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To cite this article: Shannon Blajeski (2020) Family support, forming careers, and breaking the disability mindset: implications for addressing structural barriers to employment pathways in coordinated specialty care for first-episode psychosis, *Social Work in Mental Health*, 18:5, 461-481, DOI: [10.1080/15332985.2020.1785603](https://doi.org/10.1080/15332985.2020.1785603)

To link to this article: <https://doi.org/10.1080/15332985.2020.1785603>



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Published online: 05 Jul 2020.



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Family support, forming careers, and breaking the disability mindset: implications for addressing structural barriers to employment pathways in coordinated specialty care for first-episode psychosis

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ABSTRACT

Pathways to employment are typically interrupted by first-episode psychosis (FEP) which strikes during the developmentally critical time of young adulthood. This paper reports on the key moments and messages that influenced the developing employment, education, or disability trajectories of young adults in the years following completion of Coordinated Specialty Care (CSC) for FEP. Nineteen semi-structured interviews were conducted with young adults with both lived experience of a FEP and a CSC program, from a critical case sample of 10 persons who were involved in an advocacy group. Results indicate that family support and expectations, disability narratives from mental health professionals, the realities of the modern labor market, and university disability support strongly influenced the pathway to employment, education, or disability, and that these were influenced by multiple structural realities such as family SES, disability policies, and treatment ideology, and the capacity of the labor market and universities. This paper concludes that CSC services should create a unified plan to address the structural barriers that challenge those from marginalized families, reevaluate traditional disability ideology in mental health treatment, and better support new pathways to secure employment and education for all young adults with FEP.


KEYWORDS

First-episode psychosis;
employment; education;
disability; NEET; CSC

Income through employment is an important social determinant of health, particularly in Western-industrialized nations (Silva, Loureiro, & Cardoso, 2016; WHO, 2014), yet individuals with serious mental illness (SMI), particularly those living with psychosis and schizophrenia-spectrum disorders, have historically not participated in the labor market, resulting in a high level of poverty in this population. Current unemployment rates for adults living with SMI within the public mental health system range from 80% to 90% nationally (Drake, Bond, & Becker, 2012; SAMHSA, 2012) despite evidence that points to

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the restorative effects of employment on functioning (Strickler, Whitley, Becker, & Drake, 2009). Furthermore, social security disability benefits, the primary source of income for a majority of individuals with SMI, fail to alleviate poverty, with fewer than 13% returning to work after becoming recipients in the early stages of psychiatric diagnosis (Baron & Salzer, 2002). Overall, there is a historical trend of disadvantaged socioeconomic position and labor market marginalization for adults with SMI that persists throughout their working-age years (Agerbo, Byrne, Eaton, & Mortensen, 2004).

The problem of poverty and SMI is linked to a mental health treatment system that traditionally considers employment intervention “outside the scope of treatment” (Hogan, 2008, p. 5) as well as a deep connection between disability benefits and poverty (Baron & Salzer, 2002). Providing early intervention for developing or first-episode psychosis (FEP) has shown promise in reducing disability in this population due to a focus on supported employment and education in the early stages of treatment (Killackey & Allott, 2013). Known in the United States as coordinated specialty care (CSC) teams, these early intervention programs utilize a combination of traditional psychiatric treatment services (e.g., medication, psychotherapy) with targeted employment/education and family support components (Kane et al., 2016).

Since the developmental period before disability is established is a particularly critical intervention point for poverty prevention in this group, it is an urgent research priority to learn how young adults with FEP negotiate employment and education and how interventions can facilitate this process. This study explored the experiences of young adults who experienced FEP and completed early intervention programs with a focus on the ways in which trajectories toward employment, education, and disability formed during the early stages of psychosis.

The disability-poverty connection

A combination of historical assumptions about mental illness, treatment increasingly focused on narrow illness outcomes, and a willingness to accept disability for this population have all contributed to the dire poverty statistics for adults with SMI, despite evidence that working is possible and, in fact, promotes recovery from mental illness (Sylvestre, Notten, Kerman, Polillo, & Czechowki, 2018). Within the mental health system, unemployment rates of adults with SMI receiving disability benefits are influenced by the “usual suspects”: characteristics of the illness, programs and practice, and policies (Baron & Salzer, 2002, p. 587). The characteristics of the illness argument claim that mental health symptoms such as depression, limited interpersonal skills, and cognitive issues associated with SMI are related to unemployment within this population. Mental health treatment programs do not adequately address chronic unemployment (Baron, Draine, & Salzer, 2013; Wilton, 2004),

and even when the best evidence-based job placement programs such as the individual placement and support (IPS) model are accessible, they do little to promote economic prosperity or lift individuals out of poverty (Baron et al., 2013). Finally, public disability policy has done little to move individuals with SMI out of unemployment and continues to harbor a financial disincentive to do so (O'Day & Killeen, 2002). The status quo in the mental health field is to help individuals with SMI receive disability benefits, which replaces a focus on obtaining employment and results in failure to enter or reenter the labor market (Baron & Salzer, 2002). The following section revisits theories of disability, poverty, and SMI and applies them to the FEP population.

