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On the Cusp: Pathways to Employment, Education, and Disability in First-Episode Psychosis (FEP)

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A dissertation

submitted in partial fulfillment of the

requirements for the degree of

Doctor of Philosophy

University of Washington

2019

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School of Social Work

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**Abstract**

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Poverty is a persistent problem in serious mental illness (SMI) with adult unemployment rates consistently hovering around 80%. A psychiatric paradigm shift toward early intervention for first-episode psychosis (FEP) has shown promise in supporting employment and education in early stages of treatment, but with mixed outcomes. Theories implicate existing low SES and its associated structural barriers, social drift into disability following onset in early adulthood, and disability status with its accompanying label and stigma, in the maintenance of poverty for this population. Utilizing life course theory and considering that the developmental period before disability is established is a particularly critical intervention point for poverty prevention among this group, it is an urgent research priority to learn how young adults with FEP negotiate employment and/or education and how interventions can facilitate this process. This dissertation explored the ways in which employment, education, or disability trajectories form during the early stages of living with a FEP. Utilizing a standpoint epistemological lens, which seeks to highlight the position of the marginalized, 19 interviews were conducted with a critical case sample of young adults with lived

experience of a FEP and early intervention programs to explore the key moments, messages, and structural influences that determined their trajectories towards employment, education, or disability. Results indicate that the initial life disruption from a FEP in young adulthood leads to a suspension of gainful activity, followed by a period of forward progress through overcoming their early experiences with hospitalization and medication regimes, and adjusting their self-concept after the label of psychosis. Mental health professionals sent different messages about disability or capability depending on treatment ideology, while families provided varying levels of support and encouragement based on their own SES and subsequent values. Finally, young adults who were successful in entering the labor market did so by moving into direct career pathways instead of looking for work in the secondary labor market, utilized university disability centers, and found support and direction through their involvement with the council. These conclusions have significant implications for early intervention programs, including targeting early-onset FEP, shifting employment focus to the primary labor market, promoting adjunctive peer-based support, and challenging the professional mental health discourse about disability. Implications for research include the need to better understand the pathways of FEP young adults who are not in education, employment, or training (NEET) and who face additional barriers to accessing employment programs and the labor market.

## TABLE OF CONTENTS

	Page
List of Figures.....	v
List of Tables.....	vi
Chapter 1: Background and Introduction.....	1
Serious Mental Illness (SMI).....	2
The disability-poverty connection.....	5
Addressing poverty through early intervention.....	9
Employment and first-episode psychosis (FEP).....	10
The limits of quantitative research on First-Episode Psychosis (FEP) and poverty.....	13
Purpose of this study.....	14
Chapter 2: Literature Review.....	16
The construct of poverty.....	16
Poverty and severe mental illness.....	18
Theories of poverty and serious mental illness.....	18
“On the front end”: social causation theories.....	18
Neighborhood effects.....	19
Social-Stress Hypothesis.....	20
Discrimination.....	22
“On the back end”: Social Drift Theory.....	22
Disability theories.....	25
Individual impairment/medical model of disability.....	27
Social/critical model of disability.....	28

Labeling Theory.....	29
Stigma Theory.....	30
Medicalization of poverty.....	30
Disability and FEP young adults: Modern social disability framework.....	31
Summary and conceptual model.....	32
Process of inquiry.....	36
Key moment construct.....	37
Research questions.....	37
Chapter 3 –Methods.....	38
Introduction & overview.....	38
Setting & sample.....	39
Data collection.....	41
Procedures.....	44
Protection of human subjects.....	44
Data analysis.....	46
Reflexivity statement.....	48
Chapter 4 – Trajectories & Overcoming First setbacks.....	50
Introduction.....	50
Participant personal FEP timelines.....	52
Part I: Onset of FEP: Suspension of Activity.....	57
Psychosis onset: suspension from young adulthood.....	57
Overcoming hospitalization.....	59
Overcoming medication.....	61
Part II: “Getting back out there” – Forward Progress.....	62

Reconstructing the self after diagnosis.....	63
Becoming social again.....	66
Finding peers.....	67
Ethnic minority status an additional hurdle for people of color.....	68
Chapter 5: Employment, Education, & Disability: Messages and Pathways .....	72
Part III: Mental Health Professionals and Family: Ability/Disability Messages and Support .....	72
Mental Health Professionals: Demeanor and Prognosis Influences Ability/Disability.....	72
Positive demeanor .....	73
Psychiatric prognosis .....	74
Disability messages.....	75
Practical and Tangible Support from Early Intervention Staff.....	77
Family: Support and Messages Facilitate or Hinder Progress.....	78
The presence or absence of family support.....	78
Family messages about working, education, or disability .....	80
Part IV: Forging Pathways through Employment and Education.....	82
Navigating the secondary labor market: Foregoing part-time jobs for those with a built-in pathway .....	83
Direct pathways into employment.....	85
University disability resource centers .....	86
The Young Adult Leadership Council as Adjunctive Support.....	87
Conclusion.....	89
Chapter 6: Discussion .....	90
Introduction .....	90
Relationship between Findings, Conceptual Model, and Literature.....	92

Employment & Education Trajectories .....	93
Barriers to employment & education trajectories.....	93
Facilitators to employment & education trajectories .....	96
Theoretical Connections: Social Causation, Drift, and Disability .....	97
Social Causation.....	97
Social Drift .....	98
Labeling/Stigma .....	100
Implications for Services .....	102
Target early-onset FEP with an anti-poverty lens. ....	103
Shift Supported Employment & Education (SEE) programming to the primary labor market.	104
Develop and promote adjunctive peer-based support for FEP programs. ....	105
Implement a change in the professional discourse about disability.....	106
Limitations of the Study .....	106
Implications for Research. ....	107
Conclusion.....	108
Bibliography.....	112

**LIST OF FIGURES**

Figure Number	Page
1. Conceptual model.....	33
2. Study flowchart .....	43

## LIST OF TABLES

Table Number	Page
1. Semi-structured Interview Questions .....	42
2. Code Categories for Data Analysis .....	47
3. FEP Participant Trajectories.....	51

## **ACKNOWLEDGMENTS**

This dissertation came to fruition thanks to the guidance and patience from members of my dissertation committee, and the unyielding support from Tamara Sale and Ryan Melton from the EASA Center for Excellence at Portland State University.

## **DEDICATION**

This dissertation work is dedicated to the resilient young adults of the Young Adult Leadership Council (YALC) who eagerly engaged in this study to combat the oppression of young people involved in mental health services through offering to share their own stories of bravery and persistence after a first episode of psychosis.

## CHAPTER 1: BACKGROUND AND INTRODUCTION

Income through employment is an important social determinant of health, particularly in Western industrialized nations, yet individuals with serious mental illness (SMI), particularly those living with psychosis and schizophrenia-spectrum disorders, have historically not participated in employment, resulting in a high-level of poverty for this population. Current unemployment rates for adults living with SMI within the public mental health system hover around 80% nationally despite 50% or more wanting to work (Drake, Bond, & Becker, 2012); and evidence that points to 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, fails to alleviate poverty, with fewer than 13% returning to work after becoming recipients in 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 et al., 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). Only since the early 1990s has there been a formal effort to promote employment of individuals with SMI within mental health treatment programs, through the Supported Employment model. Also known as the Individual Placement and Support model, supported employment programs were created to address unemployment within mental health treatment, rather than referring clients to community resources not specific to mental illness, such as the Department of Vocational Rehabilitation, which serves all individuals with disabilities (Drake, Bond & Becker, 2012). Unfortunately, supported employment programs are still not fully disseminated and/or embraced as

standard practice within mental health treatment centers and rates of unemployment among the SMI population remain as high as 90% in some states (SAMHSA, 2012).

Social Drift Theory posits that as psychosis emerges during the period of young adulthood, time away from developmentally normal work and school settings results in “a lack of opportunities to accumulate human capital” (Funk, Drew, & Knapp, 2012, p. 172), reduced productivity, and loss of employment and earnings (Patel et al., 2010, as cited in Lund, 2012), which may lead to poverty and often, permanent disability. A psychiatric paradigm shift toward early intervention for developing or first-episode psychosis (FEP) has shown promise in reducing disability for this population due to a focus on supporting employment and education in early stages of treatment (Killackey & Allott, 2013). Considering that the developmental period before disability is established is a particularly critical intervention point for poverty prevention among this group, it is an urgent research priority to learn how young adults with FEP negotiate employment and/or education and how interventions can facilitate this process. This dissertation aims to explore the links between disability, poverty, employment, and mental illness, with a spotlight on the ways in which trajectories toward employment, education, and disability form during the early stages of living with psychosis.

### **Serious Mental Illness (SMI)**

Serious mental illness (SMI) is defined by the National Institute of Mental Health as “a mental, behavioral, or emotional disorder resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities.” (NIMH, 2019). In particular, schizophrenia-spectrum and bipolar disorders are associated with the most severe negative functional outcomes in terms of employment. Both schizophrenia and bipolar I disorder have a lifetime incidence of 1% in the general population (Bebbington & Ramana, 1995; Messias, Chen, & Eaton, 2007). The onset of schizophrenia typically appears between ages 15-24 and is weighted

toward male gender, while late onset (post-age 30) is associated with being female (Alameida, Howard, Levy, & David, 1995). Bipolar I disorder also has an onset between ages 20-30 with a mean onset in the early 20's (Merikangas, 2011; Rowland & Marwaha, 2018).

Both schizophrenia and bipolar I disorder often present with psychosis (Mueser & McGurk, 2004; Rowland & Marwaha, 2018). Characteristics of the psychosis present during and prior to schizophrenia include the presence of positive symptoms, or those that can be readily identified, such as hallucinations and delusional thoughts that persist. Negative symptoms include social withdrawal and cognitive deficits, which are more pronounced during the early stages of the disorder (Mueser & McGurk, 2004). Bipolar disorder is characterized by periods of mania which usually include severe sleep disruption and delusional thought alternating with depressive periods. Individuals with bipolar disorder who present with mania also present with psychosis in up to 60% of cases and usually require immediate hospitalization for treatment (Dunayevich & Keck, 2000; Rowland & Marwaha, 2018).

For the duration of this dissertation, references to adults with SMI will include both individuals with schizophrenia and more chronic and unrelenting forms of bipolar I disorder, as these are historically associated with the most long-term disability and subsequent poverty (Knapp, Mangalore, & Simon, 2004). In addition, both disorders typically present with FEP and are treated in early intervention for psychosis programs, both of which are a particular focus of this study.

Before the mid-1960's, individuals with SMI typically received treatment in state institutions. Following the deinstitutionalization era, the majority of individuals with SMI began receiving treatment in community mental health centers (Turner & Tenhoo, 1978). Typical standard treatments range from psychotropic medications to case management, with more elite evidence-based practices such as Assertive Community Treatment (ACT) associated with the strongest

psychosocial outcomes such as reduced use of inpatient hospitalization and acquisition of stable housing (Bond, Drake, Mueser, & Latimer, 2001).

Previous psychiatric treatment paradigms were accepted and practiced under the belief that a schizophrenia diagnosis had a prognosis consisting of a downward slope to permanent dementia, a view that persisted until Bleuler's (1968) findings that 66% of individuals with early psychosis eventually fully recovered, while 41% did not. (Sanbrook & Harris, 2004). This study longitudinally followed first-episode individuals throughout the course of treatment and was the first to show that larger-than-expected cohorts of patients with schizophrenia diagnoses recovered and went on to live a life not dependent on the cycle of public mental health and disability benefits, and was replicated by Ciompi in 1988. This research, combined with the development of antipsychotic medication, better understanding of family roles in recovery, and patient/family advocacy, all contributed to a philosophical shift in psychiatry toward early intervention (Sanbrook & Harris, 2004).

Early intervention for psychosis programs, first developed in Australia and now propagated throughout the United States as Coordinated Specialty Care programs focus on treating psychotic illness in earlier stages. Additional early intervention for psychosis programs began in Scandinavian countries, with Australian programs becoming a central training ground in the early 1990s (McGorry, Mihalopoulos, Harrigan, & Jackson, 1996). These were eventually disseminated to other countries, including the United States, where early adopters of the model were Zucker Hillside Hospital in New York, the Oregon Early Assessment and Support Alliance (EASA), and the Personal Involvement Empowering Recovery (PIER) program in Portland, Maine (Heinssen, Goldstein, & Azrin, 2014; McFarlane et al., 2010; Melton, Roush, Sale et al., 2013). Since 2012, when U.S. policy changed to dedicate 3% of federal mental health block grants to the development of state early intervention programming, the coordinated specialty care (CSC) early intervention programs have been made available nationwide. Important considerations for early intervention

programs include reducing the duration of untreated psychosis (DUP) and having successful interventions during the “critical period” which “extends out to a maximum of 5 years from onset of illness” (Del Vecchio et al., 2015). Early intervention is also a crucial target for poverty prevention since functional outcomes such as employment remain low for adults with more chronic forms of SMI.

### **The Disability-Poverty Connection**

The experience of working impacts many aspects of life, including generating personal income, participation in the labor market, and contributing to the economy. The experience of working also results in social interaction and participation in citizenship, along with their associated social capital. Working is positively related to mental health in that it provides opportunities for skill development and social contacts (Tausig, 1999) and has a restorative impact on recovery from mental illness (Drake et al., 2011; Strickler et al., 2009). In a study of individuals with SMI, Ruesch and colleagues (2004) found that the occupation aspect of working “provided a context for establishing and maintaining not only instrumental, but also intimate relationships to men and women that cannot easily be replaced by other contexts” (p. 692) and that social support comprised 50% of the effects of a working income on quality of life. While the economic and social support aspects of working are deemed to be important social determinants of health, the inverse of these are financial poverty, relative social isolation, and associated societal marginalization, which in sum are seen to decrease health and overall life expectancy (Frier et al., 2018; Marmot & Wilkinson, 2006), and lead to undertreatment of health issues (Parks, 2008), all of which further complicate pathways to employment.

Adults living with SMI and disability have longer periods of unemployment and receipt of Social Security benefits than do any other group such as those with physical disabilities or other

chronic health issues (Knapp, Mangalore, & Simon, 2004), and thus they experience a daily reality of both economic poverty and the effects of social marginalization throughout most of their adult lives. A combination of historical assumptions about mental illness, treatment increasingly focused only 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 et al., 2018). Within the auspices of the mental health system, the unemployment rates associated with disability and adults with SMI are influenced by the “usual suspects” (Baron & Salzer, 2002, p. 587) including the characteristics of the illness, programs and practice, and policies. The characteristics of the illness argument claims that mental health symptoms such as depression, limited interpersonal skills, and cognitive issues associated with SMI are related to unemployment among this population. Mental health treatment programs do not adequately address chronic unemployment (Baron, Draine, & Salzer, 2013; Wilton, 2003) and even when the best evidence-based job placement programs such as the IPS model are accessible, they do little to promote economic prosperity or lift individuals out of poverty (Baron, Draine, & Salzer, 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).

Disability statistics indicate that people with mental illness account for 30-50% of all the unemployed disabled in OECD countries, meaning that while all groups with disabilities struggle with unemployment, those with mental illness comprise the largest proportion of the combined group (OECD, 2009). In the U.S., it has been well documented that adults living with SMI generally depend on Social Security Administration (SSA) benefits (Social Security Disability Insurance (SSDI) and Supplemental Security Insurance (SSI)) as a primary source of income. A 2014 survey found that 713,000 adults with mental illness received SSA benefits (Social Security Administration, 2015),

while other studies cite this number to be as high as 3.4 million for those receiving SSI specifically (Shinn & McCormack, 2017). It has been further well documented that being a recipient of SSA support, while a necessary safety net, is associated with multiple barriers to successfully re-entering the workforce. Individuals with SMI are not only the largest group of SSI/SSDI recipients with disabilities, they are the most likely to start receiving disability payments while young and remain on this limited source of income over the period of adulthood (Baron & Salzer, 2002). In addition, young adults who receive SSI likely do not have the years of service credit to receive more income from SSDI and therefore are limited to the more meager sum from the SSI program. Furthermore, following the 1996 welfare reform act, there has been a 50-100% jump in disability enrollment, particularly among young adults (Hansen, Bourgois, & Drucker, 2014), due to the fact that Temporary Assistance to Needy Families or (TANF) became less stable, and individuals have been guided toward SSI applications in its place (Wamhoff & Wiseman, 2006). This increase in disability enrollment rates over the last two decades has been characterized as part of a greater trend of the “medicalization of poverty” (Hansen et al., 2014; Whittle et al., 2017) in which symptomology made worse by the presence of poverty contributes to greater provision of disability benefits as well as transferring responsibility from the welfare state to the medical (in this case, mental health) professions.

