

Considering Early Intervention Programming for Major Depressive Disorder

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Abstract

Major depressive disorder is the most prevalent global disability (WHO, 2015) and accounts for nearly half of lost workplace productivity in America (Stewart, Ricci, Chee, Hahn, & Morganstein, 2003). It is also exceptionally treatable (NIMH, 2013), which makes it a strong candidate for an early intervention program run by the Social Security Administration in the interest of reducing reliance on disability benefits and facilitating personal independence for sufferers of depression. This research examines the importance of early intervention models in dealing with mental health disabilities, since vocational rehabilitation intervention is not shown to be effective in re-integrating individuals who have already left the workforce. This research develops a set of recommendations for a potential early intervention program geared toward individuals with major depressive disorder. Semi-structured interviews were conducted with clients from permanent supportive housing agencies in New Orleans, developing themes and suggestions based on reports of their lived experiences with depression and the workforce.

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Background

According to the World Health Organization, depression is the most prevalent global disability (2015). The National Institute of Mental Health determined recently that nearly 7 percent of the United States' civilian noninstitutional population suffers from at least one major depressive episode per year (2014). This is significant to both the Social Security Administration (SSA) and the national workforce, since more than 840,000 people received disability benefits due to mood disorders in 2014 (SSA, 2014), and the Bureau of Labor Statistics found in a national study that "at all levels of education, persons with a disability were much less likely to be employed than were their counterparts with no disability" (2015, p. 2).

It is therefore important to note that depression is treatable. The National Institute of Mental Health reports that all cases of depression, even the most severe, can be treated (NIMH, 2015, p. 10). In other words, major depressive disorder (MDD) is a treatable condition that continues to disable hundreds of thousands of people annually. This makes it a strong candidate for inclusion in an SSA early intervention program – perhaps, if individuals at risk for unemployment on the basis of MDD could be identified and treated earlier they would be able to maintain their independence and have a superior quality of life. The purpose of this qualitative study is to understand what early intervention measures could be taken to assist individuals with MDD and other affective disorders to remain in the workforce or maintain otherwise independent lifestyles rather than depending on long-term disability benefits for survival.

Since one of the SSA's primary organizational goals is to promote work and independence (SSA, 2015), it is important to consider early intervention programming, as recent evaluation suggests that SSA's Ticket to Work and Work Incentives Improvement Act (TTW) does not yield significant returns to the workforce (Mathematica, 2013), and that rehabilitation programming offered after workforce exit as a whole is generally not successful (Dean, 2012). Although the SSA offers no form of short-term disability, it is in the process of developing research about the possibility of implementing an early intervention program to help at-risk citizens maintain independent lifestyles and remain in the workforce. One preliminary SSA study of early intervention examines a range of models geared toward individuals with psychotic disorders (Weaver, 2015). Also, a panel of experts was assembled in 2015 to produce a report presenting recommendations for generalized treatment of future early intervention programming efforts (SSA, 2015). This panel recommended against implementing programs that look the same for all participants; rather, it suggests, packages must be designed for applicants according to their own individual type of need. The panel provided a number of recommendations, among which were: offering employment supports as a part of job development, including short-term wage subsidies, targeting efforts to younger members of the population, and developing standardized protocols to identify individuals at risk of mental health disability (SSA, 2015).

Weaver (2015) emphasizes the potential for early intervention to prevent individuals from dropping out of the workforce, noting that some warning signs can be evident even on a systemic level, since "health and earnings often begin to decline well before complete disability onset or receipt of DI benefits" (p. 3). Weaver's study provides examples of several different models of early intervention for individuals with psychotic disorders, including the SSA's Mental Health Treatment Study (MHTS) (Frey et al., 2011), a large national randomized controlled trial of SSDI benefit recipients with either psychotic or affective disorders. The MHTS implemented Individual Placement and Support (IPS) services in twenty three national sites, and determined

that integrated mental health and employment support services facilitated a 61 percent employment rate (a 20 percent higher rate than the control group), and significant improvements in mental health status and quality of life. The IPS model contains many lessons that would be useful in the development of a similar effort to support individuals with affective disorders within the disability system. While the majority of SSA research related to early intervention targets treatment for psychotic disorders, IPS is designed to improve outcomes for anyone with a severe mental disorder (Becker, Swanson, Bond, & Merrens, 2011). The model is founded on a set of eight principles, based on comprehensive coverage and availability, integration of vocational and mental health support services, and self-determination. Support services are tailored to the individual's needs and preferences, and are available for as long as they are desired (Becker, Swanson, Bond, & Merrens, 2011). IPS has been tested in fifteen randomized control trials since 1996. An average of 60 percent of participants receiving IPS services obtained competitive employment in these trials, as opposed to an average of 24 percent of participants receiving other vocational services (Becker, Drake, & Bond, 2011). It is the only existing employment model with research to support its effectiveness for people with behavioral health needs (Drake, Bond, Becker, Swanson, & Langfitt-Reese, 2015), with no studies yet indicating a subgroup that did not benefit significantly from these services (IPS Works, 2014).

