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Participants' Assessment of the Impact of Behavioral Health Self-Direction on Recovery

Bevin Croft, MA, MPP and

Human Services Research Institute, 2336 Massachusetts Avenue, Cambridge, MA 02140,
Phone: 617-335-0738, Fax: 617-492-7401, bcroft@hsri.org and The Heller School for Social
Policy and Management, Brandeis University, 415 South Street, MS 035, Waltham, MA 02454

Susan Parish, PhD, MSW

Lurie Institute for Disability Policy, The Heller School for Social Policy and Management, Brandeis
University, 415 South Street, MS 035, Waltham, MA 02454, slp@brandeis.edu

In self-direction, individuals manage a flexible service dollar budget, selecting and purchasing services and supports to meet goals developed through a person-centered planning process (Doty, Mahoney, & Sciegaj, 2010). States have implemented a range of self-direction programs that have been tailored to meet service and support needs of older adults and people with physical disabilities, developmental disabilities, traumatic brain injury, and more recently, people with serious mental health and co-occurring substance use problems (Alakeson, 2008; Sciegaj et al., 2014). As of 2013, the most recent year available, seven states had behavioral health self-direction programs serving approximately 700 people (Croft, Simon-Rusinowitz, Loughlin, & Mahoney, 2013). These programs are heterogeneous in regard to the size and scope of the budget, financing mechanisms, and oversight and administration activities (Croft et al., 2013). In all programs, however, participants work closely with specially-trained brokers and have the option of purchasing goods and/or services that are typically considered non-clinical, such as transportation, computers, dental services, employment supports, and other living expenses (Croft et al., 2013; Webber, Treacy, Carr, Clark, & Parker, 2014). Self-direction is part of the American health and behavioral health systems' shift toward person-centered care, which calls for an increased emphasis on the role of the participant in the service delivery process (Institute of Medicine, 2001). This climate change is most markedly reflected in provisions in the Affordable Care Act that focus on integrated, person-centered modes of service delivery (Croft & Parish, 2013; Mechanic, 2012).

The Cash & Counseling Demonstration and Evaluation, the largest self-direction trial to date, was a randomized experiment involving over 6,700 Medicaid personal care beneficiaries with long-term service and support needs in three states (Doty, Mahoney, & Simon-Rusinowitz, 2007). In the Demonstration, those receiving self-direction consistently reported better quality of life, higher levels of life satisfaction, and reduced unmet disability-related needs (Carlson, Foster, Dale, & Brown, 2007). In two sub-analyses, self-directing participants with mental health diagnoses fared better than controls on measures of

satisfaction and quality of life (Shen, Smyer, Mahoney, Simon-Rusinowitz, et al., 2008; Shen, Smyer, Mahoney, Loughlin, et al., 2008). Although these results suggest self-direction is appropriate for persons with mental health conditions, people in the sub-group analyses were probably not representative of the larger population with serious mental illness and co-occurring substance use problems who receive publicly-funded behavioral health services.

Existing behavioral health self-direction programs are small, and most have no formal evaluation component. Two studies of American behavioral health self-direction programs appear in the peer-reviewed literature. In 2008, Cook and colleagues compared functioning and service utilization outcomes for 106 self-directing participants before and after program entry. After joining the program, participants spent significantly more days in the community versus inpatient and forensic settings, and had better mental health functioning (Cook et al., 2008). Another study of self-directing participants documented modest improvement in clinician-rated functioning and high rates of community tenure (Spaulding-Givens & Lacasse, 2015). Despite the growing availability of behavioral health self-direction programs, the existing research is sparse (Webber et al., 2014). The present study begins to address this dearth by examining participants' perspectives of self-direction in relation to recovery.

Mental health recovery emerged from the psychiatric consumer survivor movement and is now widely endorsed by policymakers and practitioners alike as the goal of a modern behavioral health system (Chamberlin, 1990; New Freedom Commission on Mental Health, 2003; SAMHSA, 2011). Recovery is a non-linear process involving various aspects of personal growth across multiple life domains, including interpersonal relationships, hope, physical and emotional wellness, and a fully integrated life in the community (Anthony, 1993). Whitley and Drake (2010) organized the recovery concept into five broad dimensions that each relate to achieving a higher quality of life: *clinical*, including reducing mental health symptoms and engagement with traditional or medical treatments; *functional*, involving gains in education, employment, and housing; *physical* such as exercise and reducing unhealthy substance use; *social*, related to community engagement and meaningful relationships outside of the behavioral health system; and *existential*, encompassing spirituality, self-efficacy, and empowerment. These five dimensions provide a framework of possible recovery outcomes of self-direction (Whitley & Drake, 2010). In self-direction, the flexible budget, person-centered planning process, and programmatic support to achieve self-identified goals are integrated to enhance one or more of these recovery outcomes for participants.