The prevailing paradigm regarding receipt of disability benefits is that an individual must demonstrate that they are unable to work based on an individual impairment. Also known as the impairment/medical model of disability, this dominant paradigm requires that a medical diagnosis be made by a mental health professional in order to then submit a claim to the Social Security Administration that one is unable to work due to the individual impairment, in this case, severe mental illness (Social Security Administration, 2018). There are several major issues with this dominant paradigm. First, there is the issue of the large amounts of personal time that individuals

invest to apply for disability benefits. The time between initiation of first social security disability application and actual financial reward lasts an average of 27 months, mostly due to the appeal processes (David, 2011). Furthermore, individuals are encouraged not to work during this waiting period which would threaten their disability status, resulting in a long period of unemployment. Similarly, re-entry to the labor force carries inherent risks of reduced benefits, and the accompanying benefits counseling for transition back to work is not always readily available (Baron & Salzer, 2002). Finally, the medical model of disability presumes that the impairment of mental illness disables, while failing to see that impairment waxes and wanes, particularly with treatments oriented toward restoring functioning. This impacts young adults most significantly in that the negative effects of unemployment prior to the initial psychosis diagnosis adds a complicated barrier to overcoming poverty once entering the mental health system and/or receiving disability benefits.

Studies on the interaction between SMI and poverty have found that the disability benefits being suggested by treatment staff have a negative influence on individuals' capacity to later move into the labor market (Agerbo et al., 2004). Early research on what many see as the disability-poverty trap indicated that messages from parents and mental health professionals during the initial hospitalization phase ultimately impacted an individual's identity of being "disabled" and unable to work (Estroff et al., 1997). The status quo in the mental health field is to assist an individual with SMI to receive disability benefits, which replaces a standard focus on obtaining employment, resulting in failure to enter or re-enter the labor market (Baron & Salzer, 2002). This standard of assisting with disability benefits has been professionalized and thus continues as the dominant paradigm within mental health treatment. In sum, the acceptance of living on SSA benefits as an alternative to employment, within both the mental health system and by the public in general "removes focus from attempting to re-enter the labor market, arguably [it] incapacitates people who might otherwise work at least part-time for legal wages" (Hansen et al., 2014, p. 82). Finally, the

process of coming to terms with the label of “mentally ill” and “disabled,” with its internalization of a deviant identity and lifestyle, has a lingering impact on the future productivity of the person (Goffman, 1973; Gove, 2004) and may result in stigma and possible discrimination in hiring due to mental disability (Kinson, Hon, Lee, Abdin, & Verma, 2018).

### **Addressing Poverty through Early Intervention**

The recent paradigm shift in the timing of intensive mental health treatment provides new opportunities to explore the beginnings of these disabled or non-disabled trajectories 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 both illness chronicity (Devylder, 2017), and address the developmental needs of those approaching young adulthood such as pathways to employment or education (Birchwood, Todd, & Jackson, 1998). Additionally, because of the developmental timing of their intervention, 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 two years of treatment.

Two main studies have explored initial recovery outcomes associated with early intervention programs. The Early Psychosis Prevention and Intervention Centre (EPPIC) study (2010) followed individuals with early psychosis from the Australian program up to 7 years later and found a 37-59% rate of symptom recovery and that 39% of the original sample were employed (Henry et al., 2010). The Recovery after an Initial Schizophrenia Episode (RAISE) study found improvement in quality of life, symptoms, and increased school and work involvement compared with treatment as usual (TAU) (Kane et al., 2016; Rosenheck et al., 2017). While findings from the RAISE study have shown that a higher than normal percentage of early intervention clients worked or went back to work compared to TAU clients, it also found that those receiving social security disability benefits

did not, and that receipt of these benefits were not significantly reduced by being in CSC care (Rosenheck et al., 2017). A recent study on 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., 2017). Finally, recent studies on FEP and employment outcomes suggest that while employment programs within CSC care are effective at increasing the number of days in work or school activities, they do not increase income enough to leave SSA benefits (Drake, Frey, Karakus, Salkever, Bond, & Goldman, 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 the promise that CSC programs are uniquely positioned to delay or prevent disability through promoting “early returns to employment” (Drake et al., 2013).

### **Employment and FEP**

Studies on FEP and employment show positive effects on the recovery process for those who participate in the labor market. Employment support in general has been shown to keep individuals with SMI engaged in the necessary social networks to support an identity of “active worker” rather than “passive patient” (Borg & Kristiansen, 2008, p. 517, as cited in Tew et al., 2012). Employment is associated with better adjustment for those with FEP when compared to those who are not employed as shown by less service use and fewer disability or welfare payments over time (Drake et al., 2013), improved symptoms (Burns et al., 2009), and an overall decline in disability (Alvarez-Jimanez et al., 2012; Krupa et al., 2012).

A number of studies have examined the predictors of employment in FEP with the strongest associations being prior work history (Santesteban-Echarri et al., 2017), education (Santesteban-Echarri et al., 2017, neurocognitive functioning (Alott et al., 2013; Chang et al., 2014; Santesteban-

Echarri et al., 2017; Tandberg et al., 2011), and female gender (Santesteban-Echarri et al., 2017). Male gender became a predictor when combined with education (Hegelstad et al., 2017). Negative predictors of employment among a FEP population include a longer DUP and greater negative symptoms (Turner et al., 2009), which coincidentally are part of the subgroup of FEP with early onset (<18 years-old), poorer quality of life and less work history (Brown et al., 2000). Marsa et al., (2017) found that psychosis symptom severity did not independently predict long-term disability; rather, levels of personal insight, and socioeconomic factors such as living independently and economic wages positively influenced employment after three years. Taken together, these studies indicate that those with onset of FEP before age 18, with no early work history, and a longer period of time with negative symptoms have a more difficult path to employment than those with an onset of psychosis in young adulthood with a previous work history. However, they also indicate that positive symptoms of psychosis such as hallucinations and delusions, are not negatively associated with later employment, which defies popular public opinion about mental illness.

Emerging empirical research on employment for the FEP population underscores the importance of early intervention with an employment component in improvement of employment outcomes, however these studies have methodological challenges in assessing employment for all young adults with FEP. A recent major critique on IPS supported employment research finds that they often exclude those who do not self-refer to employment services and therefore report results on only those with existing motivation to work (Rosenheck et al., 2016). Baksheev et al. (2012) completed a randomized controlled trial comparing early intervention with an Individual Placement and Support (IPS) employment/education intervention component to early intervention treatment as usual (TAU). Individuals were similar on baseline demographics and functioning and randomized to either the TAU early intervention program or one with a specific fidelity IPS intervention. Controlling for all previously studied clinical and demographic variables, the authors found that

compared to TAU, the IPS intervention by itself resulted in participants being 16x more likely to participate in employment and education at follow-up and no significance for those clinical and demographic factors that had predicted employment outcomes in prior studies. However, Baksheev et al., (2012) also failed to enroll all FEP young adults, relying on case manager referral based on self-interest in employment. Therefore, while they do show that employment interventions within early intervention models help obtain employment, this is limited to those who are likely self-selecting into the programs, possibly because they lack additional barriers to employment. Abdel-Baki et al., (2013) found that no demographic variables (including prior employment at baseline) predicted employment, but rather, the intervention led to increasing levels of stable employment (i.e., working increasing amount of hours over time) in a 4-year follow-up, however, the authors reported a loss of 40% of subjects over a two-year period, and therefore based their findings on 60% of the original sample.

Of the FEP and employment studies that did include all participants regardless of the motivation to work (Rosenheck et al., 2016; Srihari et al., 2015), findings indicate that involvement in work and school activities increased for those in a FEP program with access to supported employment and education (SEE) services. In particular, Rosenheck et al., (2016) found that being in the FEP program offered additional motivational enhancements for those who entered the program without stated interest in work or school as they increased their motivation within the first six months, with 58.2% increasing their involvement in SEE vs. 6.1% in treatment as usual. This has important implications for the function of early intervention programs in assessing and engaging young adults in working and school, rather than passively allowing only those who float naturally to SEE interventions to receive this intervention.

## **The Limits of Quantitative Research on FEP and Poverty**

Considering the connection between disability and poverty and also the consistent findings of low employment rates among adults with SMI, it is of utmost importance that researchers begin to study “what works” to promote employment and income at an earlier developmental age, particularly for those who are not in education or employment and who present in treatment with adverse social conditions that negatively impact their access to employment interventions. A thorough examination of these issues requires researchers to utilize frameworks that can capture the multidimensional aspects of poverty and other negative social conditions. There are two main issues with research on poverty and employment for those with SMI: 1) Research on poverty has been criticized for being overly driven by politicized ideology and based on individual-level theories such as Rational Choice Theory, while excluding structural issues such as “wage decline, labor market failure, and rising inequality” (O’Connor, 2001, p. 5); and 2) Quantitative intervention studies do little to explain how the structural issues that enforce poverty or encourage labor market flourishing are experienced outside of the context of intervention (Denzin, 2017). For example, in the above referenced studies on FEP and employment, findings indicated that exposure to an intervention condition (in this case, employment services within a FEP program), resulted in more access to the labor market than controls, however, it has also been stated by the researchers that this access to the labor market hasn’t resulted in enough gainful employment to leave SSA benefits (Drake et al., 2016; Rosenheck et al., 2017). Structural context such as low educational attainment before onset of a FEP, being a person of color, and having low family SES, may in fact inhibit access to employment programs (Browne et al., 2000), while receipt of disability benefits may negatively influence self-concept as a full-time worker in the labor market (Estroff et al., 1997).

In contrast, qualitative studies in mental health research can illuminate the unique situations experienced by those socially marginalized members of a vulnerable group with such famous example as Hopper's (1988) study of homelessness and Estroff & Lamb's (1981) study of adults with SMI in the community. Utilizing qualitative methods provides illustrations of how "...emphasis on the uniqueness of each life holds up the individual case as the measure of the effectiveness of all applied programs." (Denzin, 2017, p. 12) or how the intervention is experienced by individuals. Moreover, critical frameworks and/or case selection illuminates the most oppressed and vulnerable cases of a population as well as identifies the structural issues influencing employment or poverty outcomes (Garrow & Hazenfeld, 2015). Qualitative and critical research frameworks can therefore enhance quantitative studies on interventions and social outcomes.

### **Purpose of this Study**

This dissertation studies the theoretical and empirical overlap between psychosis-based mental illness, poverty, disability, and employment, by investigating the ways in which these are conceptualized within the context of the lives of young adults with FEP. It explores the experiences of negotiating employment, education, or disability benefits among young adults with early psychosis with a particular focus on learning about key moments both during the program and after completion, such as family support and prognosis given by mental health professionals. Findings generated from this study have the potential to better inform mental health policy and practice with FEP young adults, by better understanding the pathways to employment and education.

This dissertation is organized into six chapters. Following this introductory chapter, Chapter 2 reviews the literature on poverty and serious mental illness including theories on social causation, social drift, and disability -and applies these to a FEP population. It then reviews the current empirical research on employment and a FEP population and concludes with a conceptual model of

how young adults recovering from a FEP are influenced by family, mental health professionals, and society, particularly as it relates to returning to or initiating employment and education.

Chapter 3 situates the study within a critical case sampling framework and outlines the qualitative research project methods and data analysis procedures utilized to address the research questions. Chapters 4 and 5 present the findings of the study in two ways. Chapter 4 presents the proximal experiences of FEP that divert the young adult from normative pathways; such as high school, college, or the workforce and how these are initially overcome by young adults. Chapter 5 reviews the key moments and messages regarding employment, education, and/or disability pathways experienced from family and mental health professionals as well as the ways in which FEP young adults navigate structural issues with the labor market and universities. Finally, Chapter 6 begins with a discussion of the study, followed by suggested additions to the conceptual model and implications for further research and practice.

## CHAPTER 2. LITERATURE REVIEW

The World Health Organization considers poverty to be “the world’s most ruthless killer and the greatest cause of suffering on earth” (Murali & Oyeboode, 2004, p. 216), and people with mental illness have a higher risk factor for descending into poverty than those living in the general population (Funk, Drew, & Knapp, 2012). This chapter explores the associations between poverty and SMI by unpacking the theoretical associations between poverty in the etiology of and effect of FEP as well as examining how disability is implicated in the maintenance of a poverty state. It ends with the presentation of an ecological conceptual model presenting the ways in which FEP young adults receive feedback from their family, mental health professionals, and society during their pathway to either employment, education, or disability as well as a description of a pre-engagement meeting with the group of young adults that further informed the research aims of this study.

### **The Construct of Poverty**

Poverty is typically measured by absolute and relative terms. Absolute poverty generally refers to the minimum threshold of affordability for a household, and has been the subject of major critique as it is based on the food needs of families rather than other cost of living needs such as housing (Rank, Hirschl, & Braunstein, 2015). Relative poverty describes those households that fall below 50% of the median area income, indicating that those households will have a more difficult time affording everyday living expenses in comparison to the upper half of households in a given area. According to the Federal Poverty Line measure of absolute poverty, the 2019 poverty level was \$12,490 USD per year for a single person, encompassing approximately 13% of the U.S. population (U.S. Department of Health & Human Services, 2019) while U.S. relative poverty rates are at 17.8% (OECD, 2018). Research on poverty across the lifespan using the Panel Study of

Income Dynamics (PSID) data found that poverty spells are more likely than not to be short, meaning that households dip in and out of relative poverty with roughly 41% of adults aged 25-64 experiencing at least a year of poverty over a lifetime (Rank, Hirschl, & Braunstein, 2015). Poverty is also more concentrated in young adulthood and in older adulthood (Rank, Hirschl, & Braunstein, 2015). Finally, poverty is associated with a myriad of social disadvantages such as homelessness, illiteracy, and lack of access to education and the labor market.

Taking these poverty rates into consideration, an adult with SMI living on the more limited supplemental security income (SSI) benefit would be receiving approximately \$9,000.00 per year, which is well below the most stringent absolute poverty level. In addition to the high unemployment rate of adults with SMI reported in Chapter 1, rates of unemployment in a FEP population range from 25% to 65% unemployment at admission (Rinaldi et al., 2010) which is higher than the 9% unemployment rate of young adults (age 16-24) in the general population (U.S. Bureau of Labor, 2017). Furthermore, employment tends to rapidly decrease after initial FEP hospitalization, at least temporarily (Harris et al., 2005; Ramsey, Stewart & Compton, 2012; Rinaldi et al., 2010). Rates of homelessness for SMI adults range from 11%, internationally, to 26% in the U.S. (Folsom & Jeste, 2002; U.S. Department of Housing and Urban Development, 2011). A recent study on Washington State's first episode psychosis program found that 1 in 5 young adults were homeless or experienced housing instability within two years of first intake (Hong, Hughes, Lucenko, & Felder, 2018), indicating that a proportion of FEP young adults may also experience homelessness at the time of onset or within the early phases of the illness. The following section reviews the theoretical connections between poverty and mental illness, including those based on the establishment of disability, and considers their application to a FEP population.

## Theories of Poverty and Serious Mental Illness

There are multiple complexities in the causal relationship between poverty and mental illness. These relationships can best be framed on a continuum between those that are related to conditions present before onset or treatment of mental illness and those that occur after the person has been living with mental illness for some time. On the front end are theories of social causation, which posit that poverty and low SES conditions play a role in the etiology of SMI, while on the back end Social Drift Theory or Social Selection Theory presume that earning potential declines after the onset of mental illness, leading to poverty (Dohrenwend et al., 1992). In addition, Social Drift Theory encompasses the disability construct (that is, both the status and self-identity as “being disabled”), which theoretically contributes in myriad ways to time away from the workforce and entails not only the direct loss of earnings, but also the loss of job experience, career building skills, and socialization pathways to successful employment.