Currently, the SSA offers workforce return incentives for disability recipients in the form of the Ticket to Work program, which allows beneficiaries to ease back into the workforce with employment assistance and some protective features that work to reduce the individual's reliance on disability benefits, while still providing them with healthcare and basic financial security in the case that they need to stop working (SSA, 2016). However, the most recent evaluation of Ticket to Work outcomes suggests that this program has only a limited reductive effect on benefit reliance, and Mathematica found that "rigorous impact analyses failed to provide strong evidence of its impact on employment" (2013). Furthermore, no such services are currently offered to citizens who are precariously situated in the workforce and not yet enrolled in disability programs. Dean (2012) emphasizes the importance of offering vocational rehabilitation services to individuals prior to their exiting the workforce, citing Thornton et al.'s (2003) report that vocational rehabilitation services are ineffective for beneficiaries who have been out of the workforce for two years or more. This is a very meaningful consideration for efforts to allow individuals to remain independent and reduce public reliance on disability benefits. Dean (2012) goes on to cite Waddell et al.'s (2003) findings that vocational rehabilitation interventions are most effective when started within 3-6 months of an individual's sickness absence, and that there is progressively less effectiveness shown for interventions used after 6 months of absence.

Other research efforts have been conducted to examine the effects of early intervention programs for individuals dealing with MDD. Reynolds et al. (2012) suggest that targeted risk-reduction strategies for depression in older adults could improve workforce problems and reduce the economic burden of depression on multiple systemic levels. Bohmen et al. (2011) conducted a large-scale study in Texas (the Working Well Demonstration to Maintain Independence and Employment, which received grant funding from the Ticket to Work and Work Incentives Improvement Act) to provide early intervention case management assistance, extensive health care coverage, and expedited health services as employment supports for working individuals with all types of disabilities. Contrary to expectations, the study did not find that individuals receiving the assistance worked more than the control group, although it did find that the treatment group ultimately relied very slightly less on disability benefits (Bohmen et al., 2011). The study was then extended to sites in Minnesota, Hawaii, and Kansas, yielding a similar lack of improved work outcomes (Mathematica, 2013). One factor that may have improved outcomes

in the study could have been an increased emphasis on mental health treatment, as was successful in the previously mentioned interventions for psychotic disorders. However, the Bohmen study used a generalized approach, which provided the same services for all participants, including those who were disabled for physical reasons alone. These outcomes indicate that different disabilities demand different interventions – in particular, mental disorders require different treatments than physical disorders.

Several meta-analyses exist that indicate success with early intervention efforts for depression. Barrera, Torres & Muñoz (2007) identified seventeen randomized controlled trials focused on preventing the onset of depression or on preventing depression relapse, and concluded that up to 50 percent of depression onset and relapse can be feasibly prevented with cognitive behavioral therapy groups or individualized sessions. Murray & Jenkins (1998) advocate for improved screening and response strategies for primary care providers, public health awareness and education campaigns for the public, and earlier identification of individuals in high-risk groups.

In general, however, existing literature describes surprisingly few efforts to develop early interventions for MDD in American adults, even though the prevalence and treatability of depression indicate that these efforts are warranted and could prove to be quite beneficial. Such interventions, though, should be designed with an explicit focus on the specific conditions associated with affective disorders, and interventions shown to improve outcomes for sufferers of depression in particular. This kind of knowledge exists most immediately with those individuals who themselves have MDD and have left the workforce, and who are now considered disabled and dependent. These individuals are best positioned to provide insight into the reality of the struggles to maintain employment in the face of depression, and of the specific obstacles that have been prohibitive to their independence. As a group, they also have a rich variety of experiences with different mental health resources and can identify which aspects of these resources were particularly effective or unhelpful. Since relatively little literature is currently available on this subject, the purpose of the study was to carry out a qualitative cross-sectional study of individuals diagnosed with affective disorders and receiving Social Security benefits, to assist in identifying recommendations for a potential early intervention program to provide improved supports for individuals who are not yet disabled and to help them remain independent if possible. These efforts would also ideally improve the Disability Determination Process by providing a more standardized protocol for responding to applications related to affective disorders that meet some disability criteria but not all.

Method

The study took place in New Orleans, with participants recruited from the clientele of three permanent supportive housing agencies, two of which provided on-site housing. The third facilitated independent supported housing throughout the Greater New Orleans area and provided case management services. Interviews were conducted in available offices at agency headquarter sites.

Design. A qualitative grounded theory approach was used with purposive sampling. Grounded theory allows for the generation of fresh and relatively unbiased hypotheses from the data collection process (Rubin & Babbie, 2010), which ultimately were strongly compatible with the limited amount of existing research on this topic.

Sampling. Case managers and agency managers at three permanent supportive housing agencies were provided recruitment flyers to distribute or display. At one of these facilities, this researcher spoke at a community meeting to recruit participants, and scheduled interviews with eligible community members with the assistance of the agency director, who was able to confirm diagnoses and receipt of benefits. At the other two facilities, case managers and agency directors identified eligible residents, approached them about their interest in participating, and coordinated interviews accordingly. The recruitment procedure yielded a total of twenty interviews, which ranged in length from twelve to eighty minutes. Two participants did not technically meet eligibility criteria due to being still in the process of applying for benefits, but their long-term disability and current engagement in the SSA application process were helpful in the attempt to identify issues with Disability Determination Service (DDS) processes. Each participant was given a \$25 grocery gift card as compensation for participation.

Data collection. Data was collected between August and December of 2016. The recruitment process, interview scripts, consent forms and compensation agreements were approved by the Tulane Institutional Review Board. Participants reviewed and signed a confidentiality agreement, consent to record and transcribe, and provided demographic information before the interview began. Interviews consisted of two separate tracks of questioning depending on whether the participant received SSI (Supplemental Security Income), which is strictly need-based and not dependent on prior work history, SSDI (Social Security Disability Insurance), which is based on work history and an individual's contributions to Social Security taxes over time, or both (Social Security Red Book, 2017). However, it became clear that some individuals who only qualified for SSI had significant work histories anyway, in which case the SSDI interview track was used instead (see Appendices B & C for interview guides).

