contemporary models of disablement, such as the World Health Organization’s International Classification of Functioning, Disability and Health (ICF) view disability as multidimensional, resulting from health, personal and environmental conditions [2]. Thus, while a health condition may be associated with impairments and limitations that can restrict participation in a valued role such as work, characteristics of the person that are unrelated to the health condition and environmental factors may moderate these effects, acting either as facilitators or barriers. Mental health researchers and advocates have begun delineating barriers that range from person characteristics like symptom severity and work history to characteristics of the job and environmental factors such as problems negotiating entitlement and human service systems [1,5,31,40,46,53]. These data suggest that employment is influenced by a myriad of factors, only some of which are addressed by current rehabilitation practices.

While certain barriers are commonly acknowledged [40], few studies have investigated the perspectives of those on the “front line” of services; namely consumers themselves and direct employment service providers. In particular, a consumer perspective and focus on facilitators as well as barriers has not been fully explored regarding employment for people with SMI [27]. Input from these stakeholders can help elaborate which factors are most important and pinpoint possibilities for change [14]. As mental health researchers increasingly turn to qualitative methodologies to elicit rich phenomenological data, focus groups appear to be particularly useful for disentangling complex phenomena[7,20,42,47]. The primary goals of the current study were to develop a stakeholder-informed perspective regarding factors that influence employment success and to generate recommendations relevant to employment services.

2. Method

2.1. Recruitment sites

Through contracts with multiple agencies, the Massachusetts Department of Mental Health (MA/DMH) funds a range of community-based rehabilitation programs in six geographic areas. These programs serve people with SMI who meet MA/DMH criteria regarding diagnosis and functional status and include Clubhouse, supported employment, and day rehabilitation programs. The three program types have certain key differences with respect to employment services. The clubhouse model of psychiatric rehabilitation has been widely described in the literature [8,25,36]. Clubhouses provide services within an intentional therapeutic community. Structured work-focused activities are available throughout the day within the club, and members can obtain integrated employment in the community through a variety of options. Transitional employment (TE), most commonly associated with Clubhouses, involves part-time, time-limited, entry-level, prevailing-wage employment in agency-owned jobs that are developed for the club as a whole rather than for an individual member. Club staff provide on-the-job training and support for members placed in TE jobs, and guarantee coverage for absent workers [10,43]. When a member completes the pre-determined duration of the job placement (commonly 6–9 months), another member is offered the job. Clubhouses also provide individualized job development and supported employment services, helping members obtain their own time-unlimited, part- or full-time jobs [29]. Clubhouse staff function in a generalist role in that they assist members with not only employment, but also any community living needs members may have (e.g. housing, entitlements, education, social and other health-related needs). Across the state, 29 Clubhouse programs serve approximately 5200 DMH clients at any time.

In contrast to Clubhouses, supported employment programs in the Massachusetts (known as Services for Education and Employment, or SEE) are staffed by employment specialists who provide individualized job development and placement services for DMH clients. SEE programs employ principles of both the Individual Placement and Support and the Choose-Get-Keep approaches to supported employment and education [9,22]. SEE employment services emphasize rapid placement into competitive, permanent supported jobs of the client’s choosing. SEE programs do not use agency-owned jobs, and typically offer very limited in-house
programming (although many offer computer training programs). SEE staff typically sit on integrated service teams, so that employment services are coordinated with other clinical services that clients receive [11]. The 20 SEE programs in Massachusetts serve approximately 2000 clients.

Day rehabilitation programs in the state are not based on a specific service model, but focus on pre-vocational, social, and daily living skill development. Typically, direct employment services are limited, but program staff may refer clients interested in employment to Clubhouse or SEE programs. The 20 day rehabilitation programs serve approximately 1100 clients.

2.2. Participating consumers

We employed a purposive sampling approach to recruit working age consumers between ages 19 and 59 who were active clients in at least one of the three rehabilitation program types [37]. In order to capture a range of perspectives, we sought consumers who were employed, unemployed but actively looking for work, and unemployed and not looking for work. We sent recruitment letters and announcements to the directors of programs throughout the state to post within their programs, instructing interested consumers to contact the authors to volunteer. To obtain a sample of 60 consumer participants, we randomly selected 10 volunteers from each MA/DMH area and invited these individuals to attend.