Social causation, social drift, and labeling theories and FEP

Theories on causal mechanisms between poverty, disability, and SMI attempt to explain how external structural situations impact a person along a developmentally normal trajectory interrupted by onset of illness, such as during the typical period of a FEP. For example, in social causation theory, it was historically thought that environmental causes such as low family socioeconomic status (SES) and the related marginalization experienced through discrimination impacted early onset of psychosis. However, research has shown that conditions of poverty do not cause mental illness but do have an adverse effect on mental health (Hanandita & Tampubolon, 2014; Read, 2010; Silvestri & Joffe, 2004; Wilkinson & Pickett, 2010) and are linked more closely to the etiology of mood disorders (Dohrenwend et al., 1992; Murali & Oyeboode, 2004; Silva et al., 2016), which are risk factors for psychosis in young people. Thus, it is important to consider early involvement in the mental health system as a risk factor for psychosis in young people.

Social drift theory presumes that the interruption of developmentally normal life activities such as post-secondary education and employment after onset of psychosis in early adulthood is responsible for downward social mobility (Aro, Aro, & Keskimaki, 1995; Beels, 1981; Dohrenwend et al., 1992). Few recent studies have examined social drift in terms of mobility, and those which compared post-illness SES with parental SES have had mixed outcomes (O'Donahgue, Roche, & Lane, 2016; Vargas et al., 2014). From a structural perspective, lost time in the labor market and prolonged time on disability benefits can create major barriers to a return to working, which is reflected in the high level of unemployment among adults in the public mental health system.

The current dominant paradigm of disability posits that the problems experienced by individuals are rooted in their medical symptoms and does not take into account external structural and contextual problems that influence returning to work (Mulvaney, 2000). Also known as the individual impairment or medical model, it continues to be standard practice in psychiatric diagnosis and treatment, social security disability policy, and society

(Goering, 2015). One example of the difficulties with the individual impairment model of disability are the inherent issues with diagnostic labeling as represented by Labeling Theory (Goffman, 1959; Gove, 2004; Scheff, 1966) in which an individual takes on a certain role after professionals assign the label. In this framework, the personal interpretation of a diagnosis often leads to role withdrawal and/or stigma, which can exacerbate negative social outcomes such as prolonged unemployment.

In contrast, the social model of disability posits that while impairment exists within the body, the disability label is imposed on the individual by external social conditions – economics, poverty, social exclusion, and discrimination – that do not accommodate the impairment into mainstream society (Goodley, 2001; Haegele & Hodge, 2016; Marks, 1997; Mulvaney, 2000). The social model also posits that imposing disability status on individuals with impairments “triggers a series of exclusion mechanisms that reinforce each other” (Foley & Chowdhury, 2007, p. 376). In essence, both the individual impairment and social models of disability are important frameworks for understanding how developing psychosis in young adulthood is influenced by programs and policies that can lead to disability and poverty.

In summary, financial poverty exists as a risk factor for later disability when there is an onset of psychosis and, in particular, when a young person disengages with employment and education pathways, and instead takes on a disability label. Furthermore, aspects of labeling and stigma encountered by mental health professionals, family, and/or U.S. society can exacerbate the internalized label of mental illness and pose a major challenge to overcoming disability and reentering employment pathways.

Addressing poverty through early intervention

The recent shift toward early intervention for psychosis within CSC programs provides new opportunities to explore the beginnings of disabled or non-disabled trajectories in individuals at a younger developmental age. As psychosis onset is a precursor to more chronic forms of schizophrenia-spectrum and bipolar disorders, it is a critical time for intervention so as to prevent illness chronicity (DeVylder, 2016) and address developmental needs such as pathways to employment and education of those approaching young adulthood (Birchwood, Todd, & Jackson, 1998). Additionally, because of the developmental timing of CSC models, these programs may be able to act as a poverty prevention agent by intervening in negative socioeconomic decline for this population through support for education and employment in the first 2 years of treatment.