This study explored participants' self-direction experiences using content analysis of 30 in-depth interviews. The central research question was guided by recovery as an initial theoretical framework and asked, how does participation in self-direction impact recovery?

Methods

The self-direction programs in this study are from a single state, were established in the early 2000s and are funded through a combination of state, local, and Medicaid dollars. The programs involve the following elements: support from a broker, person-centered planning,

and participant management of her/his individual budget. Brokers are trained in person-centered planning, social welfare resource availability, and budgeting. They are expected to regularly meet with participants, including in participants' homes, and assist with person-centered plan development based on each individual's unique, recovery-related goals. Person-centered planning begins with a person's strengths and capabilities (as opposed to clinical diagnosis or deficits) and incorporates natural supports (e.g., social and family support, church and community resources) alongside traditional services (Tondora & Pocklington, 2007). With the brokers' help, participants are expected to use the person-centered plan to set concrete and measurable goals and objectives that serve as the basis for the budget. Individuals who qualify for Medicaid, Medicare, or Veteran's benefits receive approximately \$1,600 per year, which supplements their existing insurance coverage. Uninsured participants receive approximately \$3,000 per year and are required to spend 48 percent of their budget on traditional mental health services such as psychiatry. Within the guidelines of a purchasing policy, participants link purchases to specific recovery goals in their person-centered plans. In addition to traditional services such as medication management, medications, and therapy, participants frequently use their budgets to pay for transportation, computers, dental services, and other living expenses.

Interview Guide Development and Procedure

Interviews began with open-ended questions such as "Describe your experience with the self-direction program" and "How has this program helped you to live the life you want?" The interview guide included specific questions and probes for each of the five recovery dimensions: clinical, functional, physical, existential, and social. Table 1 describes each recovery dimension and the corresponding interview guide question and probes.

An expert panel of five researchers with expertise in self-determination theory, self-direction, behavioral health services research, and program evaluation reviewed the interview guides and provided feedback for refinement. A copy of the full interview guide is available upon request.

All interviews were conducted by the first author (range 25–75 minutes; mean 40 minutes). The interviewer explained the study aims and protocol to participants before obtaining informed consent. Ten telephone and twenty in-person interviews were conducted, and all interviews were audio-recorded. The interviewer used the in-depth interview guide to structure interviews but exercised flexibility in question ordering. The interview guide was consulted throughout the interview and checked again at the end of each interview to ensure that all relevant questions were explored (Weiss, 1994). Participants were compensated \$10.

Sampling and Recruiting Strategy and Sample Characteristics

All current and former participants were eligible for inclusion in the study. A descriptive flyer was distributed by postal mail to all current and former participants whose mailing addresses were available from the self-direction programs. The flyer included a toll-free number for individuals to call if they were interested in the study. In total, 72 individuals responded to the recruitment flyer and were deemed eligible per the inclusion criteria and 62 completed the pre-screening questionnaire. Of these, 30 individuals were chosen to

maximize diversity in terms of gender, program location, insurance type, and length of time in the program. This maximum variation sampling approach is useful for identifying and exploring patterns that cut across divergent cases (Palinkas et al., 2013).

Table 2 describes interviewee characteristics. A majority were on public insurance (Medicare, Medicaid, and/or Veteran's benefits), and five were uninsured. Twenty-two interviewees were enrolled and currently receiving services at the time of the interview. For the eight former participants, reasons for leaving included reaching the program's time limit (7 years in one program area), disenrollment after being out of contact with program staff, moving out of the program area, and other changes in eligibility status. Participants' race and ethnicity was consistent with the demographic characteristics of the overall programs, but are not reported here to protect participants' confidentiality.