A total of 44 consumers participated in six focus groups, ranging from four to 10 people. The majority of consumers were male (56.8%), White (88.6%), never married (61.4%), and reported being consumers of mental health services for over 10 years (65.9%). The mean age was 41.4 years (SD = 8.37, range = 22 to 59). Only four (9.1%) participants had less than a high school education, while the majority (65.9%) had attended some college or technical school. At the time of the study, 50% of participants were employed, working from four to 40 hours per week (mean = 14). Only two worked more than 20 hours per week. Of the 22 unemployed consumers, only six (13.6%) were not looking for work. Thirty (68.2%) participants were recruited from Clubhouses, six (13.6%) from SEE and five (11.4%) from day rehabilitation programs. Six Clubhouse members (13.6%) were also receiving SEE services at the time of the study.

2.3. Participating providers

We also used a purposive sampling approach to recruit provider participants. We limited employment service providers to those working in Clubhouse or SEE programs because these programs directly provide employment services, while day rehabilitation programs do not. We sent invitation letters describing the study to program directors, who distributed letters to staff who directly provided employment services. Potential provider participants called us to volunteer. The small number of volunteers did not warrant random selection of participants. Instead, all volunteer providers were invited to participate.

A total of 30 providers participated in six focus groups, ranging in size from two to six people. The majority of providers were female (80%), White (86.6%), with a mean age of 38 (SD = 11.44, range = 22 to 64). Providers came from Clubhouse (n = 17, 56.7%) and SEE programs (n = 13, 43.3%), and reported having worked in the rehabilitation field an average of 9.5 years (SD = 7.15, range = 0.5 to 26). Most held graduate degrees (40%) or Bachelor’s degrees (40%) and seven (23.3%) individuals identified themselves as being a licensed or credentialed provider (e.g. licensed social worker, rehabilitation counselor).

2.4. Focus group procedures

Two focus groups – one with consumers only and one with providers only – were held at centrally located case management sites in each of the six MA/DMH areas, for a total of 12 groups. Groups met once for 2 1/2 to 3 hours and were co-moderated by the two authors. At each meeting, we introduced ourselves as independent researchers, provided an overview of the study’s purpose, reviewed consent forms, and obtained written consent from each participant. Participants also completed brief demographic data forms. We began both consumer and provider groups by posing two broad questions: 1) what factors most help persons with SMI get and keep jobs (facilitators) and 2) what factors most prevent persons with SMI from getting and keeping jobs (barriers)? We used non-assumptive probes and follow-up questions to encourage participants to elaborate and provide examples from their own experiences and/or the experiences of others they knew [30,39]. We also asked participants to recommend strategies to diminish barriers or enhance facilitators that had been discussed. Not surprisingly, provider and consumer ways of talking about these issues differed consider-
ably. Providers typically abstracted from their experiences working with multiple consumers, while consumers most often told personal stories about their own employment experiences. Group sessions were audio-recorded. We also took field notes during each session, including recording participants’ comments on large flipchart paper to help participants keep track of the factors discussed. Each consumer was paid $35.00 for participating, but providers were not paid.

2.5. Data analysis

Handwritten field notes were typed and audiotapes were transcribed verbatim by a professional transcriptionist, and then checked by the two authors for accuracy. Using “grounded theory” methods [50], analyses began immediately after each pair of consumer and provider groups were held. Each author separately reviewed typed field notes to identify an initial set of codes (themes), and then undertook a line-by-line open coding of the transcripts to further identify emerging themes. Consumer and provider transcripts were initially analyzed separately. In the initial stages of the coding process, we wrote analytic memos that helped us identify and track themes and to create provisional conceptual categories. Emerging themes were examined to determine if they were consistent with existing categories or represented new categories. This constant-comparative method continued as new themes emerged and new categories and subcategories were developed and linked [15,50]. Because we began data analysis immediately after initial focus groups, we were able to continuously confirm and refine emerging themes and categories with participants in later groups. In this way, participants in later groups served in a peer de-briefing capacity, an important process in establishing credibility of qualitative data [37].