Recent studies that examined employment outcomes after CSC programs include the Recovery After an Initial Schizophrenia Episode (RAISE) study (Kane et al., 2016) which found improvement in quality

of life, symptoms, and increased school and work involvement compared with treatment as usual. While findings from this study showed that a higher percentage of early intervention clients worked or went back to work compared with treatment-as-usual clients, it also found that the same was not true of those receiving social security disability benefits and that receipt of these benefits was not significantly reduced by being in CSC care (Rosenheck, Estroff, et al., 2017). A recent study of the NAVIGATE early psychosis program showed that 40% of first-episode young adults served by the program were on social security disability benefits at the end of the 2-year follow-up period (Rosenheck et al., 2016), which may indicate that not all young people with FEP in CSC programs are returning to work and school. Finally, recent studies on FEP and employment outcomes suggest that while employment programs in CSC are effective at increasing the number of days in work or school activities, they do not increase income enough to warrant discontinuing social security benefits (Drake et al., 2016). The authors proposed a need for more research on the ways in which disability benefits are initiated during the course of early psychosis treatment, which is particularly important given that CSC programs are uniquely positioned to delay or prevent disability by promoting “early returns to employment” in the young adulthood developmental period (Drake, Xie, Bond, Mchugo, & Caton, 2013).

Given the pervasive poverty outcomes associated with long-term disability in SMI, it is crucial to explore how young adults experience the initial FEP period and return to or initiate employment or educational pathways. This paper reports on a comprehensive study that explored the following research questions: 1) What key moments during an early psychosis pathway appear to shape the self-concept, aspirations, and expectations, and ultimately, direction toward working/career or disability status among young adults? 2) How do these key moments appear to be influenced by contact and messages from others such as service providers, family, and friends? and 3) “What larger societal/structural themes appear to influence either employment or disability trajectories and how have these been experienced by these individuals?”

Methods

As this study is exploratory, qualitative methods were used to collect and interpret data. This study is informed by feminist standpoint epistemology that seeks to explore the experiences of marginalized groups as well as the structural contexts that impacts them (Garrow & Hasenfeld, 2015). Feminist standpoint epistemology assumes the following guiding principles during the research process: 1) considers the sociopolitical and

cultural contexts that influence the research; 2) rejects value neutrality of the researcher; and 3) starts from the position of the marginalized (Garrow & Hasenfeld, 2015).

Setting and sample

The Young Adult Leadership Council (YALC) is a peer group comprising members who identify as participants (past or current) in the Early Assessment and Support Alliance (EASA) early intervention for psychosis program and have lived experience of psychosis. EASA serves individuals aged 15 to 25 years who are experiencing first episode psychosis in Oregon. Each EASA program follows practice guidelines consistent with best practices in early psychosis, including assertive community outreach, supportive counseling, family psychoeducation, medication interventions, and supported employment and education. In addition to functioning as a peer group, the council helps to shape the direction of EASA, emphasizing participatory decision-making, and peer support (Early Assessment & Support Alliance, 2018).

A critical case sampling plan was deployed to locate a case that would “yield the most information and have the greatest impact on the development of knowledge” and “make a point quite dramatically or particularly important in the scheme of things” (Patton, 1990, p. 236). The YALC was chosen as the target sample for this study due to members’ lived experience with FEP, the young adult age of participants, and participants’ past involvement with CSC care. The dimensions of a critical case in the scope of this project consisted of young adults with early psychosis diagnoses who had completed their early intervention program and initiated, returned to, or struggled with an employment or educational track. Although the fact that the council held meetings at a university may have made this sample easier to recruit, it is important to note that only 1 of the 10 participants attended this university, and that the council’s work was not affiliated with the educational aspect of the university, but rather used a community research office for the available meeting space and support. These young adults are also a model for what “can” be successful in the prevention of a disability trajectory; thus, it is important to study their experiences to extend logical generalizations to other groups with early psychosis (Patton, 1990, p. 236). In other words, it is logical that if these young adults in this context have achieved some success in establishing career pathways, then other young adults in different contexts could do the same. The sampling plan aimed to enroll, obtain consent from, and interview up to 10 young adult participants for a series of two interviews per person. Inclusion criteria used were lived experience with psychosis; age 18 to 30 years; prior service recipient of the CSC program; and the capacity and willingness to provide informed consent, which was assessed using the human subjects

protocol. A target of 10 participants was chosen to gain variation in experiences and rich data without reaching beyond redundancy in experiences (Lincoln & Guba, 1985, as cited in Patton, 1990).

Data collection

Semi-structured interviews were chosen for their potential to elicit rich description of individuals' perceptions and experiences (Denzin, 2017). A two-interview series format was utilized to allow for engagement with the participant during the first interview and identify areas to access deeper content from questions during the second interview. Interview questions were structured based on the three research questions. In addition to the interviews, basic demographic information and duration of time with psychosis were collected from participant report.