Analytic Method

Transcript accuracy was verified by reviewing them against audio-recordings. Cleaned, validated transcripts were loaded into qualitative analysis software (NVivo 10). Content analysis, which involves both inductive and deductive approaches, is appropriate for applied research of this kind (Pope, Ziebland, & Mays, 2000). This method involves classifying large amounts of information into smaller, more efficient categories to increase understanding of the phenomena (Hsieh & Shannon, 2005). Content analysis was used to test the recovery model framework to understand how self-direction relates to recovery while also exploring emergent phenomena. Other themes or unique relationships between themes emerged inductively through the analytic process (Charmaz, 1983; Pope et al., 2000).

First, each transcript was read completely to capture general impressions. Using these general impressions and the *a priori* recovery model framework, the authors developed an initial coding scheme consisting of higher-order dimensions of recovery, sub-categories within each dimension, and additional emergent themes. Then, passages of text in each transcript were classified according to the coding framework. In this initial open coding phase, some themes were collapsed, while others were expanded into multiple themes to capture variations. Additional phenomena that did not fit into the original framework emerged and were added as new themes. This iterative process resulted in a consistent, final coding scheme, which was then used to analyze all transcripts. Throughout the study and beginning in the earliest stages of data collection, analytic memoing techniques were used to capture impressions, identify discrete phenomena, document areas of convergence and divergence between themes, outline relationships or patterns of themes or phenomena, and generally reflect on insights gained through the site visits and interviews (Charmaz, 2006; Emerson, et al., 1995).

Member checking, a process in which a subset of participants are presenting with findings and invited to react to them, is critical for establishing credibility of qualitative research findings (Flick, 2007; Lincoln & Guba, 1985). Six participants purposively selected to ensure equal representation from each program were provided a written draft and given a verbal summary of the findings. Participants were asked if the authors had mischaracterized the program in any way or missed areas of importance. All six individuals endorsed the

accuracy and adequacy of the findings and highlighted particular findings that resonated with their own experiences. To further ensure rigor, the authors worked to identify disconfirming cases, systematically documenting instances in which the data did not fit identified themes, to capture variations in program impact and identify issues for further exploration (Smith, 2007).

The study protocol, interview guides, and informed consent materials were reviewed and approved by the researchers' university Institutional Review Board and the state's research review board. The study authors have no known conflicts of interest to report.

Results

Figure 1 provides a graphic representation of the final set of themes that emerged from the analysis. One theme – *Meeting Basic Needs* – emerged as a prerequisite to achieving progress in other areas for many participants. *Substance Use Recovery* also emerged as a separate theme. Much of the remaining interview content fell into each of the five original recovery dimensions, *Clinical*, *Functional*, *Physical*, *Social*, and *Existential Recovery*. While the original framework was somewhat static in its composition, with discrete dimensions and sub-dimensions, the themes that emerged in this analysis were more dynamic and inter-related. In particular, themes in the Existential dimension cut across the other categories and seemed to enhance participant experience in the other dimensions.

Meeting Basic Needs

A majority of respondents described a dynamic in which program participation helped them to meet basic material needs that had been impeding them from achieving or even setting personal goals. In this sense, meeting basic needs was a prerequisite for the other recovery dimensions. Basic needs ranged from dental and eye care to assistance with groceries, rent, utilities and furniture. Individuals living in rural areas regarded transportation as particularly essential. While some interviewees made basic needs-related purchases with their budgets, others obtained goods and services through separate entitlement programs (e.g., furniture donation programs, assistance with utilities) with broker assistance. These interviewees said they would not have been able to afford these basic purchases or access these resources without the assistance of the self-direction program. By meeting basic needs, interviewees reported that the self-direction programs cleared the way to greater wellness by relieving stress and providing peace of mind. For example, one participant noted, "The program has relieved a lot of stress in my life. I'm not worried about being able to pay...and I've got clothes."

Six interviewees expressed confusion and frustration at what they saw as inconsistent policies, particularly for purchases that address basic needs like rent, transportation, and household goods. This was the most common criticism of the program. These participants reported relying on the broker to tell them whether a purchase was allowable. Six other interviewees reported lacking knowledge about allowable purchases until they asked, evincing a lack of understanding of policies overall. One said, "As much as I tried to look through the paperwork, I would think I would have it and then [the broker] would say, 'No it doesn't work that way.' And it didn't make any sense."

Clinical Recovery

Accessing Psychiatry and Medication Management—All but two interviewees reported taking psychiatric medications to help manage mental health conditions. These 28 individuals said that before self-direction, their mental health treatment options were limited to brief medication management visits at a public mental health clinic. In both program areas, interviewees said the public mental health clinics were difficult to access by public transportation and had long waits and high staff turnover rates. One participant reported, "The last time I went there two weeks ago I had to wait, it was a two-and-a-half hour wait." Despite these problems, all interviewees chose to remain with the public clinics for their psychiatry services.