### **On the “front end”: Social causation theories.**

While the incidence of SMI consistently remains at 1% worldwide, the following social and environmental factors begin to explain the possible links between poverty and living with mental illness found in epidemiological studies. Brill (1979) noted that although there may be associations between poverty and psychosis, it is important to remember that poverty does not in itself cause psychosis, as not all poor people develop psychosis, and wealth in itself does not protect someone from developing psychosis. Rank (2011) synthesizes the overall relationship between poverty and mental health or illness through three elements: lack of resources, added stress, and environmental/community context. In essence, a lack of resources leads to added stress which has a negative effect on overall mental wellness. In combination, lack of resources and associated added stress are compounded when a household resides in an environmental context of high poverty,

which increases exposure to environmental toxins and crime. The integration of environmental, social, and structural conditions and their effect on illness are described as variants of Social Causation Theory. These three variants of Social Causation Theory include: 1) *neighborhood effects*, which explore the consistent findings between low SES, disorganized, and urban settings and SMI; 2) *social-stress hypotheses*, which posit that the stress, possibly encountered in these neighborhood environments, is implicated as the trigger for adverse mental health; and 3) *discrimination effects*, which deal with the associations between the negative conditions of low SES neighborhoods, poverty, and being a person of color, and the subsequent structural barriers.

### ***Neighborhood effects.***

Social causation theories first evolved from decades of early research on mental disorders linking schizophrenia to poorer geographic areas within cities. The famous Faris and Dunham (1939) study found higher rates of mental illness in poorer, more disorganized, and detached areas of urban Chicago, and led to 50 additional studies in American and European cities linking rates of mental illness to impoverished parts of urban areas (Read, 2010). Perhaps the most important aspect of the Faris and Dunham (1939) study was the implications for aspects of stress associated with classism, which was further explored as an underlying causal mechanism by Hollingshead & Redlich, (1958). Further studies have since found few associations between social class at time of birth and development of schizophrenia, except for a moderate increase with fathers in the lowest social class (Corcoran et al., 2009). Harrison et al., (2001) used a case-control design to examine rates of schizophrenia by family income level and neighborhood and found a strong significant association between the two, however, they only relied on cases who already were receiving services rather than a community survey. Finally, Silver, Mulvey, & Swanson (2002) examined the effects of neighborhood structure of 261 U.S. Census tracts with diagnostics on 11,686 community-level

respondents and found that while poor neighborhoods had more incidence of depression, substance use disorder, and schizophrenia, associations between neighborhood disadvantage on schizophrenia disappeared after controlling for individual-level factors. In a systematic review of studies on social causation and first episode psychosis, 'O Donaghue et al., (2016) found that while many studies show strong associations between social deprivation and onset of psychosis, these associations lose significance when controlling for neighborhood and individual-level factors. The authors emphasize that more research is needed regarding the ways in which neighborhood characteristics such as social disorganization contribute to structural barriers such as attaining social support as well as ways that individuals with schizophrenia may drift into low SES situations and neighborhoods.

***Social-stress hypotheses.***

These above findings implicate models of social stress as one proposed mechanism of the social causation argument. Social stress hypotheses provide a clearer explanation for the proposed mechanism between poverty and psychosis. Stress theory (Selye, 1955) and structural strain theory (Merton, 1957) offered important theoretical contributions to the understanding of the interactions between societal stress and onset of psychiatric illness. An attempt at integrating psychosocial and medical model ideas of SMI in the late 1970s resulted in a proposed biopsychosocial model of schizophrenia (Zubin & Spring, 1977), which incorporated the intersection between external stress and genetic predisposition to the illness (Read, 2010). This theory proposed a framework whereby an individual with a biological predisposition to schizophrenia will, through exposure to stress, express their first symptoms (Rudnick & Lumberg, 2012). This framework underpins the modern stress-vulnerability model (Mueser & McGurk, 2004; Nuecterlein & Dawson, 1984) that provides a conceptual model of the ways in which environmental stressors moderate the biological

predisposition to develop schizophrenia and the ways in which coping skills, social support, and meaningful activity can also moderate the presentation of symptoms.

Current research shows that low socioeconomic status has not been shown to independently predict onset of first psychosis, but rather is mediated through other related risk factors, such as depression, that are “disproportionately experienced by poor people” (Boydell, van Os, McKenzie, & Murray, 2004; as cited in Read, 2010, p. 10). Studies examining the role of poverty in mental health find that conditions of poverty do not cause mental illness, but do have an adverse effect on mental health (Hanandita & Tampubolon, 2014; Silvestri & Joffe, 2004; Wilkinsen & Pickett, 2010) and are linked more closely to the etiology of mood disorders (Dohrenwend et al., 1992; Murali & Oyeboode, 2004; Silva, Loureiro, & Cardoso, 2016); establishing that the stress associated with low-income, high-stress neighborhoods contributes to affective disorders such as depression (Silver, Mulvey, & Swanson, 2002). Low family socioeconomic status (SES) is associated with exposure to parental psychopathology, maltreatment, and family violence as well as elevated odds of being classified as having a severe mental disorder (McLaughlin et al., 2011, p. 1089). In summary, a linkage of adverse events and conditions present in childhood may increase risk factors for childhood onset of mood disorder, which can then lead to psychosis as well as be complicated by the general adversity of the associated social conditions present in say, high school. This is further complicated by the fact that the prodromal stage of psychosis, i.e., the precursor state to acute psychosis, can present through the same behaviors as mood disorders, such as depressed mood and isolation. This creates additional difficulties for accurate diagnosis in the pre-age 18 group. In sum, poverty “acts through economic stressors such as unemployment and unstable housing” (p. 274) to precede mood disorders such as depression and anxiety, which are themselves a risk factor for psychosis (Kuruville & Jacob, 2007).

### ***Discrimination.***

The preceding critiques of social causation at the neighborhood and social stress level bring to question the impact of discrimination in diagnosis. Foucault (1965) studied how the 17th century European society practice of segregating those with leprosy eventually led to the everyday practice of segregating the mentally ill and later, the poor. Abramowitz and Dokecki (1977) examined clinical discrimination and found that among studies on social class and mental illness, “more severe diagnoses were applied to poorer people than to wealthy people with the same symptoms” (cited in Read, 2010, pg. 13). Elements of discrimination due to low SES and/or race may have resulted in a trend toward higher incidence of SMI diagnoses for those living in poor neighborhoods.

Furthermore, as described in the next section, once diagnosed, an individual may experience downward social mobility due to the lost working income during early stages of illness and treatment and therefore reside in low income neighborhoods. Additionally, a disturbing discriminatory trend exists in treatment, where individuals from lower social classes, including members of marginalized racial groups, are more likely to receive pharmacological treatment rather than therapy, (Johnstone, 2000); receive more first-generation antipsychotics vs. modern medications (Daumit et al., 2003; Herbeck et al., 2004; Robinson et al., 2014) and spend longer time in treatment, including hospital readmissions (Johnstone, 2000). Taken together, these issues with discrimination complicate the social causation argument.

### **On the back end: Social Drift Theory.**

Since the incidence of SMI has remained consistent at 1% of the population and is present in all socioeconomic classes, and unemployment rates in adult schizophrenia remains stable at 80%, it is implied that some downward financial drift occurs, particularly with those who live with the more chronic form of their illnesses. Social Drift Theory, also referred to as Social Selection Theory

and “lost potential theory” explicates the downward mobility experienced by individuals living with SMI as adults. Beels (1981) proposed that the onset of psychiatric disorders occurs within the crucial developmental phase of young adulthood when one typically gains 1) employment within the market; 2) intimate or stable relationships outside of the family of origin; and 3) general social networks within which to “exchange goods” (p. 65). Social drift among those with a FEP is related to the timing of onset during the critical young adulthood developmental period and subsequent lost time in the workforce and education due to the illness and disability status (Aro et al., 1995; Dohrenwend et al., 1992). For those who develop mental illness in the high-school years, high school dropout rates have been reported to be as high as 50% (Cook, 2006) indicating a drift process that may begin sooner for those with earlier FEP onset.

Empirical studies on social drift and SMI tend to examine drift by comparing an individual’s social mobility with that of their parents and have found contradictory results. For example, ‘O Donaghue et al., (2014) found that while 40% of a FEP sample experienced downward mobility, 25% experienced upward mobility before onset. Furthermore, those who either maintained social class or experienced upward mobility post-FEP were at greater risk of hopelessness and suicide. This finding indicates that the experience of maintaining social mobility after FEP is not straightforward. Vargas et al., (2014) compared two similar groups of adults with schizophrenia receiving treatment in community settings and found that those with access to more educational resources based on the education level of the mother, with subsequent access to privately-funded care, had more downward social mobility and overall vocational decline when compared to a similar group who started with fewer educational resources and received care from a public rehabilitation program. The authors posit that this inconsistency in the relationship between SES and later working income indicates that wealth itself may not protect against social drift once the illness has progressed. Browne et al., (2000) found variations in the relationship between parental social class

at the time of admission and prognosis with higher social class associated with less severe delusions and hallucinations while those from lower social classes accessed treatment at later ages. This supports existing research which shows that access to care could be difficult for those belonging to lower social classes and that a longer duration of untreated psychosis results in poorer prognosis (Birchwood et al., 2013; Compton et al., 2011). These studies begin to indicate that social drift is complex when intertwined with issues of social class. They also indicate that being in a position of poverty before first psychiatric treatment may additionally hinder normal developmental stages of entering the labor market or a career development track while also noting that higher SES at onset is not necessarily protective of social drift.

A last important aspect related to social drift are the realities of the modern labor market, and the ways in which they influence both employment availability and the work of mental health professionals in the supported employment arena. The U.S. labor market is characterized by “labor market liabilities” and divided into the “primary” and “secondary” markets. Labor market liabilities are based on the idea that individuals are not universally equal when accessing the job market based on both demographic variables such as race, gender, and education level and access to social capital through contacts or lack thereof (Baron & Salzer, 2002). The primary market is that which contains high-paying jobs, with opportunities for promotion, while the secondary market is characterized by high turnover and less pay, and little opportunities for promotion (Heyman, 2000, as cited in Baron & Salzer, 2002). Higher education promotes access to the primary labor market, while the secondary labor market is thought to be accessed by those with “weaker ties to the labor market” (Piore, 1970, as cited in Ryan, 2008, p. 112).

As mentioned earlier in Chapter 1, supported employment programs do help people obtain employment, but that employment is rarely enough to lift an individual out of poverty. While supported employment programs focus on “competitive employment” in contrast to the former

“sheltered workshop” environment of the vocational rehabilitation predecessor (Bond, Anthony, Rutman, & Drake, 1988), the standard focus on job placement in the secondary labor market limits the options for gainful employment for those with FEP and those with SMI. Social drift after a FEP may also be complicated by individual labor market liabilities if not addressed through employment services.

In summary, the downward “drift” associated with unemployment, disability, and subsequent poverty rates for those with SMI begins either shortly before or shortly after onset of a FEP during the critical time of young adulthood. Given that current rates of functional recovery and returning to education following onset of FEP are as high as 60%, social drift may be better described as a temporary suspension from earning potential rather than a permanent idea of downward drift, and can possibly be prevented with a shift in focus to the primary labor market by early intervention employment programs.

### **Disability Theories.**

Disability is a multidimensional construct “based on personal, environmental, and social factors as well as level of impairment” (Bartlett, Lewis, & Thorold, 2006, as cited in Drake et al., 2012, p. 111). As such, the concept of disability contains physiological, functional, and social dimensions. The concept of disability in the U.S. evolved from policies to address “crippled” individuals returning from combat in WWI who were visibly unemployed and begging in public places (Schweik, 2009). Schweik’s (2009) work explored how the concept of “cripple” evolved into “handicap” while finally evolving into the term “disability,” the latter of which contained the construct of not being “able” to work. The “disability” label is now the dominant term used by medical providers, public policy, employers, and society, all presuming that what were once “handicaps” now render someone unemployable.

In 1990 the Americans with Disabilities Act (ADA) added persons with disabilities as a protected group to the Civil Rights Act, using evidence that although equal from a human rights perspective, they faced additional levels of societal and workplace discrimination (Shaw, Chan, & McMahon, 2002). The ADA prohibits workplace discrimination on the basis of disabilities with specific titles for private, government, and service employers (U.S. Department of Justice, Civil Rights Division, 1990). However, employment rates among persons with disabilities has steadily declined since the inception of the ADA (Deliere, 2000), and mental disabilities are described as the “least protected and most misunderstood” part of the ADA, with claims of discrimination for mental disorder surpassing all other disabilities by 1998 (Hantula & Reilly, 1996, p. 110; Stefan, 2002, as cited in Sheid, 2005). Studies have shown that the process of applying for mental health disability benefits after the onset of psychotic illness can contribute to more time outside of the labor market and more life years spent in poverty. After individuals with mental illness start receiving disability benefits, as little as 0.5% return to work, even though many people with schizophrenia report that employment was an essential feature of their personal recoveries (Strickler, Whitley, Becker, & Drake, 2009). While neither SSDI nor SSI were designed to replace a working income, both have typically become the central source of earnings for those with SMI, in essence holding this population at the poverty level (Berkowitz, 1987).

Disability theories generally fall into two main areas of thought. The first is that disability exists within the individual, where some type of pathology is officially diagnosed from a medical professional and this pathology, in essence, prevents the individual from actively holding a job. This is often referred to as the medical model of disability. The second theory posits that disability is socially-constructed by various groups such as individuals, families, medical professionals, and society. This is known as the social model or critical disability theory. The social model of disability is also intertwined with a historical problem of disability (and subsequent poverty) being maintained

by failed social policies such as deinstitutionalization, welfare reform, and housing policy (Hansen, Bourgois, & Drucker, 2014; Martone, 2014).

***Individual impairment/medical model of disability.***

The individual or medical model of disability posits that impairment lies within an individual's specific pathology and is the dominant paradigm in psychiatric diagnosis and treatment, within Social Security disability policy, and within society (Goering, 2015). As described in Chapter 1, an individual must demonstrate that their symptoms hinder their ability to work, requiring a medical diagnosis made by a mental health professional in order to then submit a claim to the Social Security Administration. This current operational structure of disability relies on what disability scholars call "cognitive authority," or the power of medical professionals to determine disability. The SSA then bases its decision to grant financial disability benefits on the intersection between this medical diagnosis and personal work history (Social Security Administration, 2019), making medical professionals the "gatekeepers" of disability within the medical model (Haegele & Hodge, 2016).

Within the medical model of disability, impairments within the body or mind stem from illness, injury, or health conditions (Forhan, 2009, as cited in Haegele & Hodge, 2016). These impairments are viewed as deficiencies when compared against the norm. Impairments are viewed as "fixable" through the use of medical treatments and rehabilitation, and when impairments are not eliminated, individuals are placed into institutionalized settings to accommodate the disability such as special education classrooms (Haegele & Hodge, 2016).

The medical/impairment model of disability is widely considered by disability studies scholars to be a limited model by its failure to consider interactions with cognitive, emotional, or social/contextual dimensions (Marks, 1997; Mulvaney, 2007). A further critique of the medical model of disability is that the professional process of diagnostic labeling has inadvertently

constructed a group of “others,” who are impaired and whose collective impairments legitimize the professions of those diagnosing and “treating” disability (Peters, 1996, as cited in Mulvaney, 2007). In other words, groups of certain professional helpers such as psychiatrists and public mental health workers oversee large populations of disabled individuals with SMI, putting them in a disempowered position that may further foster dependence and disability.

***Social/critical model of disability.***

The social model of disability is governed by thought that impairment interacts with external social conditions such as economics, poverty, social exclusion, and discrimination (Marks, 1997; Mulvaney, 2007). Under the social model of disability, impairment exists within the body, while disability is imposed on the individual by external social conditions that do not accommodate the impairment into mainstream society (Goodley, 2001; Haegele & Hodge, 2016). The social model of disability evolved from social movements where people labeled as disabled claimed that “restrictions imposed on disabled people are not a natural consequence of their impairment, but are a product of a social environment that fails to take account of their differences” (Marks, 1997, p. 88). It is also conceptualized as a form of social oppression through which restrictions are imposed on individuals with impairments, and as Foley & Chowdhury (2007) reported, “triggers a series of exclusion mechanisms that reinforce each other” (p. 376). The British Council of Disabled People has distinguished between “impairment as a physical or mental condition and disability as a cultural stigma associated with being impaired” (Burchardt, 2000; as cited in Foley & Chowdhury, 2007, p. 375). In many aspects, the social model of disability attempts to define and explain the cultural aspects of the disability label, which often persist beyond the impairment itself.