Procedure

This study received full human subjects approval from the University of Washington. To recruit study participants, the researcher attended monthly YALC meetings, distributed flyers, and described the study. Individuals self-selected to be participants and the researcher followed up by text message to screen for inclusion criteria, obtain consent, and schedule the first interview, usually within 2 weeks of the date individuals volunteered. Interviews were held in a place of participants' choosing: usually their home, a meeting room at the local university or library, or a park. The second interview occurred roughly 2–4 weeks following the first interview. Following completion of the interviews and the first round of data analysis, a focus group comprised participants was held in the university setting where the YALC typically met. During the focus group, the researcher reviewed the purpose of the study, a summary of demographics such as mean gender and age, and resultant themes, and facilitated a discussion to confirm/disconfirm themes, thereby enhancing trustworthiness. Interviews were audio-recorded using a handheld recorder and the researcher also kept jottings of their own reactions. Interviews were transcribed by the researcher as well as a transcription service. All participants were compensated 75 USD at the end of the second interview.

Data analysis

Data were analyzed in four stages using a template approach. The template approach determines codes on an a priori basis and from emerging codes, allowing for the “interweaving of inductive and deductive thinking,” and provides an organizational structure using a template or “bins” (Bloomberg & Volpe, 2015, p. 192). First, all transcripts were read to understand the

storyline being told in the data and coded for the areas derived from the literature on poverty, disability, employment, and psychosis, as well as emerging themes. Second, a priori-coded excerpts were grouped by area, i.e., structural influences, and moved into bins where each excerpt could be organized within the parent category, while emerging themes were moved into a separate document. Third, the themes and descriptors from both a priori and emerging codes were moved into a diagram to attempt to illustrate any ordering patterns or relationships between them. Fourth, the excerpts within each bin and the emerging theme excerpts were coded for more detailed descriptors which were transferred to a final codebook. As a final step, the peer focus group was utilized as a form of member checking to enhance trustworthiness of results.

Results

A total of 10 young adults were interviewed, with a mean age of 26 (SD = 1.60) and were on average 5.7 years post-FEP. The sample was evenly split by male and female gender, and 70% of the sample was white while 30% identified themselves as racial/ethnic minorities – one Mexican-American, one Asian/

Table 1. FEP participant trajectories.

| Name ^a | Years post-FEP | Age at FEP | Family SES | Activity prior to FEP | Unemp./not in school | Current Occup. | Disability benefit |
|-------------------|----------------|------------|------------|---------------------------------------|---------------------------------------|--|--------------------|
| Evan | 8 | 21 | Low | College student | 9 months | OT intern | Yes |
| Patty | 7 | 16 | Low | High school | Never employed. | Unemp/SSI | Yes |
| Matthew | 6 | 21 | Upper | College student/ part-time work | 6 months | 3rd year law student | No |
| Mark | 5 | 20 | Middle | College student/ part-time work | 9 months | Full-time peer specialist/family business | No |
| Mike | 2 | 21 | Middle | College student | 3 months | Full-time peer specialist | No |
| Elizabeth | 6 | 21 | Upper | College student | 36 months | BA completed, working part-time | Yes |
| Meg | 9 | 19 | Middle | Part-time work | 6 months | Works full-time as peer specialist/part-time college | No |
| David | 6 | 19 | Middle | High school | Never employed. | Unemp/SSI | Yes |
| Jessica | 3 | 22 | Upper | College student/ working part-time | 3 months/7–8 months with grandparents | Full-time insurance industry | No |
| Sandy | 5 | 23 | Middle | Working full-time applying | Varied attempts at part-time work | Unemp. | No but |

^aNames are pseudonyms.

Pacific Islander, and one Asian-American. Table 1 presents the current employment, education, or disability status of the sample. Four of the young adults were pursuing post-secondary education and/or working, with two working full time and not engaged in educational activities, for a total of six individuals employed. Three individuals were unemployed and had not previously held employment, though one was in the early process of pursuing higher education. Four individuals utilized disability benefits, two as a supplement while continuing to finish educational programs and the other two reporting the disability benefits as their sole income. One individual was newly considering social security disability after a lengthy period of unemployment. Pseudonyms are used for all participants.

Family: tangible support and expectations for employment

Across all interviews, both tangible support from family such as providing housing, and family messages that communicated expectations about returning to employment or education were described as key determinants of forward motion in the post-treatment years. Additionally, both tangible support from family and expectations for the future were influenced by family SES, such as education level and income.

One key moment was the realization when I found out when my friends and family aren't going to give up on me, they're just not going to continue to let me go down that road and just keep cycling, you know they're going to pick me up when I fall, and whatever I need they're there, doesn't matter. (Mark, aged 23 years)

Mark considered family support to be integral to his eventual success returning to his job. In his case, as in others, the family had the financial means to allow their child to continue living at home and support them while they were unemployed and stabilizing post-FEP. In contrast, participants whose parents were financially unable to support their child returning to the home had persistent struggles due to insecure housing and lack of support in general. These struggles prolonged their time in disability states instead of enabling them to create a plan for employment or education. In the following passage, Patty describes the lack of support she received from family, which she blamed for her long struggle to reach a period of stability and her disengagement from education.