Expanding Clinical Treatment—Ten interviewees used their self-directed budgets to purchase therapy and social work services that were not covered by insurance or had large co-payments. Two former participants noted they were on a waitlist to re-enroll in the program and reported plans to use the program primarily to expand treatment because of an unmet need for social work services. By building the costs of these services into their person-centered plans, participants were able to engage with or continue seeing providers they felt were helping them to work toward or maintain wellness. One participant said, "I would have had fewer choices [for mental health treatment] if it hadn't been for [self-direction]. It would have been only med management and the meds."

Interviewees sought providers who specialized in particular issues such as domestic violence, trauma, or co-occurring neurological conditions. In particular, four interviewees endorsed the value of trauma-focused therapies:

I'm finding out that I have some pretty serious mental issues [stemming from trauma]...just different things that the [traditional mental health system] hasn't been able to really touch. [Self-direction] is helping me to flow into some therapy now that I can get really close to my issues.

Three respondents described using self-direction funds to obtain second opinions about their psychiatric diagnoses. These interviewees reported working with their mental health providers to adjust medications and explore alternative treatments that were endorsed as more effective than previous therapies. The interviewees who noted using their self-directed budgets to expand the types and focus of their treatment spoke about how the additional clinical supports helped them to develop and practice coping skills critical to maintaining mental wellness, and supported their work toward other non-clinical goals.

Interviewees expressed satisfaction with the mental health services that they chose and purchased. They reported seeing value in maintaining therapeutic relationships with providers over time. They also reported benefits from providers who were accessible by telephone during nights and weekends and more flexible with scheduling than providers from the public behavioral health clinic.

Importantly, interviewees reported barriers in accessing clinical treatment, even with the additional support and flexibility offered by the program. These individuals cited an overall scarcity of mental health treatment providers from which to choose. These individuals

reported challenges with finding providers who were accepting new patients and whom they could afford with their self-direction budget. Participants stated it was challenging to reach clinic staff, and that even when they could reach them, none were accepting new patients:

...I did make some calls to find a psychiatrist. Forget it. It's off the wall ridiculous to find one, and then when you get them on the phone the price is so ridiculous that it's just outrageous, like \$500 dollars for the initial conference...I talked to someone two months ago and the first available visit they had was [in four months].

Avoiding Hospitalization—Four individuals noted that self-direction helped them manage crises and reduce the need for emergency and inpatient services. Some attributed decreased psychiatric hospitalizations to improved access to community supports, which they were able to secure because of the self-direction program. Others attributed reduced inpatient use to the direct support provided by their broker and knowing the program was there to support them in general.

[Self-direction] addresses moving on...It's like society adding a little support to say, 'We really want to see you get better.' Overall, I've committed myself enough times to have accumulated over two years of inpatient before [entering the program over four years ago]. And I haven't been since [self-directing]... you can't deny that through [self-direction], society is saying, 'Hey, we're with you, to pull yourself up.'

Functional Recovery

Employment, Education, and Training—Eleven interviewees reported working on employment-related goals, and three secured part-time employment with the program's support. Several individuals pursued training and obtained paid or unpaid positions as peer specialists, providing peer support to other individuals in the mental health system. One participant put it this way: "I feel I need to create a career which is in service to what I've been through."

Participants purchased computers, computer courses, and internet connections to conduct job searches, maintain professional web pages, or engage in work-related computing such as scheduling and email. Participants reported receiving broker support identifying potential employers and preparing for job interviews. An individual planned to use her/his budget to obtain the services of a job coach to provide on-the-job support. Another planned to purchase membership in a professional society that offered a job mentorship program. Two individuals said they used their budgets to start their own businesses. One of these participants noted that having her/his own business afforded her/him the flexibility s/he needed to maintain employment:

I couldn't handle the stress of working for someone else, so I created a...business which made me feel good too in that I was providing this service for people in need. And there were a lot of factors there that worked for me...if I was ill or if I was stressed out and I was unable to work a certain day, I could say to a client, 'We need to schedule...next week instead of this week.'...So, it worked on a lot of levels for me.

Five respondents reported enrollment in a variety of educational programs, including college, GED, and job training. They used funds to support their education. Five others articulated plans to pursue education-related goals.