An important study on disability and SMI individuals by Estroff et al. (1997) found that the social model of disability was in fact in operation among a cohort of 169 individuals in the early

course of psychiatric illness, who were recruited from hospital settings. Estroff et al. (1997) tested three conceptual models of applying for either SSI or SSDI (an impairment model, a labeling model, and a needs/resources/dependence model) and found that disability benefits were often suggested by hospital staff or family, the latter to reduce the financial burdens associated with caretaking, and that there was some association between an individual receiving disability benefits and taking on the individual impairment/dependence role, which was ultimately socially-influenced. Williams and Collins (2002) found that the “construction of the disabled self” resulted from an intersection between family, others who have experienced mental illness, mental health professionals, and society (p. 302), indicating that one’s view of one’s self was socially constructed by those around them.

### ***Labeling Theory.***

An important underlying aspect of a social model of disability is Labeling Theory, which explains the ways an individual takes on a certain role after others construct that role and expectations by assigning the label (Scheff, 1966). Labeling Theory in the context of mental illness is most associated with Goffman’s (1961) work, *The Moral Career of the Mental Patient*. Goffman found that hospitalization and its associated roles for close family members was responsible for the transformation of a person into a “mental patient” and that the associated stigma of this label led to profound changes during and after the hospitalization period. Gove (2004) found different patterns of self-labeling such as a person with a “nervous breakdown” that is temporary in nature and one having “mental illness” with the latter more prone to use terms such as “crazy” or “psychotic.” These labels also lend themselves to differences in the use of public vs. private hospitals.

Link, Cullen, Struening, Shrout, & Dohrenwend (1989) presented a Modified Labeling Theory to address Scheff’s (1966) model. Modified Labeling Theory offers an explanation for the additional sense of devaluation and discrimination experienced by individuals with a mental illness

label. In this framework, the personal interpretation of the labeling experience leads to further personal withdrawal, which can exacerbate negative social outcomes such as prolonged unemployment.

### ***Stigma Theory.***

Labeling Theory leads directly into a discussion of stigma, defined as “[a] mark separating individuals from one another based on a socially conferred judgment that some persons or groups are tainted and “less than.” (Pescosolido, Martin, Lang, & Olafsdottir, 2008, p. 431). Stigma leads to stereotypes and discrimination based on labels applied to those considered “other” and this historically applies to those classified as “mentally ill” (Foucault, 1965; Link & Phelan, 2001). Stigma applied to those with mental illness has historically been a function of lack of public knowledge about mental illness which constructs the category of “unknown.” This category is then continually reinforced by societal interactions leading to a new form of labeling. Stigma in mental health is generally divided into three categories: 1) social stigma; 2) self-stigma; and 3) health professional stigma (Ahmedani, 2011). Social stigma refers generally to the definition reviewed above (Goffman, 1963; Link & Phelan, 2001). Self-stigma refers to the individual response to the negative labeling and oft-accompanied discrimination felt by others (Crocker, 1999). This can include those attitudes and social distance experienced at the hand of mental health professionals as health professional stigma (Lauber, Nordt & Rossler, 2005).

### **Medicalization of poverty.**

Finally, modern structural critiques implicate the entire psychiatric system of diagnosis and disability as part of the “medicalization of poverty” where conditions brought forth by living in impoverished conditions are classified as psychiatric problems rather than addressed as secondary effects of poverty (Hansen, Bourgois, & Drucker, 2014). Theorized to be a result of constrained

welfare funding in the neoliberal era (Teghtsoonian, 2009), this critique posits that health (and in this case, mental health) systems are tasked with translating the problems associated with poverty to illnesses to treat, and as such, are now implicated in their maintenance. It also profoundly affects vulnerable populations as the “potential stigma of disability and mental illness is reinterpreted as a legitimate responsibility because it is one of the few available routes to stable survival income” (Hansen, Bougois & Drucker, 2014, p. 81). Disability benefit income is thus a side effect of the mental health system’s inability to provide channels to an earning track for those with SMI.

### **Disability and FEP Young Adults: Modern Social Disability Framework**

This review of disability theories points to a number of important considerations for young adults with a FEP. First, utilizing the individual impairment model of disability with FEP young adults seems contraindicated for this population because not all individuals with a first or several episodes of psychosis will be disabled by their condition, even though some may be. It is of further critical importance not to assume permanency in disability; the research has shown the temporary nature of time away from the workforce as related to the episodic nature of SMI particularly in young adulthood.

For those young adults who have previously worked or engaged in post-secondary education, there is a danger in applying disability concepts in that the stigma and social marginalization associated with being labeled “psychotic” and then deemed “disabled” can challenge an individual’s participation in the labor market. Young adults with an early onset of FEP before the age of 18 may very well be recipients of social security disability insurance before they enter adulthood. Studies show that the period of transition to adulthood is not well-supported by schools and that the post-high school outcomes of students with disabilities is even worse (Smith & Routel, 2010) indicating that those individuals with an early onset of FEP in high-school may not receive

support from their school system, and thus may rely more on family and mental health professionals for transition to adulthood. Furthermore, the inclusion of multiple disadvantaged identities such as racial minority status and low SES further compound the struggles into the labor market for those with disabilities compared to the dominant population (Wilder, Jackson, & Smith, 2001; Smith & Routel, 2010) indicating that ethnic minority and/or low SES status in addition to a FEP may additionally hinder pathways to the labor market.

A second issue with disability and young adults with FEP is the need for mental health providers to assess for and address labor market liabilities such as a lack of education or other structural barriers to the labor market. Doing so will require early intervention providers to accept that impairment may be temporary and presuming chronicity will not assist these individuals in moving toward working or education trajectories. A solution to the issue of poverty and disability may be for early intervention programs to utilize a social model of disability lens in their treatment of individuals with FEP, assessing how the particular individual's labor market liabilities may fit or not fit the local context of employment and focus on career planning in order to accommodate any difficulty with symptom management.

### **Summary and Conceptual Model**

This literature review indicates that the condition of poverty negatively impacts both SMI and FEP whether present before the onset of the illness as in theories of social causation, or a condition resulting from time away from employment as in Social Drift Theory. Furthermore, the disability label legitimizes the status and entitlements of dependency, as well as myriad forms of discrimination. The onus of prevention of poverty falls on the mental health treatment system, and early intervention programs in particular, which may not be adequately equipped to assist a young adult out of poverty given the limitations of existing employment models and realities of the modern

labor market. A young adult with FEP thus is navigating both an illness and their own self-concepts and aspirations, which are in turn heavily influenced by family, mental health professionals, and society during this crucial time. These elements combine to inform the conceptual model shown in Figure 1. The conceptual model is ecological in nature, with the young adult being nested within overlapping social contexts representing family, early treatment staff, and structural or societal realities.

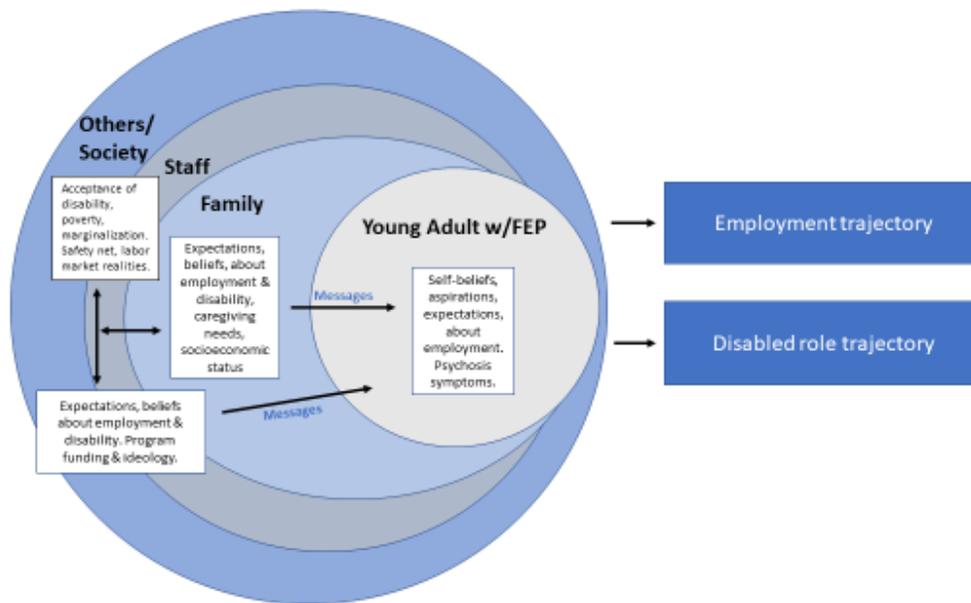


Figure 1. Conceptual model

### **The young adult with FEP.**

The young adult with FEP is in a developmental transition from dependence on family to eventual social and financial independence through entry into the labor market at the same time as they are navigating early symptoms of mental illness. Entry to the labor market for young adults is significantly associated with education (Luciano & Meara, 2015), as well as accessed through various forms of human capital (De Silva, McKenzie, Hartham, & Huttly, 2005). The normative

development of personal self-concept and aspirations during this period can be negatively influenced by variation in illness severity during early diagnosis with most young adults with FEP having some recovery time during which they are not involved in school or working pursuits until stable (Birchwood & Fiorillo, 2000). It can further be hindered by dealing with stigma as a result of the diagnostic labeling process (Amendani, 2011; Crocker, 1999; Goffman, 1963; Lauber, Nordt, & Rossler, 2005). Additionally, these developmental tasks can be interwoven with potentially positive elements of the social environment such as a supportive family, strong educational system, and a culture free from discriminatory barriers to social mobility. As such, the pathway to the labor force for young adults is influenced by individual, economic, and social determinants along the way. This conceptual model posits that young adult ability or disability trajectories are not only symptom-driven, they are also influenced by messages from family, early treatment staff, and society.

#### **Family members of FEP young adults.**

The second circle in the model represents family and parents in particular. Family is typically still active in the lives of young adults when a FEP occurs, and family involvement in FEP programs is as high as 95% (Drapalski, Piscitelli, Lee, Medoff, & Dixon, 2018). Families and/or parents influence the pathway toward employment or disability for their child as they navigate early psychosis (Estroff et al., 1997; Williams & Collins, 2002). This process has been shown to unfold through explanatory models of illness (Larsen, Johannessen, & Opjordsmoen, 1998; Sadeghieh Ahari, S., Nikpou, H., Molavi, P., Abdi, R., Amani, F., & Shirinzadeh, B., 2014; Sin, Moone, & Harris, 2008), through which families interpret psychosis, caregiving needs of the family (Estroff et al., 1997), family socioeconomic status (Browne et al., 2000; Drake, 2013), and associated expectations of young adults' employment trajectories in general. Furthermore, psychiatric

prognosis is often communicated by parents and this prognosis is also influenced by their encounters with early treatment staff, and by societal attitudes about psychosis.

### **Early treatment staff.**

When young adults are first diagnosed and assessed, early intervention staff and other first-line psychiatric treatment providers, such as those in the inpatient psychiatric units, communicate psychiatric prognosis, attitudes about recovery, and expectations and perceptions about working or disabled trajectories. These spoken perceptions and prognoses interact with family and the young adult to create meaning around psychiatric illness and ability (Willams & Collins, 2002) and have powerful impacts on employment or disability trajectories (Sylvestre et al., 2018). Furthermore, treatment programs are influenced by organizational realities, such as state-level funding availability, and ideologies, such as support for employment focus within the agency, which has been shown to sharply impact the trajectories of young adults with psychosis (Jorm, Abdel-Baki et al., 2013; Baksheev et al., 2012; Jacobs & Rogers, 1997).

### **Societal structural issues.**

Finally, societal structural issues operate at multiple levels affecting the young adult's life and interact with each aspect of the conceptual model (early treatment providers, family, young adult). Examples of these interactions include social and political marginalization of those living with mental illness, which "leads to acceptance of poverty in this group" (Sylvestre et al., 2018, p. 154), transactions with the welfare system and safety net programs, stigma and discrimination, and the realities of the labor market (Funk et al., 2012; Lund, 2012, Read, 2010). These societal structural issues interact with and influence early treatment staff, families, and ultimately, the young adult with FEP as they navigate their pathway in young adulthood.

Considering that young adults with FEP are a marginalized group and ultimately interpret messages about working from within their social environments, such as the early intervention program, family, and society, and that able/disabled trajectories are socially constructed by members of these groups during the early intervention process, this dissertation aims to explore how this interpretive process evolved through their early experiences with psychosis, the early intervention program, and family/society messages. The perspective of this dissertation is that young adults experiencing a FEP have their own sense of agency which is influenced by their treatment environments and their own life experiences and that certain determinants act to spur or inhibit progress toward employment trajectories.

### **Process of Inquiry**

A pre-study meeting was held with the Young Adult Leadership Council (YALC), a group of young adults with lived experience of psychosis, who have received services from an early intervention program and act as advocates for programming and policy aimed at improving services for early psychosis. The intent of this meeting was to engage with a marginalized population in their own setting, provide an overview of the study, identify myself as a researcher with my own intersectionality and experience as a former clinician, and elicit feedback on the study. Following a description of the poverty-disability connection and theories supporting this study, I elicited feedback on the proposed ideas about data collection. The conversation indicated that pathways toward working and career development were influenced by others' concepts of recovery and living with psychosis, others' expectations of them regarding a career/working path, and individual abilities. The group further described a range of "everyday" contacts or important moments that shaped the trajectory toward working or career development.

**Key moment construct.**

These important moments described by the informants mirrored the determinants in the pathway between onset and employment as described in the research. These key moments represent a categorical term for a range of factors such as interventions, experiences or messages, that have the common property of being highly determinant of a trajectory toward employment or disability when experienced by the young adults. Together with the conceptual model for this study, the pre-study meeting discussion contributed to 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?
3. What larger societal/structural themes appear to influence either employment or disability trajectories and how have these been experienced by these individuals?

## CHAPTER 3. METHOD

### Introduction and Overview

This dissertation work is concerned with the social problem of low rates of employment and high rates of poverty among individuals with SMI as well as the accompanying disability rates among this population. Considering that the developmental period before disability is established as a particularly critical intervention point for poverty prevention among this group, it is an urgent research priority to learn how young adults with FEP negotiate employment and/or education pathways. Young adults with FEP are a marginalized group and ultimately interpret messages about working and about disability from within their social environments, such as the early intervention program, family, and society. This chapter describes my methods for interrogating the ways in which employment or disabled trajectories are formed during the early stages of living with psychosis among a group of FEP young adults and how these trajectories may be shaped through a complex messaging and interpretive process that evolves through their early experiences with psychosis, involvement in an early intervention program, and the broader messages received from family and society.

As this study is exploratory in nature, qualitative methods were used to collect and interpret data. In addition to being framed by the intersection between psychosis, poverty, disability, and employment, and the conceptual model in chapter two, this study is also informed by feminist standpoint epistemology which seeks to explore the experiences of marginalized groups as well as the structural contexts that impact them. Feminist standpoint epistemology assumes the following guiding principles during the research process: 1) 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 & Hazenfeld, 2015). This study is further influenced by the special

considerations needed to sample a hard to reach population, defined as one that is difficult to locate due to small numbers in the population or because the commonalities of the group do not manifest in the everyday (Marpsat & Razafindratsima, 2010). Since young adults who have had FEP are difficult to locate in the general population, I relied on a strategic engagement process to access a group of young adults with lived experience of a FEP who are actively engaged in local advocacy.