As analysis progressed and data appeared saturated, it became apparent that certain person and environmental factors were consistently discussed by participants. Our final step in the analysis was to determine if they were consistent with existing categories or represented new categories. This constant-comparative method continued as new themes emerged and new categories and subcategories were developed and linked [15,50]. Because we began data analysis immediately after initial focus groups, we were able to continuously confirm and refine emerging themes and categories with participants in later groups. In this way, participants in later groups served in a peer de-briefing capacity, an important process in establishing credibility of qualitative data [37].

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Table 1
Person and environmental facilitators and barriers to employment

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<tr>
<th>Facilitators</th>
<th>Barriers</th>
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<td>Coping with symptoms</td>
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<td>– Social skills</td>
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<td>– Belief in self</td>
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<td>– Higher work expectations</td>
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<td><strong>ENVIRONMENTAL FACTORS</strong></td>
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<td>Relevant interventions</td>
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<td>– Skills training</td>
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<td>– Individualized interventions</td>
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<td>– Ongoing support as needed</td>
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<td>Positive relationships</td>
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<td>– Client-provider partnership</td>
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<td>– Mutual warmth, trust, respect</td>
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<td>Connection to a program</td>
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<td>– Support from other clients</td>
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<td>– Seeing others succeed</td>
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<td>Mental health and other services</td>
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<td>– Integrated team meetings</td>
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<td>– Good communication among providers</td>
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<td>A Recovery expectation among providers</td>
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<td>– Shared value regarding work</td>
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<td>Entitlement Programs</td>
<td>SSDI/SSI Disincentives</td>
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<td>– Trial work periods and earning limits</td>
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<td>Social Security System complexity</td>
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<td>– Overwhelming application and review processes</td>
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<td>– Lack of easy access to information</td>
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<td>– Discourteous SSA workers</td>
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<td>– Recognition and support from family and friends</td>
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able to fit-in at work was captured by one provider’s comment: “If you don’t have any interests, then how are you going to express yourself on an interview? How are you going to be that personable person . . . how are you going to have lunch with you co-workers?”

Equally important to work skills, participants noted the relevance of attitudes and age-related life experiences. Of these, consumers and providers most emphasized how positive attitudes can act as facilitators to employment. One consumer shared her perspective: “What it comes down to, you can look at something and you can take it one way or the other . . . if you take your mental illness as debilitating, then it is going to be debilitating for you, but there are always ways you can
grow around things if you look to them.” In contrast, all participants acknowledged how over-dependency on mental health and entitlement programs creates barriers that can undermine work motivation. One provider commented, “There’s a definite fear of losing benefits and entitlements. [A sense of] ‘I want to work so I can live more comfortably, but I also want to be taken care of... kind of wanting it all.”

Finally, providers mentioned how age-related experiences can be both a barrier and facilitator to employment success. While younger consumers were seen as less institutionalized and as having higher work expectations, they also were seen as likely to minimize the impact of their illness. On the other hand, older consumers were viewed as realistic and reliable, but potentially more institutionalized with lowered work expectations. One provider explained: “I think the younger the people... the broader the expectations. They are more open to getting a degree and going to college, less in the cycle of only having an entry-level job. It’s the difference between the ones who have been raised in the community and the ones that have been institutionalized.”

3.2. Environmental factors

Service systems issues, particularly related to rehabilitation and mental health services, were key themes throughout all discussions. In addition, participants emphasized broader environmental factors relating to entitlement programs, the economy, jobs, and non-human resources, stigma and social supports.

3.2.1. Rehabilitation services
3.2.1.1. Specific service strategies

Providers representing different employment models articulated a host of common experiences and had similar perspectives regarding helpful approaches. For example, both Clubhouse and SEE providers described using in-house training opportunities, such as computer training and job preparation training for interviewing, “dressing-for-success” or disclosing on the job. Many Clubhouses offer computer training provided in the context of the work-ordered day. “In the Clubhouse... [our members] want a better quality job. So in order to get them those types of jobs, they are going to need those skills.” This approach was echoed by a SEE provider who said, “We have groups... [that address] job readiness issues. And then we have computer classes which has turned out to be a nice way to get some people started.” These educational opportunities were seen as increasing consumers’ ability to compete in today’s workplace.