Measures. All interviews included questions about psychosocial and treatment background, onset of symptoms, work experience, experience with the Disability Determination Process (DDP), and perceptions or knowledge about depression. Both interview tracks were quite similar throughout, but the SSDI track included slightly different wording and slightly more extensive investigation of the individual's experiences in the workforce. This consisted of questions about what kinds of supports were available or notably lacking in their previous jobs, whether emotional, organizational, or related to formal resource referrals. They were also asked about their exits from the workforce, and about missing resources that might have allowed them to remain employed. Everyone was asked about the decision to begin the SSA application process, what types of professionals aided in this decision, and what kinds of resources or supports might have made sustained employment or independence more attainable during or prior to that period of time. Finally, everyone was asked what they thought about the application and selection process, and if they had any particularly frustrating experiences or suggestions for how to simplify the process. Interviews were semi-structured, and generally conversations were loosely organized, allowing participants to introduce new directions as they deemed necessary.

Participants. Twenty individual, face-to-face interviews were conducted, ranging in length from twelve to eighty minutes. Eligible participants were over 18, resided in the Greater New Orleans area, were diagnosed with Major Depressive Disorder, and received Social Security disability benefits. Participants ranged in age from 29 to 69, with a mean age of 55 years old ($s=8.8$) (See Table 1 in Appendix). Nine participants (45 percent) were female and eleven (55

percent) were male. Eleven were born and raised in New Orleans, five had moved to New Orleans from other parts of the state, and five had moved from other states. All had been diagnosed with depression at some point, though five were later re-diagnosed with Bipolar II. Eleven had received additional diagnoses, including other psychiatric and/or physical conditions. All but two actively received Social Security disability benefits, and the other two had recently applied for benefits and were waiting to receive determination decisions.

Data analysis. Semi-structured interviews facilitated the analysis of themes through open coding, emerging from discussion with participants. Interviews were transcribed, coded, and analyzed at two levels: first, a preliminary deductive analysis organized material according to specific question-answer categories (see Appendices B & C), and then a second, inductive analysis was performed to identify unanticipated emergent themes. Open coding yielded a variety of emergent themes, including personal philosophy on depression, coping, and work, extended discussion of prior mental and physical health treatment or other health-related experiences, and the identification of specific systems issues not raised by interview questions. These were sub-sectioned into further categories including the downsides of living on benefits, specific resource feedback, problems with navigating social stigma, history of family support, prior access to health care, and histories of trauma and physical health issues.

All digital data was transcribed verbatim by the investigator. Demographic questions were not included in the interview recordings, and any potentially identifying information was removed or disguised in interview transcripts to protect participant confidentiality. Transcripts were loaded into QSR International's NVivo 11 Pro software for analysis. Analysis was then compared to existing literature on Disability Determination Services (DDS), behavioral health early intervention models, and work rehabilitation models.

Qualitative validity strategies were used to establish credibility of the analysis. Data was triangulated in comparison to existing studies. Informal member checking was conducted primarily during interviews, by asking for clarification on specific answers, or by re-stating interpretations and allowing for participant input.

Results

Two analyses, the first organized by interview question and the second developed inductively by the emergence of themes, revealed insights and patterns that were ultimately organized into the following categories: employment experiences; awareness and access; mental health supports; and the Disability Determination Process.

Employment experiences. Participants, for the most part, had a good deal of work experience behind them:

- Their lifetime participation in the workforce ranged in approximation from two months to forty years, with an average of nineteen years spent in the workforce overall.
- Types of jobs included construction, military, engineering, nursing, security, custodial, and home health care work, but the most commonly cited type of long term work was in food service, with eight participants (40 percent) identifying it as their primary field of employment.

- Individuals left work for the following reasons: six left due to severe physical illness or injury, three left after traumatic life events, five left after experiencing a gradual increase in difficulty managing depressive symptoms, and two were fired as a direct result of depressive symptoms.
- Effects of depressive symptoms on work varied; most reported that the symptoms made working significantly more difficult, but several reported viewing work as an escape from symptoms.
- Revealing depression to employers had different outcomes, with most respondents not reporting symptoms at all, either for fear of being penalized at work or because they were not aware of their conditions themselves. Two had sympathetic employers and long, satisfying work experiences, and two others reported having been fired as a direct result of depressive symptoms.
- Attitudes toward work were mostly positive, with eleven respondents stating they would prefer working to living on the disability rolls.

Many important insights emerged when discussing the convergence of depression and employment. The majority of people indicated that depression impacted their work experiences in significant negative ways. One participant reported that work exacerbated his symptoms, which impacted his performance: “I started having thoughts of suicide, I started getting really anxious, I couldn’t deal with simple problems – I’d get so frustrated I’d start crying or yelling, didn’t really know what was happening.” Three participants, though, mentioned that they viewed work as an escape from depression and that symptoms became worse after they left the workforce.

Participants reported a range of experiences in dealing with employers in relation to their depression. An overwhelming majority reported that their employers were not aware, primarily because they did not disclose their condition, fearing that the workplace would become hostile if they did. Three reported that they themselves were not aware of their depression while working, or were not depressed at the time. Two participants reported that their employers knew they were depressed and were supportive. One man stated: “They knew I was having some problems, and they gave me a couple extra days off here and there just to go sit in the park...they were super nice. Super understanding, yes.” The other reported: “I didn’t know that I was depressed when I was working, just knew some days that I couldn’t get out of the house...but he understood that, so I didn’t lose my job or anything, he worked with me.” Both of these respondents reported maintaining employment at these places of business for over a decade, leaving only after experiencing major personal crises that forced them out of work.