## **Setting and Sample**

### **Young Adult Leadership Council.**

The Young Adult Leadership Council (YALC) is a peer-group comprised of members who identify as participants (past or current) served by the Early Assessment and Support Alliance (EASA) early intervention for psychosis program, and have lived experience of psychosis. EASA serves individuals aged 15-25 throughout the state of Oregon, who are experiencing first episode psychosis. Each EASA program follows practice guidelines consistent with best practices in early psychosis, including assertive community outreach, supportive counseling, family psychoeducation, medication interventions, supported employment and education. Members of the council come from all geographic areas in Oregon, including rural areas, and meet monthly in urban downtown Portland, where they are compensated for their travel time, helping those who travel from rural areas. In addition to functioning as a peer group, the council helps to shape the direction of EASA, emphasizing participatory decision-making and peer support. They seek to guide the direction of the EASA programs by: providing an experience of healing and growth, creating an outlet for expression, educating and supporting EASA participants and graduates, responding to/gathering and using feedback, and advocating for change (easacommunity.org, 2018). It also serves as a resume-building activity for young adults who may not be engaged in typical pathways to employment.

The YALC was chosen as the target sample for this study due to their lived experience with FEP, the young adult age of the participants, the participants' involvement with early intervention programming, as and the unique sample characteristics that are associated with participants' engagement with advocacy for early psychosis. These experiences made these young adults a critical case for sampling, one that can "yield the most information and have the greatest impact on the development of knowledge" (Patton, 1990, p. 236) as well as "make a point quite dramatically or is particularly important in the scheme of things" (Patton, 1990, p. 236). 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. These young adults are a model of sorts 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 addition, I had connections to the research group attached to the EASA program which provided a referral to the YALC for the study.

The sampling plan aimed to enroll, consent, and interview up to 10 young adult participants, for two interviews each. Inclusion criteria used were: 1) lived experience with psychosis; 2) age 18-30; 3) had experience with an early intervention program; and 4) the capacity and willingness to provide informed consent which was assessed using the human subjects protocol, discussed later. Given the content and breadth across young adult participants, a target of 10 was chosen to gain variation in experiences and rich data without reaching beyond redundancy (Lincoln & Guba, 1985, as cited in Patton, 1990).

Prior to data collection activities, a pre-study meeting was held with YALC with the primary intent to engage with them in their own setting, provide an overview of the study, identify myself as a researcher with my own intersectionality and experience as a former clinician, and elicit feedback

on the initial design. Following a description of the poverty-disability connection and theories supporting this study, I elicited feedback on the proposed ideas about data collection and confirmed the research questions as referenced in chapter 2.

### **Data Collection**

Semi-structured interviews were chosen for their potential to elicit rich description of the individuals' perceptions and experiences (Denzin & Lincoln, 2013). While interviews were semi-structured in their use of strategic interview questions, they were completed in an unstructured conversation style using elements of Motivational Interviewing including 'OARS', which stands for open-ended questions, affirmations, reflections, and summaries (Miller & Rollnick, 2002). The use of OARS within semi-structured qualitative interviews helps to "better facilitate dialogue," "acknowledge difficulties and affirm past experiences that demonstrate strength," and summarize in a way that "tests hypotheses" (Miller & Rollnick, 2002, pp. 73-75). In addition to the use of Motivational Interviewing techniques, a two-interview series format was chosen in order to allow for engagement with the participant over the first interview as well as identifying areas from the first interview to access deeper context from questions during the second interview. The first interview was comprised of questions about their current perceived successes, work/career or other daily activities, past prognosis from treatment providers, family and others, dealing with symptoms, and key moments or turning points in their pathway. The second interview included questions which built upon the responses of the first interview, such as descriptions of the identified key moments and interactions with key people as well as structural or contextual influences which may have been implicit within the first interview. Sample interview questions for each interview can be seen in Table 1 and are based on the three research questions. In addition to the interviews, basic demographic information including gender, race/ethnicity, socioeconomic background, and duration

of untreated psychosis were also collected during the interviews. The flowchart of data collection is shown in Figure 2.

Table 1.

*Semi-structured interview questions.*

<u>Interview Questions</u>	<u>Conceptual Area of Inquiry</u>
1. Tell me about the things you're proud of in your life right now. [Where and what are you doing for work or pursuing in school?]	Activities of the young adult at post-treatment present.
2. If you can, tell me a little bit about what you were doing in your life when you first experienced psychosis. How did the onset of these first symptoms impact your activities and life at the time?	Activities of the young adult before and during onset of FEP.
3. There can be a timeframe during psychosis when the symptoms that you're experiencing can make it hard to keep doing your regular tasks, like going to school or your job. Can you tell me a little about how your regular daily activities were impacted at that time?	The impact of illness on daily activities.
4. How did you get to where you are at now? Were there people in your life who guided you? What kinds of things did they say or do?	The influence of family, friends, and mental health professionals.
5. If you were to name a few key moments in your current path, what would those be? (If not discussed, ask how EASA and family (parents) influenced this process)	Important determinants of direction toward employment/education or disability pathways.
6. Did anyone whom you've worked with when you were first diagnosed give you what is referred to as a "prognosis"? What did they tell you about psychosis?	The influence of mental health professionals on employment/education or disability pathways.
7. What about your parents or significant family members? Did they have reactions about your diagnosis? How do they view	The influence of family on employment/education or disability pathways.

your going back to school or working?

- |   |   |
|---|---|
| 8. While you worked with EASA (or before you came to EASA) did anyone talk with you about applying for disability benefits? If so, tell me about that.  | The concept of disability and process of disability benefit applications. |
| 9. So, returning to what we first discussed, what are your goals as it relates to [state activity]?   | Assessing current activities, self-concept, & aspirations.                |
| 10. In thinking about your recovery process and moving forward, what do you hope will happen in your life over the next five years? Prompt for: (what kind of plans do you have for working/school over the next five years?) | Assessing future orientation, self-concept & aspirations.                 |
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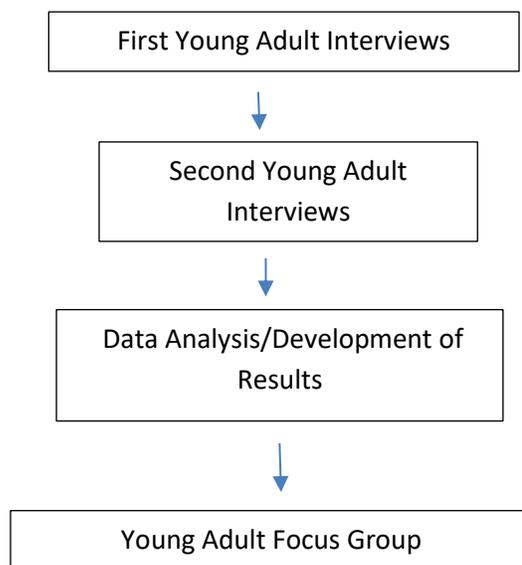


Figure 2. Study flowchart.

## **Procedures**

In total, 10 young adults who were current and/or former members of the YALC were consented and interviewed for a total of 19 interviews. One individual was interviewed twice as long for a single interview due to travel constraints. Recruitment into the study occurred by my attending monthly YALC meetings, handing out flyers and describing the study. Individuals self-selected to be participants and I followed up by text message to screen for inclusion criteria and to schedule the consent and first interview, usually within two weeks of the meeting. Interviews were held in a place of their choosing; usually their home, a meeting room at the local university or library, or a park, if most convenient. Following completion of interviews and the first round of data analysis, a focus group was held at the university setting where the YALC typically meets. During the focus group, I reviewed the purpose of the study, basic demographics and resultant themes and facilitated a discussion about the themes. Figure 2 illustrates the progression of data collection procedures. Interviews were audio-recorded using a handheld recorder and I also kept notes and jottings of my own reactions. Interviews were transcribed by myself and by a transcription service and everyday conversational lexical fillers such as “um” were kept. However, because the nature of the analysis was not concerned with conversational structure, these lexical fillers were edited out of the final quotes displayed in the findings and these quotes were naturalized into paragraph form for the purpose of analyzing the language contained within (Bucholtz, 2000). Additionally, I audio-recorded and wrote memos following each successive wave of interviews, to capture emerging themes and reactions to interviews.

## **Protection of Human Subjects**

This study involved the recruitment, consent and participation of adults who were 18 or over and presumed to be competent despite having struggled with psychosis. It received full

Human Subjects approval from the University of Washington. Consent forms included a description of the purposes of the study, the affiliation of the investigator, and that the decision to either decline or participate in the study was both voluntary and confidential. During the time of consent, I explained the study procedures, allowed for questions, and assured that the young adults had the time they needed to consider their participation. Young adults in the YALC were presumed to be competent adults with the autonomy to read/listen and comprehend the information about the study, as well as make the voluntary decision to participate. Normal consent procedures were followed by an assessment of mental clarity and orientation to place before completing the consent process. No formal clinical method was completed regarding capacity for consent. This assessment of mental clarity was completed by my describing the study procedures and asking questions about their preference to be interviewed. All participants were oriented to the information about the study and were able to self-determine where they wanted to be interviewed and what time of day was preferable. In addition to checking on orientation to place, I asked a follow-up question about activities toward working or school to check for understanding of the interview itself. All participants were oriented to these contexts when assessed. No paranoid, delusional thoughts, or related impairments in reasoning and judgment emerged at any point during the study that impeded understanding of the purposes of the study, the risks and benefits of participation, or the participants understanding that their participation in the study was voluntary, and thus all 10 recruited participants completed the study.

### **Benefits/risks.**

All research involves some risk of discomfort and discussing disability due to symptoms of psychosis is a sensitive topic. The potential benefits of this study included the opportunity to share one's story of the recovery process, including personal gains in employment and education. The

risks in this study which were outlined in the consent were possible personal discomfort which could have come up when discussing sensitive topics. These were addressed by the researcher by pausing to debrief with the individual, or taking a break before continuing. Additionally, there was a risk of breaching confidentiality in the case where an excerpt or description can be traced back to an individual within publications. To mitigate this risk, I excluded specific quotes that seemed unique and/or traceable to a specific individual in a specific context (e.g., someone working at a specific employer says something about that employer).

### **Data Analysis**

Data was analyzed in four ways using a template approach. A template approach determines codes from both 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, 2016, p. 192). First all transcripts were read to understand the story-line of what was being told in the data and coded for the areas described in the conceptual model as derived from research questions 1-3 as well as emerging themes. Second, a priori-coded excerpts were grouped by key area 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. This diagram was presented to the focus group and participants’ feedback assisted in confirming/disconfirming themes and descriptors. For example, when I presented the temporal nature of findings ranging from suspension of everyday activity to navigating employment, the participants emphasized that navigating employment is an ongoing issue. Overcoming stigma was also clarified and explained more in-depth, assisting with construct validity as well as reliability. Fourth, the excerpts within each bin and the emerging theme

excerpts were coded for more detailed descriptors which were transferred to a final codebook. This fourth and final step allowed for checking accuracy of the final list of themes including the deductive and inductive theme areas. It also allowed for the refinement of descriptors within themes across all data. Table 2 illustrates preliminary codes and final code areas structured by category.

Table 2.

*Code Categories for Data Analysis*

<u>Conceptual Model Categories</u>	<u>Code Categories (initial)</u>	<u>Final Themes</u>
<i>Individual-level</i>	<i>Taking time away – Temporary suspension of everyday activity.</i>	<i>Onset of FEP: Suspension of Activity and Forward Progress.</i>
Key moments Key people/messages Individual symptoms Professional prognosis Family prognosis Work/career concept Ability/disability concept	Family Support – practical Family Support – messages about working/school Unable to work	Psychosis onset: suspension from young adulthood. Overcoming the hospitalization experience. Overcoming medication.
<i>Structural level</i>	<i>Getting back out there</i>	<i>“Getting back out there”: forward progress.</i>
Socioeconomic status Stigma/discrimination Societal/professional expectations Realities of the labor market	Overcoming stigma/self-meaning making Overcoming medication Overcoming hospitalization Become social again Racism as additional issue for POC Finding peers Barriers from low SES hindering progress Concepts about working Affirming counselors – EASA – practical support + not giving up. Affirming counselors – Breaks the traditional mindset that MI=disability	Reconstructing the self as young adult after FEP diagnosis. Becoming social again. Finding peers. Ethnic minority additional hurdle.  <i>Mental Health Professionals: Demeanor and Prognosis Influences Ability/Disability.</i> Professional demeanor. Psychiatric prognosis. Disability messages Practical and Tangible Support from Early Intervention Staff

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*Navigating the labor market and/or college programs*

Built-in pathway (internship, volunteering, job corps)  
 Tools to cope on the job  
 Supportive person at work  
 YALC  
 Peer support specialist  
 University disability resources

*Family: Support and Messages Facilitate or Hinder Progress*

The presence or absence of family support.  
 Family messages about working, education, or disability.

*Forging Pathways through Employment & Education*

Foregoing the secondary labor market for a built-in career path.  
 Direct pathways to employment.  
 University disability centers.  
 Young Adult Leadership Council (YALC) as adjunctive support

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### **Reflexivity statement.**

As a social welfare scholar, I brought to this study preconceived notions about restorative justice to oppressed populations as well as past experience as a mental health clinician. Taken together, these experiences have influenced my own views of the plight of poverty for those living with schizophrenia and struggling through early psychosis. My viewpoint is that promoting fair access to employment and unblocking mobility channels for this population can positively impact social oppression and marginalization. My experience as a clinician and program evaluator allowed me to witness that there are far larger groups of individuals who want to return to employment than are offered employment services, that employment services do not always meet their needs, and that the resultant lingering poverty leaves them in dire straits. Therefore, there are some ideological assumptions in this study that income through participation in the workforce is restorative and that structural barriers inhibit employment and educational progress. Additionally, my past experience as

a clinician certainly influenced the content of the semi-structured interviews, though by allowing for transparency of my positionality as a researcher, and using elements of MI, the participants steered the conversation toward the realities of young adulthood outside of the intervention. I also attempted to enter each interview as an open slate, allowing for participants to fill the interview time with their unique stories so as not to overly drive the nature of the interviews with my own biases. Finally, by returning initial themes to the participant focus group, I was able to member-check my interpretation of their responses and resultant themes with the participants themselves.

## CHAPTER 4 – TRAJECTORIES & OVERCOMING FIRST SETBACKS

### Introduction

This study employed a series of qualitative interviews with a group of young adults who had experienced a FEP, had spent time receiving treatment from an early intervention program, and volunteered for work on a leadership council. Through these interviews I explored the pathways between the experience of a FEP and returning to or initiating an employment/education or disability trajectory. In particular I was interested in which key moments, people and messages were perceived as having influenced the young adult toward employment/education/disability as well as how structural factors influenced these pathways.

Ten individual participants aged 23-29 completed a series of two interviews over a three-month period. The basic demographics of this sample were a mean age of 26, a median age of onset of 21, evenly split between male and female gender, with none identifying as non-binary gender, and 30% racial minority/70% white. Table 3 illustrates first FEP onset, activity before FEP onset, family SES at time of onset, time unemployed/not in school post-FEP, current occupation and number of years since first FEP, and finally, whether they receive social security disability benefits. The demographics of the recruited sample slightly skewed toward the employed individuals (70%) from well-to-do families (40%), however, 50% of the sample were either receiving or in the process of applying for disability benefits, and 30% were from lower SES backgrounds, indicating that the sample was mixed in its pre-treatment demographics. These demographics begin to illustrate the trajectories from the FEP to the participants' current activities over a two to five-year period.

Table 3.

*FEP Participant Trajectories*

<u>Age at FEP</u>	<u>Years post-FEP</u>	<u>Family SES</u>	<u>Activity prior to FEP</u>	<u>Time Unemp./not in school</u>	<u>Current Occup.</u>	<u>Disability Benefit</u>
21	8	Low	College student	9 months	OT intern	Yes
16	7	Low	High school	Never employed.	Unemployed/SSI	Yes
21	6	Upper	College student/part-time work	6 months	3 <sup>rd</sup> year law student	No
20	5	Middle	College student/part-time work	9 months	Full-time peer specialist/family business	No
21	2	Middle	College student	3 months	Full-time peer specialist	No
21	6	Upper	College student	36 months	BA completed, working part-time	Yes
19	9	Middle	Part-time work	6 months	Works full-time as peer specialist/part-time college	No
19	6	Middle	High school	Never employed.	Unemployed/SSI	Yes
22	3	Upper	College student/working part-time	3 months/7-8 months with grandparents	Full-time insurance industry	No
23	5	Middle	Working full-time	Varied attempts at part-time work	Unemployed	No but applying

This chapter begins with a description of each participant based on their personal timeline before and after the FEP as displayed in Table 2. A description of results follow, spotlighting the

experiences between the first episode and the period of returning to normal activity through the perspective of the individual young adult. This section begins with a description of the two phases of adjusting to psychosis; 1) suspension of activity, and 2) forward progress, followed by the specific descriptors of particular types of experiences reported as key moments during these time periods. This section illustrates important turning points in the lives of FEP young adults as they struggle to overcome the experience of first episode psychosis and return to the normal everyday experiences of young adulthood.