Both Clubhouse and SEE providers talked of the importance of individualized, person-centered approaches, matching jobs to consumer interests, and providing supports for as long as people need them. A SEE provider whose program emphasizes rapid placement said, “I guess each person is different... some people need to get right in and get a job, some people need to volunteer, and still others try a job a few times and it doesn’t work... we say ‘you need some more support... let’s try [a Clubhouse] again’.” Similarly, a provider from a Clubhouse noted that while many of their members want competitive jobs of their own, “... not everybody is necessarily looking for that... some people are content just being involved on a part time basis [through TE] and staying connected with the Clubhouse to maintain their health.” Above all, providers emphasized the need to individualize interventions, “[You’ve] got to find the hook for people, because everybody has a reason that they’re going to want to stay with their job.” Both consumers and providers lamented the prevalence of interventions that seemed irrelevant to work, particularly in inpatient settings. One provider related the experience of a consumer with whom she had worked, “[he said] he had been hospitalized time and time again, but he never got well, because the only expectation was that he would paint ceramic elephants.”

3.2.1.2. Relationships with service providers and programs

All participants drew special attention to the importance of warm, trusting, and respectful partnerships between providers and consumers, acknowledging the time such relationships need to develop. One consumer said, “What I found helpful was the person was just a nice person and we got along and his [job] contacts were just perfect.” Another added, “I’m treated as equal, I’m not considered, ‘oh you’re less than ‘cause you’re only a member.’” Providers spoke of the importance of being hopeful as consumers try jobs: “Once I get to... know somebody, I can say, ‘... I think this is the time for you and this is a good spot for you.’ My faith in them [is important]... they trust that I’m not going to ask them to do something they’re not able to do.” Conversely, both providers and consumers viewed the development of supportive, mutual relationships as being inhibited by high staff turnover.

Beyond relationships with individual providers, consumers emphasized the importance of feeling con-
nected to programs and to other consumers engaged in similar struggles. In discussing her difficulty holding down jobs, one consumer said: "The program . . . being rooted there enabled me to take a look on the inside. I was so familiar with the people because I saw them so often that it was unthreatening for me . . . and now I've been at a supported job for two months". Still another consumer added: "When I see somebody else doing it, it makes me say, well if they can do it, look they've got this problem . . . look at what they're doing . . . I might not have all the same strengths or the same weaknesses, but that doesn't mean I can't give it a fair shot either."

3.2.2. Mental health service system
3.2.2.1. Service coordination and values

Most strikingly, providers agreed that communication and coordination gaps exist across the spectrum of human services, presenting a major service-level barrier to employment. These gaps reflect both a lack of formal structures to enhance communication (e.g. integrated team meetings) as well as deeper conflicts in terms of values and priorities of "rehabilitation" versus "clinical" service providers. Many providers described a medical hierarchy that grants lower status to the rehabilitation field. One provider surmised, "The biggest barrier is getting together all of us who serve this individual" while another added, "One person I work with got a job and the response from his case manager was 'we can't switch his appointments, they must come first. He needs his therapy.'" Providers elaborated upon the clash between rehabilitation models focusing on consumer strengths and problem-focused clinical models: "[Clinicians] are more conservative oftentimes in terms of peoples' capabilities, like thinking, 'well work may be too stressful for them right now, they can't handle it', whereas in rehab, you're just sort of like, everybody can do something at some level."

Both SEE and Clubhouse providers spoke of the ongoing struggle to maintain good communication with clinicians that work with their clients. As a SEE provider stated, "I really insist on being part of the team. If an ISP (individual service planning) meeting happens and I'm not there, then I will talk with the case manager . . . or to that person's supervisor". A Clubhouse provider echoed, "Case management here has been great about involving us in ISP meetings . . . it wasn't the case five years ago. We really worked hard with case management to change that . . . so we are pretty much involved in the team." Furthermore, many employment providers felt that psychiatrists do not always consider how medications impact work. "The person is doing well and the doctor wants to do a med change. When they come off their meds . . . it takes six months to get used to that change. Now they can't get up and go to work."