However, most respondents sensed that it would not be “safe” to disclose their depression to their employers. One woman stated simply, “I was afraid I wouldn’t have a job if I let on.” She may very well have been right – one man described being forced out of his job as a result of his depression: “I wound up losing my job, well, they say I wasn’t fired, they said they wanted me to go get evaluated...[and then] I lost everything...I just lost my job for no reason.”

Most respondents indicated that if they felt they were able, they would prefer working to remaining on the disability rolls. Many expressed feeling delegitimized or demoralized by their inability to participate in the workforce. One man expressed the desire to work in a way that articulated the way many other individuals also seemed to feel: “I found a lot of self-fulfillment in work, having the responsibility of a job and going to it...we’re very conditioned to believe that if you want some kind of value in your life, work’s gonna be it.” Another woman reported that unemployment took effort to adjust to: “It took me a long time to accept that I couldn’t

work. ‘Cause I still was trying to work, and I know now I couldn’t give it my all, I had to sit back and take care of me. It was something. At first, I felt worthless, or like I’m not useful no more to others, it took a lot from me. Especially when you’re used to working, and then suddenly you have to stop. And you know that you’ve been independent, and then you have to depend on someone else. It took a lot out of me.” However, respondents also generally felt that the barriers preventing their return to work were too significant to overcome. They listed depression, physical problems, stigma, resume gaps, and criminal records as prohibitive factors. These barriers are significant, and given that the majority of participants attributed their workforce exits to mental health issues, their sentiments correspond well with research that suggests preventative mental health supports could help to preserve workforce retention, but that barriers after exiting the workforce are extremely prohibitive to return.

Awareness and access. One very common thread of discussion dealt with the issue of awareness of depression and prior access to mental health resources:

- Lack of awareness of depressive symptoms until later in life was a common theme.
- Mental health treatment came late for most respondents. Thirteen reported that they did not receive either diagnosis or treatment until they were hospitalized for suicide attempts or had already become disabled, some in spite of previous attempts to seek help. Most characterized their path to treatment as complicated, difficult, and not resulting in professional supports until they had already reached dire circumstances.
- Public health education campaigns about the signs of mental health problems was suggested by several respondents, as they indicated that such information may have encouraged them to seek treatment earlier.

Multiple participants reported that they were not aware of their depression until late in their lives, or did not recognize the symptoms as indicators of depression. One man stated: “We’re talking about the seventies. Rich people got depressed. We just muddled through.” Another said, “For a five year period I dealt with it. No medication, no treatment, nothing. Just deal with it the best I can, was the attitude. I refused to really even believe that it was considered a medical condition. I mean, to me it seemed like, well, that’s just the way it is, it’ll pass. But, turned into a five year period...you have to school somebody on stuff like that. The average person seems to have a kind of attitude about mental illnesses, even when they know something’s not right, they experience it...and still don’t do anything about it.”

Six respondents stated that they were not diagnosed with depression until after they were hospitalized for suicide attempts. Seven others reported that they did not receive any kind of treatment until they were nearly or already disabled. One man stated: “As an adult I always figured I’d get locked up and put away, or, that’s just how they did in the sixties. You’d just get put in a mental institution. I was brought up to think that way, so it was hard to talk about and I just kept it to myself...I didn’t know about a lot of programs and people out there that could help, I didn’t know any of that at all.” Another said, “I didn’t have insurance at the time, so I just dealt with it.” One woman reported that she attempted and failed to obtain treatment beginning in her teens, and was not able to access it until she became disabled in her forties. Several others also mentioned that becoming disabled provided them with access to the resources they needed, like one woman who reported that the best benefits provided her as a result of her disability were

that “I can get a doctor, and I can get a psychiatrist, and I can get somebody that’ll listen to me. That part I like and really need. [Before,] I was living alone, and it was scary. But this seems like now I’m, you know, I can reach out to somebody.”

Most people indicated that their path to resource access or mental health education and treatment was indirect and complicated, and several suggested that a public health campaign informing them about depressive symptoms and treatment options may have made a difference in their own decision-making processes regarding a workforce exit. One participant suggested that such a campaign could “catch their attention... and then maybe it’ll wake something up inside them, and make ‘em look into it in more depth.” Another disclosed a suspicion that if he had been prescribed his medication regimen while he was still working, he might never have stopped.

Mental health supports. Participants had a variety of experiences with and opinions regarding available mental health supports:

- Individual and group counseling were both viewed as important. Nine participants suggested that professional mental health supports would be crucial to the success of an early intervention program for depression, primarily in the form of individualized therapy, and five indicated that support groups or group counseling might be equally effective.
- Types of treatment currently received varied somewhat. Five participants reported actively engaging in therapy of some kind, with or without medication, and fifteen reported receiving a psychotropic medication regimen by itself.
- The quality of professional mental health services emerged as an important theme. Participants reported complaints or suggestions regarding the quality of available services, as well as positive feedback about specific aspects of received support that was helpful. Respondents indicated that professional mental health services must be high quality to be useful. They prioritized thoughtful diagnosis, allowance for self-determination, and a display of active interest in patient condition as important characteristics for quality professionals.