I had a hard time actually doing anything in school What I needed was help on my homework. Help organizing my planners. Like, what the occupational therapist did when I was in [EASA], someone to see my home and then help me with the dishes. That's what I needed. (Patty, aged 23 years)

Patty spoke of struggling to complete schoolwork without a supportive parent or an organized home environment. Her absence of parental

support had a negative influence on her educational trajectory beyond mental health treatment. A first-generation Mexican immigrant, Patty's mother struggled with her own poverty, failed attempts at college, and chronic illness, resulting in a somewhat neglectful home environment where Patty juggled responsibilities for household chores such as cooking and cleaning. Patty felt that her mood disorders were a result of chronic childhood stress and neglect. At study completion, Patty was still not employed or in school, was cycling between residential living facilities and brief stays with family, and felt that she would be unable to complete a college program without a supportive home environment and financial aid. In Patty's case, family poverty, which may have been exacerbated by the marginalization experienced as first-generation immigrants, presented a structural barrier that negatively impacted her pathway to employment or education.

In addition to family SES impacting levels of support, families communicated expectations about their adult child either returning to their employment/educational activities or remaining on disability, which may have reflected their own educational background and SES. As seen in the excerpt below, families that communicated higher expectations, such as returning to college or returning to a full-time job, tended to facilitate an employment/education trajectory.

All of the times when I was in the hospital, my hope of having a good career sustained me, like okay I'm going through this but someday I'm going to be an art therapist or some sort of good job. I mean my mom has always been very optimistic so I just try to think about the good things that have happened. I just have so much hope that I would get to go back to college and study art therapy or something like that. [Also] while I was in and out of the hospital, my brother was getting his PhD the whole time, so just seeing him, you know being able to go to school and pursue a job in his interest, made me feel like I would be able to have the same privilege. So that helps me keep going too. (Elizabeth, aged 27 years)

Elizabeth did return to university and completed her bachelor's degree. Despite continued ups and downs with a schizophrenia diagnosis, she was preparing to apply to graduate school, citing family expectations and previous familial academic work experience as keeping her going toward this goal.

In contrast, Patty received negative messages about her ability to have a career and enter the workforce, which she felt were connected with her mother's acceptance of the label of her own disability.

So I was basically pressured into taking SSI because my mom wanted more money for the household. When I was still a minor. So I've been on SSI for like 2-3 years. This is kind of complicated. Basically, out of all the time that I've been alive, my mom's only really been working for about a quarter, maybe a fifth of it. She's been disabled for another fifth of it. And then she's been super poor for the other thirds, or half. (Patty, aged 23 years)

This acceptance of disability benefits as a primary source of income by Patty's mother seemed to additionally influence her mother's outlook for her daughter based on a mental health diagnosis. During the same conversation, Patty said, "No one is going to hire you because you have a mental health diagnosis." Here Patty alluded to her failed attempts at convincing her mother to allow her to apply for jobs or to begin post-secondary education programs that would lead to jobs. Patty felt that her mother's negative prognosis stemmed from her own disappointments and failures in the workforce, some due to experiencing the effects of racism as a first-generation Mexican immigrant and, later, to chronic health issues with diabetes and mood disorders.

These contrasts between young adults navigating the post-FEP period supported by families with financial means versus those without available family support or positive messages highlight an important split between young adults continuing on a path toward working or school and those drifting to a pathway to disability and support mainly provided by the mental health system. This split is an important area of structural influence on outcome to be considered.

Mental health professionals: disability messages influenced pathways

Young adults in this study received different messages about their psychosis diagnosis, prognosis, and employment prospects from mental health professionals encountered during early hospitalization experiences and with the CSC program. In these cases, the mental health professionals may have been influenced by the realities of social disability policy and the structure of mental health treatment.

For example, Meg described the difference in prognosis or outlook communicated to her by a traditional psychiatric prescriber vs. the CSC prescriber regarding her psychosis and transition to a bipolar diagnosis:

I was on a lot of meds, so I didn't fully understand what they did yet, and then I kept going to a private psychiatrist and I asked her like, am I going to have to be on these meds for the rest of my life cause we were like kind of you know, tapering and she was like well, yeah, based on this diagnosis most people are on medication for the rest of their life. I was like, well, okay (laughs), and then I went to the psychiatrist at [CSC] and he gave me a lot more options like, some people are on medication for the rest of life, but it doesn't have to be the ones you're on right now if you don't like them, sometimes people get off their medication and never have an episode again, sometimes it may happen right away, we don't know, so it's kind of like, whatever you do we'll support you, but it was more varied outcomes then the one I was given. (Meg, aged 25 years)

Here Meg describes how psychiatric professionals who may have worked in traditional settings characterized psychosis as a permanent medical condition with perhaps a more negative outlook, while her psychiatrist with the CSC program offered more options and possible scenarios. These contrasts in

communicating early prognosis about psychosis likely stem from the developmental differences between the CSC model (young adulthood) and traditional psychiatric treatment that has viewed psychosis and schizophrenia as more chronic. Evan described a similar experience with his early intervention psychiatrist.