Consumers shared provider concerns about service coordination, but focused more on personal experiences negotiating across multiple social service systems, including mental health, child welfare, and entitlement programs. Lack of service coordination was viewed as leading to onerous and conflicting expectations from a myriad of professionals. One consumer who is a single parent shared: "I think the system, whether it's the welfare system, social security, DSS, is destined to set you up for failure. I got a job . . . and I was like, hey I'm going back to work, someday I'll go back to school. And my second day on the job, DSS calls me up and says 'oh we're taking your kid away if you're not careful.' The system says we'll help you, we want you to succeed, but you have to succeed by our rules . . . not by what you're capable of doing."

3.2.3. Entitlement programs

Most individuals served by DMH-funded program are SSDI and/or SSI beneficiaries receiving Medicare and/or Medicaid. It is not surprising, therefore, that concerns about these entitlement programs received considerable attention in virtually every group. Providers acknowledged the tension that results from helping consumers achieve steady, meaningful employment and retain maximum entitlements. No providers spoke of actively encouraging consumers to leave the disability rolls and most knew only a handful that successfully transitioned off disability.

3.2.3.1. Financial incentives vs. disincentives

Consumers and providers generally viewed social security work incentive programs (e.g. earning limits, trial work period) as actual employment barriers. Participants stressed how non-consecutive trial work periods and earning limits can actually restrict consumers' ability to gradually increase work hours, take advantage of the range of employment opportunities, and smoothly transition off disability rolls. Providers made several points in this regard: "[We are limited] in the kinds of jobs consumers can have. You can get a job as a bagger or maybe in a factory, but what else? You certainly can't get anything professional or you end up asking the employer to lower the wage, which is crazy. Or you end up turning down raises when they are doing a great job". And: "With SSDI you get that wonderful trial work period (TWP), but it gets used up the
first nine months you are working. Who needs a TWP in the very beginning of going back to work … when I really need it is two years down the line when I’m making $900 or $1000 a month”. Few providers expressed confidence that the new Ticket-to-Work/Work Incentive Improvement Act (TWWIIA) [49] legislation would result in significant changes in employment status for their clients.

Despite the fact that Massachusetts Medicaid recipients with disabilities can maintain their health insurance when they return to work, most consumers assumed that going off SSI/SSDI would automatically result in a loss of insurance. One consumer stated, “The health benefits is the biggest thing, because a lot of low income jobs don’t have very good benefits.” Moreover, while many consumers expressed ambivalence about remaining on disability benefits, going off benefits was generally perceived as too risky. “I don’t want to stay on disability, because I feel I basically function pretty well. But if you talk about the economics of it, they need to do something to make it more economically advantageous for people.”

3.2.3.2. System complexity

The complexity, confusion and misinformation inherent in the social security system were other important barriers identified by consumers and providers. Both spoke of how difficult it is to get complete and accurate information regarding SSI/SSDI programs and regulations, the overwhelming application and review processes, and impersonal and oftentimes discourteous interactions with Social Security Administration (SSA) workers. One provider stated, “I’ve been shocked how [SSA workers] treat people. They’re rude and have a serious attitude problem. They feel that people are there to get something from them … like it’s their money.” Another commented, “When our [members] go into the social security office they come out more confused then when they went in.” Yet another added, “you can’t get a person there unless you know the extension. Even if you know the extension, you will get voice mail. The bureaucracy is crippling.”

Both providers and consumers related numerous social security system “horror stories” ranging from overpayments that need to be paid back to lengthy delays in returning to benefits after being discontinued to inconsistent application of SSA regulations across offices. Also, because of a lack of coordination of benefits across entitlement programs, those receiving additional entitlements, such as housing subsidies or food stamps, shared how an increase in work income can mean a loss of these entitlements with the result of having less monthly cash despite working more.