One person described therapy as the most important factor in treating his depression: “I think communication is the epitome of healing from depression. To isolate, like I was starting to do myself before I got involved in mental health at [X], it made all the difference in the world. Cause you run into people that are having the same problems you’re having, and you share ideas, and they’re very well trained at the mental health unit for [X], and they give you ideas for how to cope with it.” This is likely an important consideration, given that only five of the twenty participants were engaged in any type of therapy, and the rest were using a medication regimen alone. Rubeis, Siegle, & Hollon (2008) determined that cognitive therapy is equally effective for treating depression as antidepressant medications, with the added benefit of providing sustained protective effects even after therapy has ended. Olfson & Marcus concluded in 2010 that the use of psychotherapy as a mental health treatment was decreasing, and reliance on psychotropic medicine alone was increasing significantly.

Another prominent theme was the quality of therapeutic services available. Several respondents complained that even though they had access to more resources now, they did not consider them to be helpful or high-quality services. Most frequently cited complaints indicated that they did not feel their mental health practitioners were sincerely engaged in their treatment or allowing patients sufficient control over their own treatment courses. One man put it this way:

“I don’t put a lot of stock in psychiatrists anymore. I generally think that if you ask three psychiatrists a question, you’ll get four different answers... it’s about money. I’d say virtually every time that’s true... They don’t talk to you, they go in there, they write their medicine and give it to you... it serves you well to read as much as you can about what they say you are, ‘cause there’s a good chance that you might not be what they say you are.” Another stated: “They just start throwing pills at you. They don’t sit and talk to you about your diagnosis. You’re sitting there, and all they want to do is throw pills at you, and you have no idea why they’re doing that.” A third man complained of his therapist’s lack of engagement in their sessions: “I have a therapist that I see and it’s – I didn’t have any social or emotional support whatsoever, and I go to him to talk things out, and whether he talks back, he usually doesn’t, but... I just wish I had somebody to talk to just to get feedback or whatever, cause it makes me feel better and maybe I could get a different angle or a different take on something that may be right underneath my nose, help maybe find a solution that I can’t find myself, and not feel isolated. I always feel like a ghost, like I’ve been overlooked, you know.”

There were a wide range of suggestions provided about which professional support services would be important for early intervention, and about how to improve existing services. One man suggested that mental health professionals delay diagnosis “to a later stage... cause it’s just too, it’s like a rush to a snap judgment. It shouldn’t be that, it shouldn’t be more important to label someone than to find out what’s wrong with them. And then tell them, well we think, we THINK, that you have this problem. We’ve taken a lot of time, a considerable amount of time, to come to this conclusion. It wasn’t just, you come into the office, sit down, and we told you this.” Frequently insurance issues in traditional treatment settings prevent delayed diagnosis, often forcing a diagnosis at intake. A less rushed approach may be useful in an early intervention program developed to ward off disability rather than rely upon diagnosis to support an application. If individuals can be treated thoughtfully and proactively for prodromal symptoms, it may be possible to prevent reliance on disabling diagnostic categories before individuals actually reach the point of disability.

Other respondents described therapeutic approaches that had been decidedly helpful for them. “When I went through [X facility], it was a whole new different world that I was into... the professionals were better. They had group sessions, things like that, everybody talking about how they’re doing, how their medicine working, it was beautiful. It was nice... and that’s where I picked up a lot of – I learned about it more.” Another reported a great deal of relief in therapy: “To be able to talk it out, without somebody looking at you sideways or something, felt so good to talk it out.” A third respondent identified the characteristics of empathy and flexibility as beneficial to his treatment: “The main thing is, they do show concern. They ain’t doing it just to get a check. They want to know actually how I’m doing. They try to pick your brain and everything, I even get tired of it. But they understand, you know, if I get tired, just let me go and do me, I’ll come back and rap with you later... I got a great deal of resources, all I got to do is open my mouth.”

Disability Determination Process. Respondents reported a variety of experiences with the DDP:

- The application process yielded mixed reviews. Seven respondents reported that they found the application process to be easy and straightforward, while seven others characterized it as complicated or difficult.

- Approximate average age of depression diagnosis was forty-four, and approximate age of successful benefits application was also forty-four.
- Approval for benefits occurred at a varied pace. Eight participants were approved for benefits after their first application, eight were approved after the second application, one was approved on the third try, and one participant reported applying and being denied repeatedly for twenty years before hiring a lawyer to help with the application.
- Professional assistance during the application was a game-changing form of support. Eight reported using professional supports such as lawyers or case managers in the application process.

When asked to describe specific complications or difficulties encountered during their application processes, most individuals cited issues in communicating consistently with SSA personnel, stating that they did not understand what made the difference between, say, a first application that was denied and a second that was approved. One participant, who claimed to have applied and been denied repeatedly for a period of twenty years before hiring an advocate, stated that he had not been able to successfully apply on his own because “if you don’t say just the right words in the right little box, you’re screwed, glued, and tattooed.” Another reported that he was denied benefits twice while living in Louisiana, but approved after he moved to Alabama. Most people who had issues with the application felt that they would not have been approved without legal assistance.

Discussion

Design limitations. There were some limitations inherent to the study design. First, a relatively small and localized sample limits generalizability, as does the fact that all study participants were recruited from permanent supportive housing agencies as opposed to a more diverse range of sources. The study’s being set in New Orleans may impact generalizability also, as it is an urban environment with a unique cultural identity – for example, groups from more rural backgrounds may not have such a high incidence of food service work, which may impact perceptions about employment support. I also neglected to include lines of questioning in the interview about the details of prior access to mental health services – although this topic came up naturally quite a bit, systemic obstacles to treatment such as health insurance seem like an important area to examine in more depth. Some themes that emerged frequently in conversation might have been more comprehensively addressed if they had been included in the standard lines of questioning, including the issue of physical health, as not everyone was asked about disabling physical conditions, and the issue of trauma, as some may not have volunteered this kind of information without being asked.