### **Participant Personal FEP Timelines**

The following participant personal timelines describe the pathways between onset of FEP and current situation. Pseudonyms are used in place of names and all identifying information has been changed or omitted.

#### *Evan – age 29*

Evan was a 29-year-old male who was enrolled in a graduate healthcare program where he was currently completing an internship. He was first diagnosed with psychosis in his early 20's while away at college, and entered the EASA program roughly six months later. Evan reported that his family support, finding peers, receiving practical support from EASA staff to explore his college major, and involvement with the YALC were key moments in his journey between psychosis and a direct pathway to a career. Although Evan was in graduate school and working part-time, he continued to utilize disability benefits stating that “the money helps a lot.”

#### *Patty, age 23*

Patty was a 23-year-old female who resided in a group home. She was not currently working nor on an educational pathway. Patty was treated for mood disorders in her early teens and experienced her first episode of psychosis when she was 16 years old. She feels that she was

overmedicated at a young age which, together with living in a high-stress environment with her family, led to her later problems. Patty's mother is a first-generation immigrant from Mexico, who lived on disability benefits stemming from multiple job endings. Patty was an honors student in high school but lost traction in her education after her first hospitalization for psychosis. In addition, she felt that her mother discouraged her from working or college due to her own past struggles. Patty desired more structural support such as stable housing and some type of job training. She was considering entering Job Corps, and used the YALC for exposure to job skills such as editing a paper.

*Matthew, age 27*

Matthew was a 27-year-old male who was finishing law school. Matthew first developed psychosis during his junior year at a small liberal arts college. Matthew struggled with multiple hospitalizations over a three-year period which also included failed attempts at a return to a different private college and working in retail environments, before he entered a language study program locally and eventually found a meaningful path to law school. Matthew attributed his success to affirming, understanding counselors in contrast to those who were not focused on engaging with him, discovering the importance of learning about his ethnic minority heritage, and entering law school.

*Meg, age 25*

Meg was a 25-year-old female who had her bachelor's degree and worked full-time as a peer specialist on a local crisis line. Meg was active in advocacy and interested in research and promotion of the importance of peer support workers in the journey of recovery from psychosis. She received tremendous support from her family and her EASA workers to navigate from unsuccessfully

working in part-time jobs to becoming a peer specialist after completing a bachelor's degree. She was considering a Master's degree in social work at the time of the interviews.

*Mark, age 23*

Mark was a 23-year-old male who was employed both as a peer specialist at a mental health agency and in his family agricultural business, which was seasonal. He attributed his family support and the additional hands-on support of the family business to his recovery and ability to work again after his first episode of psychosis. He took three months away from work at the time of his first hospitalization and his family encouraged him to return by the next season. Mark only recently became a peer specialist and continued to share his story through local speaking engagements and opportunities for advocacy.

*Elizabeth, age 27*

Elizabeth was a 27-year-old female who recently completed her bachelor's degree after a number of years struggling with psychosis. Her first diagnosis at age 21 resulted in dropping out of college, unsuccessfully trying to live independently, and multiple hospitalizations, over a period of three years. She attributed her success in completing college to parents with the resources and availability to let her live at home and transport her to college, as well as her own sense of hope and aspirations that got her through hospitalization and immediately re-enroll in college.

*Mike, age 28*

Mike was a 28-year-old male that worked as a peer specialist with an EASA team. Mike first developed psychosis around age 19, which led to being unable to work at his job and return home to live with his parents. He attributed his success to the EASA program which engaged his parents, connected him to other young people with psychosis, and most importantly, vetoed the idea of applying for disability benefits, as is routine in most mental health settings. Due to his previous

work history, his EASA staff opted instead for rapid job placement, which kept Mike employed during his initial recovery period. Mike attributed this connection to the labor market, together with learning ways to cope with symptoms on the job from EASA staff, as key moments in his making a full recovery. In addition, Mike spoke about overcoming self-stigma and the importance of integrating the diagnosis experience with normal young adulthood. At age 28 with an onset of psychosis at age 19, Mike had the furthest viewpoint from his first diagnosis and provided much insight into the experience.

*David, age 25*

David was a 25-year-old male who was unemployed, received disability benefits, and lived with his parents who were also his guardians. David had his first episode of psychosis at age 19 while in high school and went on to complete his GED, but did not enter the labor market nor college. He was about to enter a language program at a local university and had a goal of becoming a translator for social service/mental health programs. He was working with the university disability services program to identify ways to cope with his symptoms when they arise in the classroom environment, in particular his anxiety about other people.

*Jessica, age 25*

Jessica was a 25-year-old female who lives independently and works full-time for an insurance agency. She was first hospitalized for psychosis three years ago while in college and working part-time. After her second hospitalization, she moved in with her grandparents who became her primary caregivers for about 8 months. Jessica coined the importance of “getting back out there” after this period, explaining how important it was to her identity as a young adult to be able to earn her own money and live independently as an alternate option to living with family and

being unemployed. She was a staunch advocate for ethical treatment of young adults when hospitalized after feeling she was treated “less than” while experiencing hospitalizations.

*Sandy, age 28*

Sandy, was a 28-year-old female who lives with her fiancé in an apartment. She was unemployed after several unsuccessful attempts at working part-time as a cashier at local gas stations. She found that the work expectations such as working extra shifts and long hours was not congruent with her need to keep a set sleep/wake schedule. Although Sandy had her first hospitalization for psychosis at age 23, she was applying for disability for the first time to contribute to the household financially. She had an employment specialist at the local mental health agency and they have discussed additional job options such as becoming a peer specialist.

Taken together, these ten young adults paint a composite picture of overcoming early treatment experiences, receiving guidance along the way, and eventually navigating back to the employment or education pathways of young adulthood. This chapter explains how pathways to employment/education or disability were influenced by the first hospitalization experiences including first diagnosis and its associated labeling, and long, difficult regimens of psychotropic medications. Once a young person regained ability, they began a process of “getting back out there” which consisted of reintegrating their self-concept after a mental health diagnosis and learning to socialize again in public spaces. Exploring this time period is important because it describes how the often-stigmatizing experiences of early hospitalizations and associated medication regimens not only represent lost time during the early years in the labor market or educational settings, but how these experiences challenge individual self-concepts about entering the labor market.

## **Part I: Onset of FEP: Suspension of Activity**

When asked to identify key moments that influenced their pathway, the ten individuals who were interviewed painted a collective picture of a pathway that started with acute states of psychosis or initial onset of the disorder, proceeded to a psychiatric hospitalization, extended through periods of heavy and prolonged dosages of medications, and often included intensive care at home with family members. This time away from the everyday life of young adulthood ranged from just three months to several years, in the case of two individuals. Exiting this period was characterized by one participant as “getting back out there” or a return to everyday life as young adults, and this period carried additional hurdles including reconstruction of self and becoming social again for those who successfully exited. Although these descriptions of issues and key moments during and after psychosis onset occurred further upstream than the themes that directly describe participants’ experiences with employment and education, they are important contextual moments that illustrate how early experiences with psychosis and treatment begin to shape later self-concepts and capability.

### **Psychosis onset: suspension from young adulthood.**

Each young adult was involved in a normally expected daily activity for their developmental age at the time of first psychosis onset. Two individuals were in high school, six individuals were in college, and two individuals were working full-time when the onset of acute psychosis led to their first psychiatric hospitalization. This section illustrates what it was like to experience the social decline of initial psychosis, including the first hospitalization, the period of living at home, and the loss of everyday young adult activities for a period of time. Typically, individuals noted the first hospitalization and the period of months leading up to it as the catalyst of the point where they in essence abandoned their life activities such as jobs, school, and living independently. These changes caused abrupt suspension from the everyday experiences of young adulthood.

It just completely turned everything upside down. I was working and going to school— that was the beginning stages of the pursuit of my bachelor's degree, I had moved out of my parents' house so I was living with my friends, and over a year I was experiencing what I came to understand as prodromal symptoms, and as time kinda went on, I slowly started to become more isolated from folks, I ended up having to leave that job, I left school for a while, I left multiple jobs actually, throughout that timespan...2-3 jobs that I had had to not work at, and then eventually I couldn't, I got to the point that I couldn't feel safe unless I was in my room with the blankets pulled up, so eventually, without the funds to be able to do so, I had to move back to my parents as well, so it kind of turned everything upside down. – Mike, age 28

In this excerpt, Mike explains what it was like when the experience of prodromal or mood/withdrawal symptoms resulted in a downward spiral including losing both his job and independent living status, and ending with socially isolating himself in his bedroom to cope. The phrase “turned everything upside down” is a fitting description of the FEP experience for most of the participants in that it describes the abrupt halt and then regression from normal activities.

In the next excerpt, Elizabeth describes a similar period of time while psychosis was developing, consisting of dropping out of college followed by failed attempts at independent living due to the symptoms of psychosis.

I tried to go back to school but things just didn't feel right, my mom came for parents weekend and we just decided that I should come back to [city] for a little while, just to see what it was like, and I tried to, I got my own apartment in January, so I came back in October, this was 2012, so I came back and then I started hearing voices. I had to go to the hospital and stuff...I tried moving into different apartments around [city] but I still would hear these annoying voice things, a lot. You know like I tried, one time I had to put my head inside the refrigerator, like that would make it stop. I've actually tried about every single antipsychotic in the book, in that year after that, yeah they tried me on a lot of stuff and I just, it feels like there's a plastic bag around your head sort of with it. So that's how it was for about a year, you know like about every three weeks trying a different antipsychotic. – Elizabeth, age 27

In this case Elizabeth described having a difficult time while away at college where an onset of symptoms resulted in her stopping attending her classes. Her family encouraged and assisted her to return home and supported her living in her own apartment, however as her active symptoms increased in severity, it made living alone difficult. In addition, it took a year of mental health

treatment and many different trials of antipsychotic medications to stabilize her voices. In this case, the onset of her psychosis illness led to leaving education, and having to depend on family for a living situation. Similarly, Jessica discusses her difficult hospitalization, the impact of medications, and ultimately, moving in with grandparents.

And [hospitalization] was like the worst thing that ever happened to me, it was awful, and I don't want that to ever happen again. It was awful. The first time that I was hospitalized it was for two weeks, and this time I was hospitalized for like a month. And they put me on Zyprexa, I don't know if you know anything about Zyprexa, I was on a lot smaller [dose] at one point, but Zyprexa causes a lot of weight gain, they put me on a very high dose, I couldn't even think, like I know how to write really well, and I couldn't even write. I remember not being able to think, like time moving very slowly. So after I got out of the hospital I moved in with my grandparents, like actually with them, I went everywhere with them like I was a kid. – Jessica, age 25

Jessica's final line, "I went everywhere with them like I was a kid" exemplifies the regression backwards from young adulthood after FEP onset as described similarly in the previous two quotes. Taken together, these excerpts illustrate the ways in which onset of psychosis interrupts college, jobs, and independent living situations of normal young adulthood and result in a backward regression to a period of time spent living in family homes and in intensive mental health treatment programs or cycles of hospitalizations. This backward regression, in essence disrupts the normal channels of employment, education, and independent living and results in a temporary period of disability.

### ***Overcoming the hospitalization experience.***

As described in the previous section, the initial onset of psychosis symptoms usually resulted in a psychiatric hospitalization which all participants described as ranging from somewhat to very traumatic. In part, this is due to their shock after being labeled with a mental illness diagnosis, as well as having to stay in the hospital for periods ranging from a few days to months at a time. Individuals often described their experience of first hospitalization as one where they felt they

“weren’t treated like a person,” were often subjected to stigmatizing treatment by staff, and were usually heavily medicated.

So I ended up staying in the hospital for 8 days, and I was, you know that was the worst part for me, was the hospital, it-it was, yeah, scary for me, and basically I felt like I was being forced because I basically was, they’re like “you can’t leave” and so, I stayed there for 8 days and while I was there I did not want to take the medications they were giving me, I kind of felt almost like they were trying to poison me, I was so like, on edge and I didn’t trust anyone at that point, I didn’t even trust my family. – Mark, age 23

In this case Mark found the hospitalization experience to be confusing and the attending psychiatric staff to be difficult to trust. Mark further described the perceived lack of information provided to him by hospital staff below:

Yeah, they didn’t really explain - it was all, you have psychosis you’ve had a mental break and that was like the gist of that and they were like we think you might also have schizophrenia and they didn’t really give me detail about that and then wait, we think you’re bipolar so it was like how am I all of this, I don’t want to be all of it. – Mark, age 23

In this example, Mark found it ineffective to hear diagnoses discussed by hospital staff without providing contextual information such as how it would impact his life or prognosis. Similarly, Jessica discusses her perceived experience in the hospital:

I mean when you’re in the hospital, the way you’re treated, you’re not treated the way you would normally treat someone in the grocery store or like a quote-unquote normal person, you’re treated less-than, you’re treated inferior than, and so it’s really difficult to come out of that situation and then try to interact with other people, I mean my social skills went out the window after the hospital, the second time, because I was in the hospital for a month I felt like I didn’t know how to socialize with people, it took a long time for me to get back to the point where I could like talk to people in a normal way. I think a huge part of, from my experience, was that sense of not being treated like a normal person would be when I was in the hospital. And I don’t know why people do that, I understand there is a fear that people are acting strange, but you’re seeing them at their lowest, you aren’t seeing them at their best. It’s just a hard thing for everyone. – Jessica, age 25

This lengthy description of Jessica’s hospital experience specifically describes her feelings of being treated different because she had a psychotic break and how this had a negative impact on her sense

of self, and later abilities to be social. In addition, her comment, “it’s a hard thing for everyone” alludes to the reality that being treated as “other” due to presentation with psychosis is commonplace for young people receiving early treatment for psychosis within hospital settings. In summary, overcoming hospitalization as an experience was rife with the collective experience of feeling treated “less than” or as a label described as a cluster of psychiatric symptoms to be medicated. This interpretation of the first hospitalization experience functioned to set in place some of the first ideas of self-stigma that will be discussed in another section.

### ***Overcoming medication.***

Following their first hospitalizations for psychosis, all young adults recalled a period of adjusting to medications – in particular, to what they felt was “overmedication” and/or a period of trials of different medications. This led to additional time spent in parents’ care because they were unable to work or actively pursue schooling while adjusting to difficult physical effects of medication such as feeling “like a zombie.” Additionally, the medication itself was cited as a difficulty to overcome. As Jessica noted in the previous section, some individuals felt that the hospital prescribed heavier-than-needed medications, so the issue was one of recovering from the effects of high levels of medication on daily functioning as well as titrating down to a more tolerable amount.

Well, getting on my feet in a lot of ways, was a gradual process. So you know, there was that spring where I was really sick, and the summer was figuring out my meds, and I spent like 9 months tapering off those meds, hospital put me on a bunch of stuff that I don’t know if I should have been on. – Meg, age 25

Medication itself was vocalized as being a more troublesome barrier to working or school than psychotic symptoms themselves. Whether side effects, or overall sedation issues, the participants’ interviewed produced a collective choir of complaints about medication as a barrier to success by interfering with their daily living. The impediments stemming from taking medications inhibited a return to normal activities such as working or returning to education programs.

My very first goal was I don't want to take medication. I don't like it. It makes me feel slower. It makes my mind numb, and I don't feel like myself. I don't feel like I have very many emotions at all. I don't feel happy, I just kind of feel bland all the time. I hated it, so that was my first goal, and they helped me work to get off my medication by slowly going down on the dosage. And, after I was off, I started being able to see things more clearly, and I was more happy, and I had a more range of emotions, I would say. – Mark, age 23

“Mind-numbing” was a description used by many of the participants regarding medications. In many cases, finding a lower dosage or going off medications completely were the only options that helped individuals feel capable again. Elizabeth discusses the ups and downs of her initial psychiatric medication regimen and how they led to inconsistent abilities:

The pills just made me feel so weird, you know one day I could walk 4 miles, and the next day I feel brain fog [and] I can't do anything. – Elizabeth, age 27

In summary, all participants cited overcoming medications as a major key moment on their pathway back to a normal young adult life. During the medication adjustment period, individuals lived at home as they were incapable of doing normal everyday work or school activities. Individual capability increased as dosages were eventually adjusted, however this remains an important key moment in the pathway between the FEP and returning to employment and/or education pathways because the time spent adjusting to medication side effects interfered with the crucial time that could have been used to re-establish employment and school. It is also notable that when asked about individual symptoms as barriers to succeeding at work or school, individuals instead talked about their serious issues with medications.