3.2.4. The economy, jobs and non-human resources

3.2.4.1. The economy and jobs

Providers commented that local economic conditions can have an impact on consumers’ ability to obtain jobs, and that job development is easier in good economic times and more difficult when the economy slows. Moreover, several providers told of employers that will “give entry level janitorial or dishwashing jobs” but are more reluctant to offer clerical or office jobs or jobs that involve direct dealings with the public. Employer attitudes can be changed, providers noted, by positive experiences hiring consumers. Both consumers and providers noted that when consumers and jobs are well matched then jobs can act as facilitators. In particular, when jobs provided a “just-right-challenge” they were viewed as fostering a sense of purpose and having a self-perpetuating effect. As one consumer put it: “If you have the type of job where you feel good about yourself and you feel like it’s a productive enough job for you, that you really have a cause and a purpose, it will come from within. You will have the motivation and the drive to … further yourself.” Other consumers spoke of how clarity of job expectations can facilitate work success: “I like to know what are my duties, tell me every one and how you want them and when you want them due. My boss was wonderful at telling me each step … I’ve been in other jobs where they kind of want you to figure that out.”

Both consumers and providers described efforts that employers made to create supportive work environments as facilitators. One consumer described a boss who was willing to make accommodations for him: “[My boss] hired me, even though I had problems. She gave me special accommodations; like I would use the phone to call the hospital … I could take breaks anytime I wanted. [When] the voices were … telling me to steal stuff, I told the boss, and she goes ‘okay’ … she said when I feel better, come back and she will hire me back.” And, one provider stated: “The best employers … are the ones that treat my folks like everybody else … the ones that are very inclusive. I have a fellow at a car dealership, who does a carved-out position, but they give him a sweater, ‘cause, you know, everyone has a sweater with the dealership’s name on it. He gets it that that kind of stuff is real helpful.”

3.2.4.2. Non-human resources

Consumers and providers identified a lack of resources, both personal financial and community services, as presenting significant barriers to employment.
For example, some consumers could not afford childcare or appropriate clothing for work. In addition, many lived in areas lacking adequate public transportation to enable them to access a full range of employment opportunities. This was particularly true for consumers living in rural parts of the state. Even in areas with good public transportation, job opportunities are often limited by a lack of fit between work and public transportation schedules, or by job locations that require traveling complex and time-consuming routes. One provider summarized, “Besides social security, transportation is the biggest problem that we run up against every single day.”

3.2.5. Relationships and stigma
3.2.5.1. Relationships with family and friends
A lack of family support was a common barrier identified by both consumers and providers. As one provider noted, “I find family members are a problem for our members. They don’t want their kids to go back to work, for a couple of reasons. They are really concerned, but also they don’t want [their child] to give up benefits”. However, this was not an unvarying experience among all participants. Some consumers did experience family members as supportive, and many identified the support and recognition of family and friends as being critical to their employment success. One consumer stated, “[What] my grandmother said to me, this made a lot of difference to me. They always had a job.” Another elaborated, “Yeah, sometimes a wife or a close friend can do more for you than even a trained clinician at Harvard Medical School.”

3.2.5.2. Stigma
Consumers described experiencing stigma on multiple levels, including everyday community interactions and images from the media. One consumer said, “It’s very easy for an individual with mental illness to be misperceived as lazy . . . they just don’t want to pull their own weight.” Furthermore, many consumers felt stigmatized by the very people from whom they expected support, namely providers and family members. As one consumer related: The worst stigma came from our own providers. We were locked in mental institutions, told ‘you can’t do anything.’ And then when we got out, ‘well you really can’t get a job because of your illness.’ The Clubhouses . . . they’re changing attitudes, but when you’re conditioned by your family saying, ‘honey, isn’t it too stressful? I’m worried about you working with those people’ [It’s like] Ma, I am that person! You have to break through the system’s own stigma.

The relationship between stigma and low self-esteem was poignantly described by one consumer: “Once you end up in the state hospital . . . as far as any type of self-esteem . . . it’s like society has flushed you down the toilet.” Many consumers talked about internalizing these destructive views and losing sight of their own competence and potential: “When you first find out you’ve got a mental illness . . . it’s like, you know, ‘you’re a retard’ type of thing. And then you’ve got the other extreme of all these people who are familiar with you for all these years, family, friends, etc., saying ‘there’s nothing wrong with you’. And so it’s like from one extreme to the other . . . you lose touch with yourself, with your own awareness of what you’re able to do . . . so that debilitates you”.