Volunteering—Seven participants reported engagement in a variety of volunteer activities. Three of these interviewees reported that volunteer work provided a path to paid employment. The others noted that volunteering helped them to stay busy, develop positive social relationships, and feel as though they were part of the community. One stated, “Because I’m not able to work, I wanted to get out and do something to make me feel productive.” Other respondents spoke about choosing volunteer positions that related to their personal experiences. These included assisting individuals experiencing homelessness, volunteering for organizations that had provided them with services or support in the past, and running support groups for individuals with similar challenges.

Independent Housing—Three respondents transitioned from group mental health housing to independent living arrangements with support from their self-direction program, and two others were in the process of finding new housing with broker support. Interviewees said their brokers supported them in finding independent arrangements and helped them apply for low-income housing. Those transitioning to independent housing reported using their self-directed budgets for rent, utility deposits, and moving expenses. A participant who had secured an apartment said:

[Getting my own apartment] was wonderful. I was so proud of myself, I was loving it. Because I was ready to get out of living with everybody else in a rooming house to having my own apartment. So it was wonderful. It really built up my self-esteem... I was really happy.

Physical Wellness

Twelve interviewees described daily struggles with a wide range of co-occurring physical health conditions that limited their ability to work, attend appointments, and participate in community life. Interviewees noted a strong connection between mental and physical health, which is consistent with the recovery paradigm. One noted, “Because you know your health, your physical being, if you’re not healthy you’re going to get depressed.”

Sixteen interviewees reported working on a variety of physical wellness goals, including weight loss, exercise, nutrition, smoking cessation, and managing chronic health conditions. Brokers reportedly provided direct support and motivation for some participants, encouraging them, and holding them accountable to their goals. As part of their efforts to achieve these goals, participants purchased tennis shoes, exercise clothes, gym and weight loss program memberships, yoga classes, bicycles, and groceries to support special diets. A participant said, “[Self-direction has] helped me before with clothing, with walking tennis shoes, things that have got me out and moving. I walk every morning now.” Three participants reported significant weight loss, and two of these participants purchased new, smaller-sized clothes with their budgets: “[Self-direction] made me want to exercise more because I’m losing weight, I’m getting new clothes, and I look good in my new clothes. It builds up my self-esteem to where I wasn’t depressed or anything.”

Other interviewees noted they were better able to manage chronic medical conditions like diabetes, arthritis, and HIV because of support and motivation from the broker and assistance purchasing foods for special diets related to health conditions. Although a majority endorsed programmatic support for physical wellness, two participants reported that self-direction funds could not be used for wellness-related goals, evincing confusion or inconsistency in program implementation.

Substance Use Recovery

Ten interviewees reported they were in recovery from an alcohol or drug problem. These individuals described substance use recovery as an ongoing process and spoke about the compounding effects of mental illness and addiction. Respondents varied in the extent to which they used the program to support their work toward substance use recovery. When asked whether self-direction can help people in their substance use recovery, an individual stated that self-direction was incompatible with the principles of Alcoholics Anonymous (AA) and that s/he worked on substance use recovery separately from her/his self-direction goals: "I really don't see it. I mean the model for Alcoholics Anonymous is the less independent you are, the better off you are." However, the remaining nine interviewees who identified as having co-occurring substance use issues endorsed a positive relationship between program participation and substance use recovery. They spoke of receiving reminders to attend mutual support meetings or using funds to pay for transportation to attend meetings. One participant indicated a preference for the program's indirect orientation in relation to substance use recovery: "I guess [the self-direction program] suggests, they only suggest, it's your choice, that's what is nice about it, but they suggest [you] go to meetings."

A participant described the self-direction program as "one piece of the pie" of services and supports that facilitate maintaining sobriety, and this view was shared by other interviewees. Another noted that moving into a permanent housing arrangement in a new neighborhood made it easier to maintain sobriety because it reduced her/his contact with drug-using acquaintances. And another participant noted that s/he had developed greater self-confidence through the program, which helped to change her/his perspective on substance use: "I can live a meaningful life now without the use of drugs, without stealing. I can live a productive life now without stealing, going out and manipulating people, hurting people to... support my habit."