Yeah, I remember my mom asked the [CSC] psychiatrist, so is he gonna be okay? This was like the first meeting. And he said, well, some people you know, they never make it, other people go on to be great professionals and great thinkers, so really the path is up to him. (Evan, aged 29 years)

Evan's perception from the psychiatrist that there were different possible paths and assigning some of the ownership onto him sent a message of self-determination about his future. This message likely empowered him as a patient and instilled a sense of personal control during treatment.

Messages from mental health professionals during the FEP process also communicated archetypes about ability and disability as related to psychosis as a mental illness label. In the first example, Matthew, a participant with financially secure parents and a partially completed undergraduate degree in computer science, was given the typical disability overview while being discharged from a psychiatric unit.

And the second thing she said was that I'm going to give you and your parents these forms to fill out so that you can get on SSI, so in her mind like I couldn't work, that was her prognosis, that you know I couldn't work, and that SSI was the best option for me, um, and uh, you know, my parents probably you know were mortified at that like, SSI no way, and they never filled out the papers, they always believed that I could work. But it was the opinion of this social worker that I couldn't work, he should be on SSI. (Matthew, aged 27 years)

The above excerpt is an example of a standard practice used by hospital social workers to assist families in applying for financial benefits. In contrast, in Mike's case, a disability benefits discussion with the CSC program was communicated in a much different way.

Yeah, and in the EASA program, that was my mom's kind of question was, because that's kind of what the thought was like well, "Oh, is this what we do now," and the folks in EASA strongly encouraged us not to do that, that we shouldn't do that, and gave us some of the reasons why behind that, so I'm pretty thankful that they had that conversation with us because otherwise um, it could have been much more difficult to maybe be in this place that I am at now. (Mike, aged 28 years)

In Mike's case, his mother asked the CSC program if they should apply for disability as a standard part of the process. After taking time to assess Mike's recent work history, the program chose to focus on strategizing with Mike a return to work rather than spend time going through the often lengthy disability application process. This is a stark contrast to the traditional practice of applying for disability benefits generally offered by mental

health professionals in the early stages of a psychosis diagnosis. Based on previous research (Estroff, Zimmer, Lachicotte, Benoit, & Donald, 1997), this may have implications for the initiation of workforce pathways. Mike summarized his experience with EASA in “breaking the disability mindset” this way:

I think EASA kind of helped to break that traditional mindset and help us to recognize that there could be more than disability and just maintaining . . . I really felt that EASA helped, the folks that I worked with in EASA, helped me to feel like I could be successful in school, and that I could work. And they helped me to find employment and when I got let go, they encouraged me to keep trying, and that sort of thing. (Mike, aged 28 years)

This theme indicates that treatment ideology, which is structurally influenced by funding streams, treatment culture, and societal ideas about mental illness, influences front-line mental health provider staff as they communicate prognosis and expectations about psychosis and recovery. These messages contained implicit ideas that further influenced the self-perception of young adults as they moved through the FEP process and may themselves be byproducts of a mental health system evolution from acceptance of disability toward promoting employment.

Impact of the modern labor market

In addition to the influence of family and mental health professionals, participants also described realities of the labor market that impacted their employment choices. During the CSC program, young adults were offered the traditional Supported Employment option (Drake et al., 2012) of obtaining part-time jobs in the secondary labor market. However, both the traditional interviewing process and unfulfilling nature of part-time, entry-level work were abandoned for a streamlined, direct pathway into a career-oriented job such as those obtained through graduate school and associated internships.

Forgoing part-time jobs for those with a built-in pathway

A majority of participants who held successful employment or completed college at the time of this study did not first succeed in just any competitive employment placement or entry-level job. When they did work in part-time jobs such as retail or other entry-level positions, the combination of a high-stress working environment and difficulty obtaining accommodations made these jobs difficult to sustain, as explained by Matthew:

I could never work in retail, I have so much admiration for people who work in retail, the amount of pressure they're under is extraordinary, they're standing the whole day. I have

so much admiration for them, because I can't do that kind of job, I've tried working at Staples, Lowes, call center, and I know I can't do those jobs.

Interviewer: What is it about it that makes it hard?

I think it's the cumulative stress of the day that adds up, I mean, you get a break, it's not enough to wipe out the stress. It's not being able to sit down and focus on one task at one time, because even if you're doing something repetitive like a cashier, you're constantly [dealing with] other demands on what you're doing, someone has a question, you don't have an answer to a question, someone brings up a weird item that doesn't have a bar code it throws everything off, I can't work like that. (Matthew, aged 27 years).