4. Discussion

Work participation provides most adults with daily structure, economic stability, and social opportunities. To be unemployed is to be cut off from a valued social role. In the words of one consumer participant, “If you have a mental illness and you can work, it decreases the stigma a lot, because this society puts a great value on working . . . you see somebody on the street, the first question they ask you is ‘are you working . . . what are you doing?’” For people with psychiatric disabilities, achieving and maintaining employment remains a significant challenge.

While acknowledging these challenges, participants expressed confidence in the ability of people with SMI to work. There was a prevailing sentiment that SMI itself is not the most significant barrier that people face. Moreover, participants felt that there are effective strategies for helping people overcome the more debilitating secondary effects of mental illness, such as disrupted education and limited work skills, lack of confidence or poor self-esteem. It was notable that participants representing different employment models agreed upon most of these effective common factors. These included instilling hope and developing trust, partnering to identify goals and maximize choices, making a good match between consumers’ abilities and preferences and jobs, supporting consumers through transitions, and recognizing achievements. Providers also underscored the value of educational and training experiences that help consumers develop competitive work.
skills. The prevailing sentiment among providers was that consumers benefit from individualized services. Some individuals need to approach employment in stages, through graduated experiences that may include in-house work-focused activity, followed by placement in an agency-owned job, as in TE. Others prefer rapid placement into competitive jobs of their own. Providers further agreed that consumers should have options and the ability to choose the approach that best fits their needs. A “one size fits all” approach to service delivery can limit consumer choices and stifle program innovation [28].

Beyond individualized employment services, coordination of services was identified as key. Among our participants, providers who were part of clinical teams were more likely to feel that employment and clinical services were coordinated and that clinicians understood and supported rehabilitation efforts. Researchers have argued that an integration of employment and clinical services encourages communication and coherent service planning, and lessens the burden on consumers for communicating across providers [11, 23].

Ironically, a service system designed to help persons with SMI sometimes poses significant barriers of its own, and a lack of communication and coordination across services was a barrier highlighted by participants. Rather than joining forces, clinical and rehabilitation communities often operate independently of one another—each fulfilling related but distinct missions. Clinicians are typically problem-focused, and treat “illness” with some combination of medications and psychotherapy. By contrast, rehabilitation programs seek to improve consumer functioning through a “wellness” approach that emphasizes consumer strengths. This philosophical tension plays out within a medical hierarchy that discourages “questioning the doctor” and oftentimes denigrates the role of rehabilitation services. The resulting poor communication and disjointed services can block consumers from achieving work goals.

Beyond service system issues, participants most often highlighted barriers imposed by the federal entitlement system. Rather than encouraging consumers to leave the disability rolls, the majority of providers dedicated their energies to preserving and maximizing consumer entitlements, which can foster dependency. In part, this seemed to reflect the belief that continuous support is necessary given the cyclical nature of many psychiatric conditions. More often, however, both providers and consumers seemed to adopt the “don’t rock the boat” attitude described by MacDonald-Wilson [34]. For people with a long-term disability who have worked out how to survive on limited income but relatively good health insurance, any efforts that might upset this fragile balance may be considered too big a risk. This is consistent with Drew et al.’s [24] recent findings that individuals receiving disability benefits from Social Security or the Veteran’s Administration participated less in vocational rehabilitation, earned less income, had a higher dropout rate, and were less likely to be competitively employed at discharge. In addition, national survey findings indicate that many consumers, fearing the loss of financial and health benefits, hesitate to use SSDI/SSI work incentives because the rules are too complex and/or because the SSA bureaucracy seems to act in an arbitrary manner [35]. Notably, Massachusetts has had a Medicaid “buy-in” program (CommonHealth) since 1996. This program, and similar programs developed by states following the enactment of TWWIIA in 1999, allows individuals who meet disability criteria but are ineligible due to work earnings, to purchase benefits through income-based premiums [16]. However, many of our participants were unaware, misinformed or distrustful of the program.