## **Part II: “Getting back out there” – Forward Progress**

After time recovering from the experience of acute psychosis, hospitalizations, and intense medication regimens, most participants began to return to their baseline after a period of 3-6 months. While the process of moving forward varied among participants, many echoed the

importance of “getting back out there” or making a first attempt at returning to normal life activities again.

So basically my mom and my dad were like “we don’t want you to go to work, we want you to have three months to just be here maybe, you know” Get out here and there, do yard work, go to the beach, basically just like a vacation for three months, you know? And so after the three months, I had agreed after the three months I would go to work, and I was ready, I was getting pretty poor, just sitting around the house a lot. – Mark, age 23

In many cases, a feeling of lack of activity due to prolonged unemployment didn’t sit well with the young adults in combination with spending a number of months living with family. After these months in family care and intensive mental health treatment, young adults began to take steps to return to aspects of normal young adulthood such as independent living, returning to college programs, or employment. During this phase, themes of reconstructing the self as a young adult after FEP diagnosis, becoming social again, and finding peers were described as key moments of direction in this pathway. The following section describes these themes from the perspective of the individuals.

### **Reconstructing the self after diagnosis.**

Participants often described having to reconstruct their own version of self after going through the first episode psychosis experience. One young adult summarized this quite clearly by saying, “It’s like you’re learning how to be a young adult again, just with psychosis.” Jessica, who had lived with her grandparents, describes below the internal process of deciding to move out from their care and into her own apartment:

I think it was that moment that I moved out that was like, okay the only person I can rely on now is me, I have to rely on myself. And yeah, I think if something would have happened they would be there for me, but like I wanted to feel like I can take care of myself, that even though I’m legally disabled, that I’ve made it this far on my own, and that I’m not going to be stigmatized, (pause) I’m not going to be stigmatized, you know. – Jessica, age 25

In this case, Jessica talked about how making an independent decision to move out into an apartment with a boyfriend and getting a job was a very important move – for her doing this meant the opposite of dependency, equated here with disability and its associated stigma. Another participant described the way that stigma made him feel, shown here through the lens of an interaction with a family member.

My aunt came up to me and she was like, "I thought you were never gonna make it through, blah, blah, blah," so it kind of made me feel better, and realize that I'm at least moving forward at that point, even though I still felt way removed from everybody else's perspective. I felt alone and isolated, I kind of felt like I was lower than everybody else in a certain way. – Mark, 23

Mark's description feeling "lower than everybody else" related to his struggles overcoming psychosis was echoed by other young adults as well. In most cases it was the reaction to the diagnosis, or the label of mental illness, that generated feelings of inadequacy, and difficulty returning to public settings such as social activities or the workplace. While Mark discussed his feelings about stigma in reaction to a family member, others described coming to terms with self-stigma during the diagnosis process is explained below by Mike:

Well after I experienced my episode of psychosis I started to take on kind of this stigma I felt for myself. I remember talking about diagnoses, um, I remember that it was something that was really difficult for me to talk about, kind of like a double edged sword because it brings an answer to the experiences that I was having but then also with something that was really hard for me to, um (long pause)

Interviewer: It makes it real.

Yeah, yeah. – Mike, age 28

In this excerpt, Mike discussed the dilemma of wanting to explain psychosis, but then at the same time almost fearing the reality that a diagnosis brings. This moment, for him, was the beginning of stigma that he needed to overcome through reconstructing his sense of self as a young adult with psychosis. While many of the young adults, especially males, discussed having to overcome the label

of psychosis as a “reconstruction of self,” they usually did not refer to it by the term “stigma” except in Mike’s case.

The process of overcoming stigma involved practice in real-world settings where individuals would use reality-testing techniques such as double-checking delusional thoughts with another person, as well as through an additional process of reconstructing the sense of self after a psychosis disorder diagnosis. These next two participants described using the psychosis experience as a way to reconstruct the new self, integrating psychosis into the existing experiences through making meaning that worked for them.

So maybe it’s not that a person climbs that mountain and goes back down and says, hey I went through psychosis, now I’m not – because when a person has that experience, that like trauma, it’s almost like you want to relive that trauma – even though it was sad, but you’re looking for that spiritual awakening again. Um so the way that I got through it and that I think a lot of people get through it of trauma and of psychosis is by (I’ll just say psychosis) um...by being okay with the symptoms um still existing, and not having to deny that they exist but just being okay with it, I guess. – Evan, age 29

Here Evan depicts a vision of the FEP experience as a mountain that remains in your life, rather recovering and leaving it in the past, you are integrating the new experience along with your sense of self. This integration of the illness experience with the self was a theme for many individuals.

Um, Well, I think it’s kind of a journey of self-discovery. So, like I’d hate to be the barer of bad news but a lot of it is bad news, it’s a lot of suffering, it’s a lot of people trying to control your life, it’s medication that makes you feel terrible and it’s dealing with voices that are oftentimes really evil, and wicked, and just derogatory, trying to tear you down. But when you get over a certain plateau of horribleness, uh and it starts to level out, then you can do some self-reflection and you can learn more about yourself and your place in the world that you might not have had if you hadn’t gone through that experience. So at this point in my life I have an understanding of reality that is very different than anything I would have had before psychosis.  
– Matthew, age 27

Matthew discusses his integration of the psychosis experience in a way that has strengthened his understanding of himself in the world, and did so by utilizing the bad experience in an educational way. During the focus group, many of the young adults agreed that even when symptoms become

under control, there is almost a sense of loss, and a need to integrate them with the new self. In essence, the process of integrating psychosis into the overall sense of self as a young adult freed the participants to continue on their young adulthood journey.

***Becoming social again.***

Another oft-described aspect of “getting back out there” was becoming social again, particularly after spending lengthy periods both in the hospital and at home with family. Become social again was characterized by the need to practice socializing after time spent outside of the everyday, or in hospitals and living with family while unemployed. Participants also recounted the need to practice socializing as part of the process of overcoming stigma as described in the previous section.

...like getting more socially connected, like those last two terms at [community college] I was trying to go to clubs and trying to get my feet in the water, I didn't have a lot of friends at that time because a lot of them, you know who saw me, weren't really supportive, so it was a lot of hanging out a lot with my family, and then rebuilding that [social] aspect of my life too. – Meg, age 25

Here Meg describes a loss of everyday social life outside of her immediate family following the period of time away. Young adults who described this phenomenon felt that they had lost opportunities to practice being social while they were away from everyday life settings such as hanging out with friends or attending classes. Mark describes how “uncomfortable” he was in normal social situations such as back at his job where he had sales interactions with the retail public.

Also it was hard for me to uh, socialize with people, because I felt kind of like I had been tainted because they told me I had psychosis and that I might have schizophrenia that I might be bipolar, you know they just kept throwing different things at me so it was hard to socialize with others because it was hard for me to feel like other people had those problems and it turns out a lot of people actually have those problems. It was just hard because I felt like I was alone, I felt like nobody really had been through what I had been through. (pause) No one would really understand and I was also just feeling anxious so it was just hard for me to socialize even without the thoughts on top of it, you know, on top of just everyday tasks, everyday socializing with customers. – Mark, age 23

Eventually, through self-described “practice” talking to customers at his job, Mark was able to increase his social confidence again, something he felt he had lost through the experiences of being diagnosed with mental illness and the stigma he had to overcome. Becoming social again was a major aspect of overcoming stigma and the time taken away from everyday life experiences following a FEP. It was described as a key moment in the transition between taking time away or a disabled state, to returning to social functioning necessary for returning to or initiating employment and education

### ***Finding Peers.***

The final theme in this section presents a unified way to address the themes of overcoming hospitalization, medication, reconstructing the self, and becoming social again through the process of finding peers. Most participants spoke highly of encountering those with lived experience with psychosis, usually through their time working with the EASA program. In most cases finding peers for the first time consisted of meeting other young adults served by EASA through social activities and family psychoeducation groups.

When I think about my experience about just being able to connect with other people in similar experiences and the impact that it made for me, I think it's important because it's really easy to feel isolated and alone in your experience. It's really easy to easy to become disconnected from the world around you, and to, to not um, just to lose that connection. And having the opportunity to talk to someone else that says, “yeah I know what that's like”, helps to lessen that impact. And at first it didn't make it all go away, and I think even still I feel that experience of like an outsider, and I think for a long time I strived to want to feel normal, and in retrospect I think it was more that I didn't want to feel abnormal. I think that being able to connect with other people that had that similar experience and that had that ability to say “yeah I know what that's like”, really helped me to not feel abnormal.  
– Mike, age 28

I mean, I think peer support can be amazing. Especially for people like this is their first time experiencing it. They don't know what's going on. Even if somebody's in a state where they don't even, they might not even know that somethings wrong, but having a person who is accepting and isn't looking at them weird, or something like

that, can really create a connection for them, or a good experience. And perhaps afterwards, or people they're in that recovery stage afterwards like they had to go to the hospital or something, or they're on all these meds, just talking to someone who's accepting who's been through it, and can say, it's not gonna be like this forever. It might suck right now, but it's not gonna be like this forever. I think that can be really important for some people. – Meg, age 25

I think another thing that had a significant impact was being able to connect with other people in the EASA program, who were more towards the end of their EASA experience and just to see where they were at and the things they were doing really helped to inspire me as well. – Mike, age 28

Mike's quote on how he used connecting with peers through EASA to combat his own feelings of stigma and how that process helped him to “not feel abnormal” was a unifying theme of the ways that individuals experienced finding peers. Peers were not only perceived as helpful during the early intervention process; young adults also reported peers to be invaluable when navigating jobs and completing school programs as they provided both social support and help with coping. Taken together, these anecdotes indicate that natural peer support is important for reducing stigma possibly through the process of modeling as well as becoming social again. This modeling aspect of peer support was considered to be a key moment in that it helped young adults see others overcoming their mental health setbacks to stay on a career pathway.

### **Ethnic minority status an additional hurdle for people of color.**

Finally, two individuals who self-identified as members of ethnic minority groups brought up the additional struggle with overcoming the hurdles of racism and living in a dominant white society at the same time of attempting to recover from a FEP. One individual, Matthew, described a long period of just “maintaining,” characterized by working at part-time jobs and taking classes before learning more about his family culture of origin.

When I discovered these letters, I learned that this mental health struggle is not new, it didn't start with me it won't end with me, all the people in my family have dealt with these mental health issues wither it's severe depression, addictions, or bipolar,

or psychosis, they've all had to deal with these mental health issues, and it was exacerbated by internment.

Over generations you assimilate to survive, but the problem with that is you lose a sense of who you are, and as you assimilate, you think of yourself as more and more white, but white people will never see you as white, you know a white person isn't just going to walk up to me and say hey you're white, just because I speak with a flawless American accent, right? I'm still going to be identified as Asian-American. So if you know nothing about your culture, you have nothing to own.

– Matthew, age 27

Matthew recounted how his family had a lot of mental illness and substance abuse history, and how as an Asian-American, he felt that his parents were disconnected from any of their culture of origin, while also living in a predominantly white community. As a result, he struggled with his own ethnic identity within his home community. Matthew told a poignant story of discovering his grandfather's original letters written to his family during time in a U.S. internment camp, and this piqued his interest in studying his own culture of origin – a key turning point in his pathway toward recovery and eventually, returning to his education.

Patty also alluded to the difficulty with fitting in to a dominant white society, in this case as a stressor that interfered with her returning to more public activities.

It's not really just having an episode that makes it hard for me to engage in school, or having financial problems, and social, like familial problems, it's also social problems, like, so you see me now and I have like this shaved mustache and my arms are shaved and my legs are shaved, I am kind of like racially Mexican, and that kind of means I grow a lot of body hair and people are incredibly critical of having body hair, especially dark body hair, instead of actually having to do the maintenance of shaving myself every day like all my major limbs and everywhere else, it's like an extra 20 minutes of my shower like every day. – Patty, age 23

In this case, Patty differentiates her daily stressors related to “fitting in” as more significant than symptoms of psychosis. Taken together, these quotes illustrate how ethnic minorities with FEP deal with both cultural stresses as members of the minority group within the dominant culture and coming to terms with psychosis. As identified key moments to overcome before reaching more

functional levels of recovery, these are important implications for early intervention models that may not be inherently culturally competent in their focus.

This chapter reviewed the individual perspective of the young adults regarding their transition between the first hospitalizations and early treatment period and returning to normal young adult life. Themes of overcoming hospitalization and medication, overcoming personal ideas of stigma and reconstruction of the self after psychosis, the importance of practicing being social again, finding peers, and struggling with ethnic identity were all important key moments in the transition between a period of regression into mental health treatment and the progression back to working or school. This chapter provides an important backdrop for the next chapter which explores the specific messages about and different pathways to working, education, and disability for these young adults.

## **CHAPTER 5 – EMPLOYMENT, EDUCATION, & DISABILITY: MESSAGES AND PATHWAYS**

This chapter describes the important moments that participants felt to have influenced their pathway toward entering or re-entering employment and post-secondary education and where these were missing. As to be expected based on previous literature, the types of support and messages communicated to young adults from family and mental health professionals regarding education, employment, and disability influenced their own self-concept regarding these pathways.

As illustrated in the participant trajectories in Chapter 4, four young adults were pursuing post-secondary education and/or working, while two additional young adults were working full-time and not in education 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. A total of four individuals utilized disability benefits, two while continuing to finish educational programs, while two reported the disability benefits as their sole income. One individual was newly considering social security disability after a lengthy time of unemployment.

In addition to overcoming their illness and returning to a baseline of daily activities, these individuals identified a series of key moments that shaped their trajectory towards employment or education, or disability and unemployment. The chapter starts out with a description of how the demeanor and prognosis of mental health professionals encountered at different times during the treatment process ultimately influenced the individuals' self-concept about their ability to initiate or return to employment and education after psychosis onset. Next, it reviews examples of practical, tangible support received from their early intervention program staff and how these also assisted with their pathway to the labor market or post-secondary education. It then reviews the ways in

which family support (or its absence) and messages received about employment, education, and disability influenced their pathways. Finally, the chapter discusses how entities outside of treatment programs influenced their success in the labor market such as taking direct pathways to the labor force rather than secondary labor market jobs, support from university disability centers, and the adjunctive support from the Young Adult Leadership Council (YALC) as a non-professional center of exchange and a way of staying connected to the labor market and education system. Collectively, these themes illustrate the key moments, people and messages that influence the pathway toward employment, education, and/or disability trajectories as well as illuminate the structural forces that influence them.

### **Part III: Mental Health Professionals and Family: Ability/Disability Messages and Support**

Mental health professionals and family members such as parents and guardians communicated certain ideologies about psychosis and an employment/education or disability trajectory, while also providing varying levels of direct support. This section first reviews the ways in which the demeanor, prognosis, messages about disability, and practical support were received by young adults with a FEP and how these became key determinants in their pathway toward either employment/education or disability.

#### **Mental health professionals: demeanor and prognosis influences ability/disability.**

Differences in professional demeanor of mental health staff and in prognosis from psychiatric providers were influential on the self-concept of young adults as it related to their abilities after psychosis onset. In particular, this section describes the positive experiences that participants had with their early intervention staff in contrast to some of the experiences and messages received from acute hospitalization staff and those in other mental health settings that may

have had a more traditional view of mental illness treatment. This shift in demeanor and prognosis was found by these young adults to be influential on their pathways to employment and education.

Additionally, this section reviews the conversations about disability benefits as initiated or avoided by the mental health professionals encountered. Participants rated the way disability was presented to them by mental health staff as either presuming disability or employability.