Social Recovery

Group Membership—Seven interviewees reported using their budgets to pay for community group memberships they could not otherwise afford. These groups involved music, art, or hobbies, and most had a charitable component (for example, donating artwork or volunteering for a charitable organization). Through identification with a community of fellow artists, hobbyists, or volunteers, interviewees spoke of developing meaningful relationships and a sense of belonging and kinship with others outside of the mental health system, a key component of recovery (Whitley & Drake, 2010). One reported, "There is a lot of camaraderie. I've made a couple really good friends."

Interviewees reported brokers encouraged them to pursue social relationships. Participants spoke about an increased capacity to connect with others, including getting more engaged in their communities, meeting new people and making new friends, and reaching out to support others when they need help.

Three interviewees belonged to advisory councils that oversee the self-direction programs. These participants endorsed the advisory council itself as contributing to their recovery. They shared personal stories and presented concepts of self-direction and recovery at conferences and meetings to promote expanding the programs. One said, "That's why I became part of [the advisory council], because I felt if I would contribute to the helping other [individuals with mental health conditions] in this state I would be able to do that."

Keeping Busy—Several interviewees discussed how self-direction helped them pursue activities for "keeping busy", which they used as a strategy for reducing isolation and managing stress, depression, and other mental health symptoms. One explained, "I have to keep my mind doing something. If I [did] not have something to do and just sat and watched TV...it wouldn't be good for me, because mentally I need to be stimulated. It keeps me going."

Program participation facilitated these activities and increased participants' motivation to leave the house and engage with the community. Interviewees also noted that by keeping active, they were able to shift focus from their mental health symptoms to more positive and constructive aspects of their lives. One interviewee said, "I've done pretty good, because at one time, I'd have those days I would just lay there in the dark, just lay there. But I've gotten well. I can get on up...I didn't want to move today, but I made myself get on up."

Existential Recovery

Independence and Self-Sufficiency—In comparing self-direction with past mental health service arrangements, participants distinguished between traditional programs doing things for them and the self-direction program helping them do things for themselves: A participant explained, "...the premise of [self-direction] is to make you independent, so it's not like they pick up the phone and make the appointment for you. They give you the resources, and then you do the research." Participants are required to set their own goals, identify services and supports, and make arrangements to obtain those services and supports. This structure reportedly kept them engaged in the service delivery process. Respondents reported investigating providers, comparing costs, and doing the "legwork" to set up appointments.

One interviewee noted that in contrast to traditional case management, where the case manager would make appointments and tell her/him what to do, self-direction emphasized participants' responsibility for their recovery:

Sure I do sometimes miss the case management system to where my case manager was like my buddy-buddy, but I'm [adult age], I need to live in the real world...I feel like that is one thing that [self-direction] has given me. I live in the real world now, and so that is one good thing.

Accountability—Participants reported that the person-centered planning process supported independence by promoting individual responsibility and accountability. Interviewees noted their brokers held them accountable to their goals by regularly checking in about progress and providing support when they struggled. For example, one participant said:

[Broker] holds me accountable... I have to answer to [her/him], because if [s/he] gives me homework, and I know s/he is coming, so I have to do something or I have to say, 'Well I didn't do it.' 'Well why?' And it's very uncomfortable.

Participants said it was motivating to be held accountable, and to have a list of clear action steps to achieve goals. These facets of the self-direction program reportedly helped participants stay on track with their goals.

Some interviewees reported that the increased accountability paired with broker support helped them to develop financial management and budgeting skills:

Some people get to spending their money and they could blow it, where [support brokers] give you a little direction, like keep you focused on certain goals, some things you wouldn't think about in life. So, they set you up with the goal sheet... and in there ... you have to project where your money is going to go and how much you're going to spend. So it gives you responsibility in money handling.

Self-Esteem and Self-Confidence—Participants said their individual budgets gave them "extra assistance" to afford things they could not normally do and feel more comfortable in social situations. They noted that purchases such as clothes and joining a bowling league were activities that non-poor people can easily afford and might take for granted. For the participants interviewed here, "having a little money to spend" to engage in valued activities promoted their self-esteem and permitted them to have a greater sense of community and belonging. One stated, "It made me feel, you know when you dress nice people look at you a little bit different. You've still got to act right, but it made me feel comfortable that I could put on shoes that didn't have holes in them."

Additionally, interviewees reported experiencing increased self-esteem through gains in other recovery domains. Participants spoke of how losing weight and getting physically healthy increased self-esteem and enabled them to more comfortably socialize with others. Others said purchasing dental care led them to feel better about themselves and more confident going into the community. One noted, "I do get better self-esteem...I can smile, not just making my mouth smile, but smile with my teeth too."