Finally, as illustrated by a recent study of mental health consumers participating in Clubhouse programs, stigma can have a strong and enduring negative effect on individual self-esteem [33]. The pervasiveness of stigma toward people with SMI was a major concern for both consumers and providers. Many employers continue to limit consumers to “back of the house” jobs where they remain invisible to the public. Perhaps even more debilitating, however, are patronizing messages from some family and mental health professionals which become internalized over time and lead to a view of self as permanently disabled. While consumers most often encountered these attitudes in traditional clinical settings, some felt a lack of real decision-making power even within rehabilitation programs where recovery and wellness models predominate.

5. Implications for services

We built upon participants’ recommendations related to key facilitators and barriers to generate implications for employment services.

5.1. Elucidate and champion the helpful common factors in employment services

There was a striking degree of concordance among “front-line” service providers in their experience of fa-
5.2. Increase communication and coordination across human service programs

While integrated services are a key feature of evidence-based employment services, there are often barriers to integration. Some of these include provider attitudes that inhibit good communication. Hierarchies within service agencies and medical establishments and differing views of treatment vs. rehabilitation may undermine coordinated efforts. Even providers who came from programs that espoused service integration acknowledged that there are barriers and that work to keep good communication and coordination among providers needs to be done on an on-going basis.

Providers shared personal success stories and “bottom-up” efforts to improve inter-agency communication and coordination. These included inviting psychiatrists and case managers for program tours or social events and keeping themselves “in the loop” of clinical activities through friendly outreach. Many providers made sure to inform clinicians of success stories, noting how effective these can be in changing clinician attitudes about employment. While bottom-up efforts might help in individual cases, participants agreed that “top-down” supports must be in place to effect widespread change. To further resolve tensions among clinicians and rehabilitation providers, administrators should consider ways to formally establish a rehabilitation presence at clinical team meetings. Participants also stressed the importance of educating state Vocational Rehabilitation agencies and the Social Security Administration workers about employment services for people with SMI. Another top-down approach might involve fostering greater collaboration among programs. For example, some consumers might benefit from the social milieu of Clubhouses and the rapid placement approach offered by many SE programs. However, competition to count client “outcomes” tends to discourage such collaboration.

5.3. Address issues within the entitlement system

Needless to say, the problems inherent in the entitlement system seemed overwhelming and hopelessly complex to most participants. One approach to reducing confusion and misinformation would be to make trained benefits counselors consistently available in clinical and rehabilitation settings. Some participants also suggested that current knowledge of entitlement systems should be considered a core competency for all employment service providers. The impact of the
5.4. Reduce stigma and foster consumer empowerment

Fostering empowerment among consumers is a critical element in the fight against social stigma. Focus group participants characterized three key elements of consumer empowerment—improving access to accurate information about human service and entitlement systems, systematically shifting control of treatment and services away from staff toward consumers, and changing attitudes of providers across mental health systems toward an expectation of recovery. This theme of empowerment also extended to mental health consumers as a group, highlighting the importance of advocacy efforts at local and national levels. For example, consumers and providers could unite their voices to demand more funding for PSR services, better enforcement of the Americans with Disability Act, and entitlement reforms. Furthermore, advocacy efforts can help challenge stigma. Increasing consumer visibility and community contact can be a powerful agent of social change [18]. Many participants spoke of how reluctant employers relinquished negative attitudes as a result of positive experiences hiring mental health consumers. In addition, community charity events, such as holiday gift drives, can promote visibility and be mutually rewarding, allowing mental health consumers to “give back” to their communities.

6. Conclusion

Our findings dovetail with current conceptualizations of disablement, such as the ICF, and speak to the importance of both person and environmental factors in employment success for people with SMI. In the current study, mental health consumers and providers represented a rich source of data, helping to further elucidate this complex phenomenon and generate practical recommendations for service enhancement. While consumer-provider relationships and individualized services were seen as a fundamental facilitator of employment success, environmental factors, including social stigma as well as human service and entitlement system barriers were generally perceived as most daunting and difficult-to-change. Efforts at service innovation must continue to explore ways to diminish these challenging barriers so that people with SMI can participate as fully as possible in work.

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References