Participant recommendations. Respondents provided a wealth of thoughtful suggestions and input related to the need for and ideal design of an early intervention program for affective disorders:

- Ten respondents (50 percent) said they believed an early intervention program would have been helpful to them when they were struggling with depression

before becoming disabled, and four more stated they believed it would be helpful to others.

- Three participants recommended a public health education campaign about affective disorders. Ten emphasized the importance of professional mental health supports, and three expressed interest in peer support services. Four suggested improved mental health services within the workplace. Five recommended temporary financial assistance to take pressure off individuals struggling to thrive with depression in the workforce.

One man stated: “I think preventative measures are necessary. I feel that’s especially necessary these days; it seems like we’ve got more occasions of mental illness these days than ever.” Another stated that he believed if he had had access to early intervention services “I never would have left my jobs.” Respondents provided a number of additional suggestions for a potential early intervention program. Several emphasized a need for awareness campaigns to inform the public about how to identify depressive symptoms, as they felt they did not know enough about depression to recognize their own symptoms, or to seek help before it was too late. This, and the fact that seven (35 percent) of the respondents were not diagnosed with depression until after being hospitalized in crisis situations, also indicates a need for improved screening in other health service contexts. An early intervention program could partner with local general medical practitioners to try and identify community members who would benefit from early intervention services to try and prevent the development of disabling depression.

The respondents also underscored the importance of support groups, individualized therapy, case management, and peer support services. Regarding this last point, several indicated interest in providing peer support services themselves. One woman suggested that a peer support service exchange program would be valuable, allowing individuals to draw upon their personal strengths to provide help to others in need: “My thing [is] cooking, helping the people when they be working, no charge. Cause I have food that I throw away...one [important] thing would be to be helpful to the next fellow.” Given that many individuals expressed a depressing feeling of uselessness upon exiting the workforce, peer support exchanges could allow program members to benefit from providing meaningful help to others who are struggling, or receiving help in their own times of need. Regarding professional mental health services, many indicated that services would only be useful if they were high quality, involving professionals who expressed an active interest in their clients’ needs and opinions, and would allow them an active voice in their treatment options.

Several participants suggested that short-term or emergency financial assistance might also be crucial to help at-risk individuals through difficult times when they might otherwise give up and turn to disability benefits as a more stable source of income, particularly if depressive symptoms were causing problems at work. One suggested that tuition assistance might also be a meaningful preventative resource, since individuals at high risk of disability do not always have access to loans or subsistence money, but would potentially return to school if this were a more financially feasible option.

Other emergent themes. The intersection of physical health and depression was notable, and an additional contributor to depression was trauma:

- Twelve respondents (60 percent) self-identified as having major physical health problems that interfered with their ability to work and exacerbated their depression.
- Physical injury or illness was the second-most commonly cited barrier for a return to work (second to mental health issues), as eight respondents indicated that they would not be able to return to jobs in their prior fields, which were too physically demanding.
- Nine respondents identified trauma as a major factor in their depression.
- Four participants attributed their depression entirely to traumatic experiences. The primary types of traumatic experiences identified by participants included the deaths of spouses and other family members, child abuse, and Hurricane Katrina. The high incidence of traumatic experiences within this study is consistent with existing research suggesting that stressful or traumatic life events are the most significant causal factors of depression and anxiety in the general population (Kinderman, Schwannauer, Pontin, & Tai, 2013).

Recommendation analysis. After comparing interview analyses with existing literature, I suggest that the IPS model is compatible with the recommendations generated by this analysis.

- IPS is designed to improve outcomes for anyone with a severe mental disorder
- The model is founded on a set of eight principles, based on comprehensive coverage and availability, integration of vocational and mental health support services, and self-determination. Support services are tailored to the individual's needs and preferences, and are available for as long as they are desired (Becker, Swanson, Bond, & Merrens, 2011).
- IPS emphasizes work supports to assist individuals in obtaining the necessary support to thrive in long-term competitive employment with mental health issues.

When asked about hypothetical work supports that might have made it possible for participants to remain employed, many stated that they believed their workforce exit was inevitable; however, some suggested that support groups, employer sensitivity and awareness training, the ability to take occasional “mental health” days off, and earlier access to medication and therapy might have made a difference in their ability to continue to work. IPS provides individualized work supports to assist people in maintaining employment, and assists them in finding jobs in supportive work environments, which is crucial considering that the majority of respondents did not feel safe disclosing their mental health issues to their employers, but that the ones who were able to do so had long and satisfying work experiences. IPS also considers anyone who wants to work to be eligible for competitive employment, which is an important value given that nine (45 percent) respondents indicated that they missed working and would prefer it to disability if they felt it were possible. IPS reports other research indicating that “approximately 2 of every 3 people with mental illness are interested in competitive employment, but less than 15% are employed” (2014).

Potential benefit to the Disability Determination Process. Early intervention programming may help to clarify ambiguity between systems issues and individual need for application evaluators, as well as reducing the number of disabled individuals nationally, by

helping to identify individuals at risk for disability for whom improved access to services may enable them to remain in the workforce.