Another individual said that working with her/his therapist and broker facilitated development of coping skills to manage anxiety and reduce social isolation, which led to improved self-esteem:

They even increased my self-esteem and limits to what I would normally do with other people. I wouldn't be able to talk with them or socialize or talk to people, because I suffer so much from schizophrenia. [Participating in the self-direction program] increased my self-esteem.

Interviewees reported that improved self-confidence and self-esteem helped them pursue meaningful relationships and engage more in the community. Two individuals spoke of how "giving back" to the community through voluntarism further increased their self-esteem. Participants described how having more self-esteem led to confidence to take on new projects and to "step out and take risks". These participants spoke of having a sense of direction that they previously lacked. One participant said, "[Self-direction] taught me how to speak for myself [and] to realize that I can ... help others."

Participants spoke about how "encouraging words" from brokers helped them to develop self-confidence. Participants said their brokers persistently encouraged them to work toward goals and held them accountable to those goals by regularly checking in. Participants also noted that their broker helped them to feel more valued by listening and "being there", which reportedly also led to greater self-esteem. One of these participants said, "[My broker] was very nurturing and...really built my confidence and made me feel like I was capable to handle the challenges that were before me."

The relationship between self-direction and self-esteem appeared to be circular for many interviewees. Participation in the program helped them to build self-esteem and self-confidence, and greater self-esteem and self-confidence left them more motivated to set and achieve their goals:

I looked back at when I first started the program that I was like, 'Wow, I can't believe I put [in the recovery plan] that I will have my own home and a car by such and such time, and I did it.' That makes me feel good about myself. So, the little goals I have now, they're not as big as those two, and I know I can do it because I did the other two.

Discussion

In-depth, semi-structured interviews with 30 self-directing participants with serious mental illness were used to examine participants' perspectives on self-direction's impact on recovery. To the best of our knowledge, this is the first study of the relationship between recovery and self-direction, and the first study of the perspectives of individuals with serious mental illness on self-direction.

An assessment of the study's limitations is needed. Relatively few former participants responded to the recruitment flyer, despite attempts to engage them. It is likely that self-selection bias favored more satisfied participants, particularly former participants who had remained in contact with the program. In the directed content analysis approach, prompts for recovery dimensions in the theoretical framework were built into the interview guide, which may have constrained responses and may not be entirely representative of participants' program experience (Hsieh & Shannon, 2005). Finally, this study was conducted in one state, which limits generalizability. There are no widely accepted fidelity standards for self-direction in behavioral health, and programs likely vary in the extent to which participants exercise independence and creativity in decision-making. Given that these factors were key in supporting participants' recovery in this study, it is possible that the findings here may not generalize to programs that offer more limited choice.

Despite its limitations, this study has important strengths. This qualitative approach permitted development of a nuanced picture of self-directing participants' experiences. The recovery framework created a starting point for understanding these experiences, and the additional themes that emerged demonstrated the complex relationship between self-direction, recovery, and programmatic and policy contexts. These findings have implications for self-direction implementation and suggest that overarching behavioral health system issues impact the relationship between self-direction and recovery.

The emergent *Basic Needs* theme highlights the importance of understanding recovery and mental health in the context of poverty. Mental health service users who receive public benefits such as Medicaid, Supplemental Security Income and Social Security Disability Insurance live on an extremely limited income and have considerable difficulty meeting their material needs (Kessler et al., 2008; Wilton, 2003). They employ various coping and survival strategies, including cost-effective shopping, budgeting, prioritizing, and saving money (Caplan, 2014). The evidence here indicates that self-directing participants incorporate a range of such strategies into their budgeting and planning process. If self-directing participants are supported to act as effective stewards of public dollars through thoughtful budgeting practices, this finding suggests the potential for program cost-savings or cost-neutrality.

But the *Basic Needs* theme also underscores deeper challenges faced by this population that cannot be remedied by self-direction alone. It highlights a need for behavioral health systems to recognize the impact of poverty and the critical role of meeting basic material needs. It supports the notion that a truly person-centered behavioral health system should include interventions that address poverty and material hardship to support self-sufficiency in a more substantial way. In this sense, self-direction sits alongside other recent initiatives and federal priorities that address the housing and employment needs of persons with serious mental illness (NFC, 2003).