Here Matthew paints a picture of his struggles with the pressures of working in a retail environment even in a specialty role as a computer technician. In this case, the attributes, tasks, and expectations for the workday in the retail environment were unrealistic for him, particularly in the years following his FEP.

In addition, a few individuals discussed losing their jobs due to employers' unwillingness to provide accommodations. Sandy lived in a small community with a limited economy for entry-level jobs. She described having multiple jobs primarily cashiering at gas stations. While she did not mind the type of work, the pressures of scheduling were a bad fit for her need to stay on a normal sleep/wake cycle.

The problem isn't getting the jobs, it's keeping the jobs lately. And part of it is dependent on the job but some of it is I set myself up for failure, this one job I told them I was available a lot and I was not as available to them as they wanted me to be, because I said I was available between 9 a.m. to 9 p.m. most days . . . He ended up having me work late one night, instead of work in the morning, so I ended up telling him because I felt mania setting in a little bit, or at least hypomania, and so I was afraid of working that late night shift again, for fear that that might come back. So I ended up telling him, and he seemed understanding, but I realized since getting to know him over the month that I worked there that he pretends like he cares but really doesn't. (Sandy, aged 28 years)

Sandy found this employer and other similar retail employers to be unsupportive of her basic work/life balance needs such as staying on a set schedule for the sleep hygiene needed when taking medications. This could indicate that there are problems with needed job accommodations found in the secondary labor market for young adults with a FEP and that living in a smaller community with fewer opportunities for education or entering into the primary labor market presents an additional barrier to successful employment pathways.

Young adults who were currently employed utilized a direct pathway into employment through specific job training and certification such as peer specialty and graduate school internships. The following excerpt describes how one individual used peer specialty training as a bridge to the labor market.

We tried all this different stuff, you know just applying for random jobs, I was like trying to get a caregiving job or something random just working in a nursing home and that

wasn't really working out, and she was like I don't really think that sort of thing is a good fit for you and that's when she brought [peer specialty] up. (Meg, aged 25 years)

In this example, Meg describes not having success looking for work using traditional interviewing and how she instead was able to parlay her lived experience into a paid position after completing peer specialty certification. Two other individuals who were in graduate education programs in health care and law chose those career pathways after having similar frustrations with the limited jobs and difficult interview processes typical of competitive employment in the secondary labor market.

University disability support

For individuals who were currently matriculating or planning to enter higher education settings, access to university disability resource centers for needed accommodations was rated positively. It also appeared to play a crucial role in their ability to achieve academic success.

I talked to the disability counselor, about if I'm feeling anxiety I can just leave and then ask the professor what I can study like in the textbook. Well the reason I wanted to get in touch with them was that whole being as careful as possible and using all my resources to find comfortability, to find my groove. So disability services, I just went in, told them what I have, looked at them, they said, are you going to be okay, I said if I ever feel tense in class I'll leave they asked if I needed anything else, I said sure maybe some extra time with testing. (David, aged 25 years)

In this case, David was hoping to start a university degree program after a prolonged period outside of employment and education. David struggled with anxiety, which often overlapped with his delusional thinking, so he worried about saying something to upset someone or becoming disruptive in the classroom environment. He spoke to disability services about his concerns and they attempted to troubleshoot techniques for success in class. In Matthew's case, the university disability resource department actually contacted his department to request additional accommodation for tutoring and meeting outside class:

The disability resources center was really supportive, they worked hand in hand with the [major] department to make sure that I didn't fall behind or fall through the cracks. I did the intensive summer program, and I would have totally failed if it wasn't for the professors at [state university] who went so far out of the way, way far out of the way to accommodate me, tutoring lessons every single week outside of class ...like private tutoring classes with a [department] teacher outside of class and that was all provided all above and beyond what they were required to do. (Matthew, aged 27 years)

Matthew's case was quite illustrative of the detailed accommodations that can be offered through the support of a disability center at a university. This type of support and advocacy from disability services, together with a very

supportive professor, were cited by Matthew as major turning points in his success in his education program. While accommodating psychosis is perhaps a relatively new issue for university disability centers, this can have a tremendous positive impact on the completion of their studies.

In summary, these young adults found multiple barriers and facilitators on an employment and education pathway beyond their completion of the CSC program – most of which are indicators of societal realities such as the structure of the modern labor market and needed support within university settings.