- Disability rates are 80 percent higher in rural American areas than in cities.
- Most disabled individuals express pro-work attitudes and would prefer to work, which has been noted in existing research and is reflected here in participant interview responses.
- Issues like stigma, criminal records, and national economic conditions frequently interfere with disabled individuals' abilities to find work.
- Individuals who struggle to maintain consistent employment may depend on disability as a permanent means of accessing a steady income, which complicates the DDP.
- Early intervention programming could work to reduce ambiguities for DDP assessors, who would be able to provide specific resources to individuals applying prematurely or do not fully meet criteria for disability.

It's important to consider the systems issues involved when it comes to disability in the United States. It is likely no coincidence that disability rates are 80 percent higher in rural, low-opportunity areas than in American cities (Bishop & Gallardo, 2011). Most disabled individuals express pro-work attitudes and want to work (IPS, 2014), but issues like stigma, criminal records, and national economic conditions frequently interfere with disabled individuals' abilities to find work. Frequently, normal work trajectories are interrupted by crisis, and individuals who are forced out of the workforce by traumatic life experiences or symptoms of mental health conditions report tremendous difficulties in breaking back into it, even with vocational rehabilitation assistance. Harris, Owen, Jones, & Caldwell (2013) point out that "while the TTW is intended to move people with disabilities into the labor market, it operates in a broader policy context of disjointed employment incentives and a benefit climate that creates barriers to moving from welfare onto employment." They point out the glaring differences in employment access and income rates for disabled individuals, suggesting that current workfare policies are insufficient to allow individuals with disabling conditions the same access to the labor market as non-disabled individuals.

Also, in an economic climate that requires proof of severe medical difficulties as a condition of public financial support, individuals who struggle to maintain consistent employment may be more likely to rely on the medical disability model as a more permanent means of accessing a steady income. This complicates the DDP, as the system must contend with a large number of individuals straddling the line between destitution and disability. An early intervention program would provide a third ruling, between acceptance and rejection, for individuals in these circumstances, minimizing the issue of ambiguity for DDP assessors and providing a more standardized approach to addressing that occurrence.

Conclusion

Early intervention may be able to help some people access supportive resources before they have become too deeply disenfranchised to maintain or obtain connection with traditional work structures, and would also help to simplify the DDP by providing an enhanced, more comprehensive protocol for directing ambiguous applications. Since depression is an exceptionally treatable condition (NIMH, 2015), it makes sense to work toward improving

treatment resources for individuals at a higher risk of disability, rather than to wait until after their formal disengagement and permanent alienation from the workforce. A biopsychosocial approach to early intervention would consider the prevalence of physical health problems, trauma, and systemic economic instability as major contributing factors to disabling affective disorders, and would work to provide solutions for these issues. Early intervention programming would allow for more nuance within the DDP, reduce ambiguity in decision-making processes by providing a more comprehensive framework for use at crucial junctures, and likely reduce overall reliance on long-term disability benefits.

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Appendix

| Table 1 | |
|-------------------------------------------|-----------------|
| <i>Participant characteristics (n=20)</i> | |
| Age in years, mean (range, SD) | 55 (29-69, 8.8) |
| Race/ethnicity, n | |
| African American | 13 |
| White | 5 |
| Native American | 2 |
| Gender, n | |
| Female | 9 |
| Male | 11 |
| Other psychiatric diagnoses, n | |
| Major Depressive Disorder only | 4 |
| Bipolar II | 5 |
| Anxiety Disorder | 3 |
| Schizophrenia | 3 |
| Schizoaffective Disorder | 1 |
| PTSD | 2 |
| Place of origin, n | |
| New Orleans | 11 |
| Elsewhere in Louisiana | 5 |
| Elsewhere in the country | 4 |

Appendix B: Interview Guide - SSDI Track

- 1) Demographics
 - a. How old are you?
 - b. How do you identify ethnically?
 - c. What is your gender identity?
 - d. Have you always lived in the New Orleans area? If not, where are you from?
 - e. Do you have any other diagnoses besides depression? If so, what are they?
- 2) When you were growing up, how did you think about work?
 - a. As a child, what did you want to be when you grew up?
 - b. What were your family's attitudes about work?
 - c. What was your first job?
- 3) Please describe your experiences in the workforce before applying for benefits.
 - a. What type of work did you do?
 - b. How long were you in the workforce?
 - c. In what ways did your depression affect your work experience?
 - d. Were your employers aware of your depression? If so, how did they respond to the issue?
 - e. Did you have any supports (emotional/resource-based/other) within your employment environment?
 - f. Please describe the factors involved with your exiting the workforce. Can you identify a "turning point" in your decision to stop working?
 - g. Do you feel there are any types of work support that could have made it possible for you to remain employed? Please describe.
 - h. How long were you out of work before applying for benefits? What did you do in the meantime?
 - i. Are there any other major considerations related to your work experience that you think I ought to know?
- 4) Please describe your experiences with diagnosis:
 - a. How old were you when you were diagnosed with Major Depressive Disorder?
 - b. Did you decide to apply for benefits before or after receiving this diagnosis? How did it factor into your decision to apply? How long after receiving the diagnosis did you begin the application process, if you had not already begun?
 - c. What type of practitioner diagnosed you with Major Depressive Disorder? What was this process like? How much time did you spend with the practitioner before receiving a diagnosis?
 - d. Did the diagnosing practitioner attempt any other types of intervention before or as you began the application process?
 - e. How did receiving the diagnosis impact your conception of your own ability to work or function otherwise?
 - f. Are there any other major considerations related to your diagnosis that you think I ought to know?
- 5) Please describe your experiences applying for Social Security benefits:
 - a. When did you first learn of SSI benefits? Did it immediately impact your decision to apply? How long after learning of them did you apply?
 - b. How old were you when you first applied?