Findings in the *Clinical Recovery* domain suggest that the program enabled some participants to expand their range of clinical treatment options and seek services and supports that were most suited to their individual needs and preferences. However, several interviewees remained unable to expand their treatment because of the limited availability of service providers in their geographic areas. Importantly, individuals may not fully benefit from the expanded choice offered by the self-direction model when adequate services and supports are unavailable.

The *Substance Use Recovery* findings suggest that self-direction programs could do more to integrate principles of substance use recovery into program functions such as broker training and person-centered planning. From the perspective of at least one participant, self-direction is at odds with the principles of mutual support groups like AA. Self-direction programs and AA-type groups could work to reach agreement about how to communicate the similarities of the two approaches. Doing so would ensure participants receive support in all salient aspects of their wellness and recovery, including substance use. Such a focus would be in line with current efforts to integrate mental health and substance use services and supports (Hutchings & King, 2009).

The findings related to *Existential Recovery* highlight the critical role of brokers in self-direction programs. A majority of interviewees described brokers as facilitating the processes through which they experienced greater self-sufficiency, independence, and self-esteem. Brokers are charged with holding participants accountable to their goals while also ensuring the program experience is person-centered and guided by the participant voice. As participants' primary point of contact, brokers played key roles in educating participants about program policies. Notably, participants differed in their interpretation and understanding of the program purchasing policy. Some said the policy was vague, complicated, and inconsistently applied. Further, contradictory opinions were held across participants about what purchases were and were not allowable. This finding suggests that clarifying the purchasing policy and increasing training may lead to program improvements that mediate the relationship between participation and recovery outcomes. Taken together, the findings suggest that self-direction programs must attend carefully to the pivotal role of brokers and the need for clear communication regarding purchasing policies.

Future research should investigate the impact of self-direction on physical and emotional health, health care access and utilization, and cost. Further, process-focused research should identify which elements of the program are critical for supporting recovery. These studies should include analyses of program purchasing policies, participant education, and broker training and support – and create tools and strategies to support successful program implementation.

Conclusion

This study documented a positive relationship between self-direction and recovery. Meeting basic needs for food, clothing, and shelter are important first steps in the recovery process for self-directing participants. The multiple dimensions of recovery are dynamic and inter-related. Gains in the existential dimension of recovery – particularly independence, self-esteem, and self-confidence – were clear for a majority of interviewees, and these gains facilitated participants' achievement of other goals. Finally, to maximize the benefits of self-direction, policy makers and practitioners must develop clearer self-direction program implementation standards and address the impacts of poverty and limited access to appropriate services and supports.

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Figure 1.
Final Thematic Framework

Table 1**Recovery Dimensions and Corresponding Interview Guide Questions**

Dimension[/]	Description	Interview Guide Question
Clinical	The reduction or control of mental health symptoms	How, if at all, has [the program] helped you to manage your mental health symptoms? [<i>prompts for medications and medication management, use of outpatient therapy, and use of emergency and inpatient services</i>]
Functional	Participation in aspects of everyday life, including housing, education, and employment	How, if at all, has [the program] helped you to meet goals related to employment, education, and housing?
Physical	Physical health and wellbeing; management of chronic medical conditions and increased healthy behaviors, including less unhealthy substance use	How, if at all, has [the program] helped you to improve your physical wellness? [<i>prompts for diet, exercise, smoking, management of co-occurring substance use issues, if present</i>]
Social	Meaningful interpersonal relationships, engagement in social activity, community integration and citizenship	How, if at all, has [the program] helped you to develop your social relations? [<i>prompts for family, friends, peers, and social activities</i>]
Existential	“Secular psychosocial factors” such as hope, self-determination, and empowerment as well as spirituality and values	How, if at all, has [the program] impacted your emotional and spiritual well-being? Your sense of hope and empowerment?

Note:

[/] Recovery dimensions are from Whitley & Drake, 2010

Table 2

Interviewee Characteristics

Characteristic	% or Mean	n or Range
Program 1	53.3%	16
Program 2	46.7%	14
Female	56.7%	17
Has insurance	83.3%	25
Current participant	73.3%	22
Former participant	26.7%	8
Time in program (total years)	3.6 years	4 months to 8 years
Time in program (current participants)	3.2 years	4 months to 8 years
Time in program (former participants)	4.5 years	9 months to 7 years
Time since participating (for former participants)	1.7 years	6 months to 3.5 years
Self-identified substance use problem	33%	10