Discussion

This study utilized critical case methodology to examine the ways in which young adults with lived FEP experience who were many years post-CSC treatment navigated employment, education, or disability pathways. Results indicate that the formation of individual goals or sense of ability post-psychosis diagnosis were influenced by the views of family members and mental health providers and by the realities of the modern labor market and university settings. All of these determinants were further influenced by structural realities such as family SES and related stratification or marginalization, the views of the mental health system in response to disability and related prognoses for employment, the realities of the modern labor market, and the availability of university disability support. Finally, while individual symptoms of psychosis were a factor at the beginning of the employment/education planning process while individuals were generally reaching their baseline of functioning prior to onset of psychosis, symptoms were not perceived as an ongoing barrier once individuals were employed or pursuing a post-secondary educational pathway. This information has important implications for CSC intervention and the supported employment and education services offered within it.

Implications for research and services

Implications for research and services for young adults with FEP include enhancements to the routine assessment and supported employment models used by CSC programs and within the mental health system in general. Within all of these recommendations, it is imperative for the mental health system to adjust its views on disability and consider that early psychosis impairment may be temporary and that individuals experiencing FEP may benefit from accommodation rather than a permanent pathway to chronic illness.

Routinely assess structural barriers

These findings suggest that mental health services need to become more effective in reducing poverty trajectories for young adults with FEP. CSC teams should create plans to better engage youth with early-onset psychosis who are not in education, employment, or training (NEET) (Iyer et al., 2018), and who likely comprise the 40% of FEP young adults leaving CSC programs on disability benefits (Rosenheck et al., 2017). This includes equipping front-line staff with a working knowledge of the adverse impact of structural inequalities on those from disadvantaged backgrounds as well as the capacity to routinely assess for these barriers. For example, a structural barrier assessment for those with early-onset (before age 18) psychosis (Boychuck, Lysaght, & Stuart, 2018; Mellor-Marsá et al., 2017), low family SES, and/or racial and ethnic minority populations (Browne et al., 2000), and those without work experience prior to FEP onset (Mellor-Marsá et al., 2017), will allow for targeted engagement of young people who are not yet on an employment or education trajectory and who may face additional obstacles related to poverty and discrimination.

Challenge traditional ideas about mental health disability

It was clear from the findings of this study that the mental health system is still in flux regarding views on disability, particularly in FEP individuals, but also that promising gains were being made by some of the CSC programs, which were “breaking the disability mindset” in the words of a participant. Considering previous research by Estroff et al. (1997) who found that social messages about accepting disability by mental health providers and family solidified disability states, it is especially beneficial for CSC programs to reverse this traditional script and promote employment or education pathways rather than accept an impoverished pathway of subsisting on disability benefits.

Shift supported employment and education to the primary labor market and engage with university disability centers

Supported Employment and Education is a modified IPS-Supported Employment model that targets young adults by focusing on both employment and the maintenance or initiation of formal education (Killackey, Jackson, & McGorry, 2008). Employment specialists are integrated in a number of early intervention programs within a team (Rosenheck et al., 2016). Baron and Salzer (2002) have studied causal links between poverty and SMI and implicated the mismatch between the traditional “train, place, support” employment model and changes in the labor market that have rendered the secondary labor market inadequate to lift individuals out of poverty. Also, Baron et al. (2013) have called for a “refocusing on primary labor market jobs”

in employment programming for those with SMI. Direct entrance into the primary labor market for career development is important, particularly for young adults with mental health disorders who could flourish without living in poverty. Finally, scant, if any, research has been done on university disability centers and FEP, underscoring that this too is a major area of needed study in tandem with CSC programs.

Limitations of the study

This study has several limitations. It relied on a critical case sample of young people drawn from a unique environment. The drawback of starting from a critical case for sampling is the limitation on broad generalization since the group is relatively homogenous through their experience with a specific model of early intervention and advocacy work. In particular, the study sample was selectively composed of young adults with FEP that possessed the capacity and motivation to volunteer for an advocacy group. However, because these young adults presented a rich resource point in the question of how trajectories are formed in early psychosis and had been out of the CSC program for an average of 5.7 years, they offered a unique perspective on pathways to employment and the role of disability.

Conclusion

In summary, this paper found that the pathway to employment and education during and after a FEP is heavily influenced by family support and expectations, which are shaped by SES, communication about disability and prognosis by mental health professionals stemming from their own treatment structures, the realities of the labor market in general, and support from university disability resources. This paper concludes that while overcoming initial stages of psychosis and returning to functioning are important, CSC services should create a unified plan to address the structural barriers that challenge those from marginalized families, reevaluate traditional disability structures in mental health treatment, and better understand and support new pathways to secure employment and formal education for all young adults with FEP.

Acknowledgments

The author would like to acknowledge the bravery and contributions of the members of the Young Adult Leadership Council and the support of the EASA Center for Excellence at Portland State University including Tamara Sale and Dr. Ryan Melton. She also acknowledges the invaluable direction from members of her dissertation committee including Dr. Gunnar Almgren, Dr. Taryn Lindhorst, Dr. Greg Townley, & Dr. Bob Mugerauer.

Disclosure statement

No potential conflict of interest was reported by the author.

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