- c. Were you approved the first time you applied?
 - d. How long have you received benefits?
 - e. Did you hire a lawyer to assist with the process?
 - f. Who assisted you with completing the application?
 - g. Who first recommended that you apply for benefits?
 - h. Which kinds of professionals were involved with any stage of the process?
 - i. What led you to decide to apply for benefits? For example, was there a “turning point” or was it a gradual decision?
 - j. Please describe your support system throughout your application process.
 - k. Are there any other major considerations related to your application process that you think I ought to know?
- 6) Please describe your experiences after being approved for benefits
- a. How do you feel about not working? How has this impacted your life experience?
 - b. Has receiving benefits generally improved or decreased your quality of life? Please describe any major changes in your situation since you began to receive benefits.
 - c. Would you be interested in working again if it meant losing your Social Security benefits? Why or why not?
 - d. Under what circumstances would you feel comfortable returning to work if it meant losing your benefits?
 - e. Please describe any barriers to your returning to work.
 - f. Do you feel it would have been easier to remain in the workforce than to try and join it again now? Why or why not?
 - g. Are there any other major considerations related to your benefits that you think I ought to know?
- 7) I’m working to develop a set of recommendations for an early intervention program for people diagnosed with Major Depressive Disorder to help them receive supports necessary to remain in the workforce. The program, if approved, would be administered by the Social Security Administration, potentially in partnership with other health and legal professionals on a local level.
- a. What do you think of this idea?
 - b. Can you think of any suggestions for the program, if it were to be implemented? Are there any specific resources that you think would be crucial to its success?
 - c. Do you think such a program might have been helpful for you? Why or why not?
 - d. Are there any other major considerations about this program or anything else we’ve discussed that you think I ought to know?

Appendix C: Interview Guide – SSI Track

- 1) Demographics (Not to be recorded)
 - a. How old are you?
 - b. How do you identify ethnically?
 - c. What is your gender identity?
 - d. Have you always lived in the New Orleans area? If not, where are you from?
 - e. Do you have any other diagnoses besides depression? If so, what are they?
- 2) When you were growing up, how did you think about work?
 - a. As a child, what did you want to be when you grew up?
 - b. What were your family's attitudes about work?
 - c. What was your first job?
- 3) Please describe your experiences with the workforce as an adult.
 - a. Do you have any work experience? Please describe.
 - i. If yes, how long were you working? What type of work did you do?
 - ii. If yes, were your employers aware of your struggles with depression? Did you have any sort of emotional or resource-based supports in your work environment?
 - b. Did your experiences with depression impact your ability to work?
 - c. Can you identify a "turning point" in your decision to disengage from or not participate in work? Please describe.
 - d. How old were you when you exited the workforce, or decided not to join?
 - e. Can you identify any other specific issues that impacted your ability to work?
 - f. Can you identify supports that might have made it possible for you to work, or to work for longer?
 - g. Are there any other major considerations related to your work experience that you think I ought to know?
- 4) Please describe your experiences with diagnosis:
 - a. How old were you when you were diagnosed with Major Depressive Disorder?
 - b. Did you decide to apply for benefits before or after receiving this diagnosis?
 - i. How did it factor into your decision to apply?
 - ii. How long after receiving the diagnosis did you begin the application process, if you had not already begun?
 - c. What type of practitioner diagnosed you with depression?
 - i. What was this process like?
 - ii. How much time did you spend with the practitioner before receiving a diagnosis?
 - d. Did the diagnosing practitioner attempt any other types of intervention before or as you began the application process?
 - e. How did receiving the diagnosis impact your conception of your own ability to work or function otherwise?
 - f. Are there any other major considerations related to your diagnosis that you think I ought to know?
- 5) Please describe your experiences applying for Social Security benefits.
 - a. When did you first learn of SSI benefits? Did it immediately impact your decision to apply? How long after learning of them did you apply?

- b. How old were you when you first applied?
 - c. Were you approved the first time you applied?
 - d. How long have you received benefits?
 - e. Did you hire a lawyer to assist with the process?
 - f. Who assisted you with completing the application?
 - g. Who first recommended that you apply for benefits?
 - h. Which kinds of professionals were involved with any stage of the process?
 - i. What led you to decide to apply for benefits? For example, was there a “turning point” or was it a gradual decision?
 - j. Are there any other major considerations related to your application process that you think I ought to know?
- 6) Please describe your experiences after beginning to receive benefits
- a. How do you feel about not working? How has this impacted your life experience?
 - b. Has receiving benefits generally improved or decreased your quality of life? Please describe any major changes in your situation since receiving benefits.
 - c. Would you be interested in working if it meant losing your Social Security benefits? Why or why not?
 - d. Under what circumstances would you feel comfortable going to work if it meant losing your benefits?
 - e. Please describe any barriers to your starting work at this time.
 - f. Do you feel it would have been easier to begin working before applying for benefits than it would now? Why or why not?
 - g. Are there any other major considerations related to your benefits that you think I ought to know?
- 7) I’m working to develop a set of recommendations for an early intervention program for people diagnosed with Major Depressive Disorder to help them receive supports necessary to remain in the workforce. The program, if approved, would be administered by the Social Security Administration, potentially in partnership with other health and legal professionals on a local level.
- a. What do you think of this idea?
 - b. Can you think of any suggestions for the program, if it were to be implemented? Are there any specific resources that you think would be crucial to its success?
 - c. Do you think such a program might have been helpful for you? Why or why not?
 - d. Are there any other major considerations about this program or anything else we’ve discussed that you think I ought to know?