***Positive demeanor.***

When asked questions about important people or messages that influenced their pathway toward working or school, many of the FEP young adults described specific providers among the many they had worked with, and when further inquired for details, they discussed the demeanor or style of the therapist. The demeanor typically described consisted of adjectives such as “warm,” “friendly,” and willing to talk to them as a person rather than as a diagnosis.

Another thing that helped me was I was able to project what was on my mind, and have somebody to talk to that I trust, and I knew I wasn't going to be judged, but they didn't just also sit there and agree with everything I had to say. They questioned why I thought that way, or, "Well, I'm not sure I agree with that, but maybe you're right." So not just shooting it down. – Mark, age 23

[She said] I'll take you at your word, and that really meant a lot to me, you know I trusted her, she was really supportive. – Matthew, age 27

In these examples, the style of listening in a person-centered way was rated as highly engaging by the young adults. Many of these stories about a particular counselor whom they experienced as affirming was in contrast to prior counselors who had a more traditional medical model approach.

Mark sums up this contrast below:

It felt more like a friend than a, "Okay, we're here to diagnose you," or, "We're here to see your progress and write a note about you." Yeah, so it really allowed me to open up easier, because it felt more real, plus she was also helping me develop skills that I could use in every day social situations. [Be]cause I used to be really, really quiet, not outgoing, it was tough for me to ... I would talk to people, but it just was for a little bit, and then I'm like, "Okay, I'm done," – Mark, age 23

In Mark's case the friendly "more real" demeanor of the early intervention staff member allowed him to engage in skills training that helped address the social difficulties which eventually helped him with anxiety at his job where he interacted with customers. In the next excerpt, Mike sums up the feeling of being empowered to have one's own choice in treatment as experienced by many in the early intervention program:

And being able to meet people where they are at, letting the person have the say in what is happening, meeting them where they are at and giving them the power, empowerment helps people who want to be there. – Mike, age 28

These examples indicate that a more "down to earth" style from the mental health professionals encountered in early intervention programs helped them to engage in a way that assisted them to move forward and into pathways of employment.

### ***Psychiatric prognosis.***

Participants were asked about how the professionals they encountered during the FEP process – both early and when enrolled in the early intervention program – communicated expectations and prognosis to them. Although the initial prognosis about mental health may seem distant from the moment that young adults experiencing a FEP enter the workforce, these initial prognoses presented by mental health professionals began to impact the self-concept that influenced their later working or disability trajectories.

First, a few young adults described receiving different messages about their future outlook after diagnosis from hospital or initial outpatient psychiatrists than when they began working with the EASA early intervention program.

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 EASA 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, and um, you know, 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 than the one I was given (laughs). – Meg, age 25

Here Meg describes how her early encounters with psychiatric professionals resulted in a negative outlook on living a life without medications, while her psychiatrist with the early intervention program offered more options and possible scenarios. Considering that the early intervention model is developmentally-aimed, while standard private psychiatry typically sees a range of individuals over the lifespan, these differences in communicating early prognosis may be common. Evan describes a similar experience with his early intervention psychiatrist.

Yeah, I remember my mom asked the 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, age 29

While the biomedical aspects of psychosis have different effects on different people, Evan's perception from the psychiatrist that there are different possible paths as well as putting some of the ownership onto him, sends a message of self-determination. This message likely empowers him as a patient and instills a sense of personal control during the treatment process. In these cases, a psychiatric prognosis with a positive, self-deterministic message about recovering from psychosis and a therapeutic empowerment style communicated by early intervention staff influenced self-concept toward an ability framework rather than a disability framework.

### ***Disability messages.***

Often family ideas about disability interacted with those recommendations from mental health professionals. In this first case, a participant with financially-secure parents and a partially-completed undergraduate education 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, um, 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, so I haven't requested all the records but the prognosis was he cannot work. He should be on SSI. – Matthew, age 27

Here we see the standard overview of applying for financial benefits provided by a hospital social worker and the ways in which it was interpreted by the young adult. In contrast, Mike's experience with disability with the EASA 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, age 28

In Mike's case, his mother asked the EASA program if they should apply for disability as a standard thing when someone has a mental illness diagnosis. Due to Mike's recent work history, the EASA program chose to focus on strategizing with Mike to return to working rather than spend time going through the often lengthy disability application process. This is a stark contrast between types of benefits counseling offered by mental health professionals, and based on previous research (Estroff et al., 2007) may have implications for the initiation of workforce pathways. Mike summarizes his experience with EASA in "breaking the disability mindset" below:

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, age 28

### **Practical and tangible support from early intervention staff.**

In addition to staff demeanor and positive prognoses with a self-deterministic message, the EASA early intervention program in particular was described as providing a range of practical and tangible support to the young adults which was attributed to helping them forge pathways to educational settings and cope with workplace difficulties.

He really helped and he drove me down to [local university], we went up that elevator in that building. We went to the advisor and sort of he's like, "So you want to do a degree here?" I'm like, "Yeah. I do." So he really helped because he got things moving like practically, physically. – Evan, age 29

In this excerpt, Evan rated the tangible support of physically going together to the exact university program that he was interested in as critical to get things moving on his pathway to starting a career in occupational therapy.

Yeah it made a significant impact in just my ability to interact with others. I remember when I first got a job after being in the EASA program, I also had to interact with coworkers and so at first it was really difficult and as time went on I think it helped me to gain confidence in myself and my abilities and working with the EASA program helped me to process the different things that I was experiencing. I remember the first time I was able to poke a hole in a delusion that I was experiencing while working and just the excitement that I was able to go back to my case manager, (yells) "I was able to do this!" Yeah, it's pretty great. – Mike, age 28

Here Mike describes some of the practical tools that EASA was reported to help individuals learn to cope with their symptoms. In this case, Mike was able to practice the coping skills taught by EASA to succeed at his job. Mike sums up an empowerment perspective offered by the EASA program in the below quote:

I think what it all comes down to is the support that is offered, and the fighting of what is traditionally thought to be, and I think the EASA program makes an impact with that positive support, that empowerment, along with everything else that it offers. – Mike, age 28

### **Family: Support and Messages that Facilitate or Hinder Progress.**

Support from family and mental health professionals had a strong directional influence on the young adults. This section describes how the presence or absence of family support impacted young adults through the psychosis process and while navigating the re-entry period to employment and school. It also reviews the key messages from family about education, employment, and disability that was perceived to provide direction in pathways to working or school.

#### ***The presence or absence of family support.***

Family support was cited as a key in the pathway to working or school following a FEP across all participants. Parents and in one case, grandparents, provided a range of emotional support as well as practical support, usually housing and basic needs during the FEP period.

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, age 23

Mark describes his realization that no matter how severe his psychosis became; his family was not going to pass judgement and instead was going to support him through the highs and lows. In addition to providing for basic needs through housing, family also provided practical support that was named by individuals as important in their later success in schooling in particular.

I did a lot of that myself, but my mom helped me because she works for [community college], so she knows a lot of the ins and outs, so I had that support from her. I mean it impact[ed] my schooling, that term going up to the hospital, I failed all my classes, and thankfully my mom brought up, “because you went to the hospital you can appeal and get all your classes withdrawn instead, so I did that and that was really helpful for my GPA (laughs). So I sent them all my records, and they said my F's could turn into W's. – Meg, age 25

In this case, Meg's mom was in tune with the nuances of navigating the college system during a withdrawal and was able to help her minimize the lost class time during acute phases of illness.

Another participant's mother drove her to her classes and helped her edit her papers – two

significant examples of practical support that likely contributed to this person's success in completing her bachelor's degree after a lengthy period of time in the hospital.

In contrast, one participant's mother was not able or willing to provide support consistently due to her own disability and financial struggles. This had a negative impact on the individual.

There [were] no other people that influenced me. The only people that I had that influenced me was my mom telling me, "You need to take meds," and the prescribers that she took me to that would tell me, "You are going to be hopeless and have a terrible life," even though I had a diagnosis, I thought I was misdiagnosed. Disorganized type schizophrenia. Not even hallucinations. Literally [for] six months, I had a hard time actually doing anything in school. It was a web school, so obviously I had plenty of opportunity to goof off, and I did. With a computer at home and nothing else to do, just looked up cartoons and listen to music. Stayed up really late. That was my life for six months...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, age 23

Patty paints a picture during her interviews of the struggles to complete school work without a supportive parent or an organized home environment. Patty's story is one where the absence of parental support and a low SES position 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. In addition, her time spent in the EASA program was at a younger age (high school) than the others in this study and thus she did not receive the employment interventions that are more commonplace with young adults who receive the EASA intervention in their early twenties. Patty is still not in employment or school, currently cycles between residential living facilities and times with family, and feels she will be unable to complete a college program without a supportive home environment and way to legitimately use student loans.

This contrast between the young adults with available parental practical support and those without it highlights an important split between a FEP young adult continuing on a path toward working or school, and those who are on a pathway to disability and supported primarily by the mental health system.

***Family messages about working, education, or disability.***

Overall, messages about disability came from both family and mental health professionals, the latter of which differed radically between those encountered in acute care settings and those with the EASA program. This section reviews the ways in which these disability messages were received and perceived by young adults with FEP.

In this first example, Elizabeth had quite a lengthy period of hospitalizations, including at the state hospital, however, she also had a family that was well-to-do, a sibling in a doctoral program, and her own aspiration to complete her undergraduate studies, once she was not in the hospital.

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, he got a PhD in biochemistry, 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, age 27

The interaction of Elizabeth's self-aspiration and her family support for higher education helped her to stay on a college completion path after stabilization.

In addition to communicating expectations about college, family also communicated ideals about returning to the workforce.

My grandparents on my mom's side, they wanted me, after my first episode, was like take the summer off, and then go back to school, and they were totally fine with me not working or anything, and over here, my grandma on my dad's side was like "you

need to be back working again” you know right after the hospital, “you need to start working again”; “I think you can be working.” – Jessica, age 25

As discussed in Part I, while family often supported time at home, most families made a concerted effort to communicate ideals of returning to work or education such as in Jessica’s case.

Communicating these ideals sent the message to young adults that working and or education was an expectation or a strong positive choice for their next steps back into young adulthood.

A clear example of family associating mental illness with disability is Patty, who did not receive positive messages about working or educational ideals, and instead received suggestions about social security disability benefits at a young age after diagnosis.

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, age 23

Here Patty communicates how her mother’s lower income status and possibly her own disability, influenced her decision to communicate an expectation that Patty would need to apply for disability when she was still under age 18. Patty has felt that her monthly disability check has helped with her day-to-day living expenses as an adult; however, the communication of Social Security disability as the primary option for financial support likely replaced conversations about working or education. Patty further touches on this topic during a different conversation about her mother discouraging her to work:

During that same conversation, she said to me, "No one is going to hire you because you have a mental health diagnosis." Same conversation, that same day in that car. – Patty, age 23

Here Patty alludes to her failed attempts at convincing her mother to allow her to apply for jobs and her interest in 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, chronic health issues with diabetes and mood disorders.

In summary, Part III reviews the contrasts between messages from family and mental health professionals about working and education, self-determination during the recovery process and disability, and how these had major influence on young adults navigating a return to working or educational pathways. This has significant implications for the ways in which early intervention programs can assess for work and educational interests and aptitude before disability benefits are introduced, particularly for these young people who are just getting started in the labor market, with a stronger intervention for those without a supportive family situation such as in the case of Patty.

#### **Part IV. Forging Pathways through Employment and Education**

Thus far I have reviewed the young adults' own individual experiences of navigating the pathway between a FEP and returning to the normal everyday experiences of normal adulthood and the ways in which family and mental health professionals have influenced their paths. This last section covers themes that emerged regarding the actual labor market and post-secondary education programs. This section is compelling because it examines the themes encountered after leaving treatment programs, therefore revealing important information about a rarely-studied time period in the lives of young adults with FEP. This section reviews the aspects of navigating the labor market and educational settings as well as the adjunctive support found through the young adult leadership council itself. Themes in this section include including foregoing the part-time jobs of the secondary labor market for those with built-in pathways, utilizing university disability services resources while in college, and how the YALC functioned as a form of non-professional, peer-based support for individuals to gain access to the labor market.

### **Navigating the secondary labor market: Foregoing part-time jobs for those with a built-in pathway.**

This section reports on the ways in which individuals navigated the labor market while in recovery from a FEP. At the time of these interviews, 50% of individuals were actively pursuing a college or graduate degree or had recently completed one while 60% of the sample were working in paid employment. A single participant was working full-time and attending college part-time. It is also important to note that 30% were neither employed nor in school activities.

Interviews revealed that accessing the labor market through entry-level jobs such as in retail settings was determined by the young adults to not be an ideal path. For some, the high stress, high demand working environment was a problem, while others found these types of employers to be unsupportive or unwilling to provide accommodations.

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 slowly cumulative 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 working a cashier, you're constantly 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. You know I was a computer technician at [retail store], but it wasn't all I did...you'd think all I did was repair computers that would be one thing, but I worked the cash register, I talked to people explained computer problems, and I'm supposed to be repairing computers on top of that, and dealing with customer complaints, selling people on warranties, it was way too much. So many demands on your time, you're getting pulled in too many directions, you're on your feet the whole time, there's no place to take a breath, relax, get back to what you're doing. I need to be able to sit at a desk focus on one thing at a time, get it done, take a break.

– Matthew, age 27

Here Matthew paints a picture of his struggles with the pressures of working in the retail environment – even in a specialty role as a computer technician. In this case, the attributes, tasks,

and expectations of the workday in the retail environment carried unrealistic expectations for him, particularly in the years following a FEP.

Similarly, Meg describes the difficulties with entering the secondary labor market through formal interviews and social expectations that may be more than a FEP young adult can handle initially.

Yeah, it made me really anxious, because you have people mad at you and stuff like that. I mean it can be really hard especially I feel like our job market is not as accommodating as it could be. Some people don't wanna work with people at all. I think that the interview process sometimes doesn't really capture how good somebody would be at their job. Like do you need an interview to just be a stock person, and put boxes away, and things like that, it would be nice to just have more ease of access into certain things and maybe jobs where there's not as much human interaction just being a little more sensitive to that. Because that's something I've heard a lot from people. I don't really wanna work with people. I just wanna do something, like people would be satisfied just doing some I guess menial task.  
– Meg, age 25

In this case, the structural realities of entering the secondary labor market include high-pressure interviews where one is expected to be able to handle social cues naturally. As Meg and others have explained in previous chapters, comfort in social situations such as a job interview takes time following a recovery period after FEP, and therefore the traditional job interview process along with other social expectations of the secondary labor market can create difficult hurdles for entry into the labor market.

In addition to barriers to working through the job application process, and the demands of retail jobs, a few individuals discussed losing their jobs due to employers being unwilling to accommodate. Sandy lives in a small community with a limited economy for entry-level jobs. She described having multiple jobs primarily cashiering at gas stations and while she didn't 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 AM to 9 PM most days.... He ended up having me work late one night, instead of work in the morning, he called me in for the first time, 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 is a very fake person, that pretends like he cares but really doesn't. – Sandy, age 28

Sandy found this 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 be an indication that there are additional 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 less opportunities for education or entering into the primary labor market is an additional barrier. In summary, the realities of the secondary labor market outlined here such as high-pressure interview processes and unrealistic workday expectations, while not receiving needed accommodations, were major barriers to successful employment for the FEP young adults in this study. While several individuals had worked at part-time jobs such as cashiering prior to, or shortly after FEP onset, none of the sample had successfully held tenure at these types of jobs.

### ***Direct pathways into employment.***

Those who were currently employed utilized a bridge or direct pathway into employment. For example, three individuals are employed as peer specialists in mental health centers, which they learned about from the early intervention program, and for which they needed very little formal training. They have in essence used peer specialty as a bridge to the labor market.

Because we tried all this different stuff, I think, you know just applying for random jobs, because I was thinking about occupational therapy at the time, I was like trying to get a caregiving job or some 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 it up. So...yeah, I was able to go to a training and I think before I went to the training and started applying for jobs, I talked to the peer support specialist at EASA and kind of asked her questions about what it would be like, and it was funny cause she (laughs) asked me if I had been in the hospital and I said, yeah and she said (exclaims) Oh good! And I was like what? And she was like well that's not good, but it's good that you have the experience because that's valuable to talk to other people about so that's kind of an interesting way to think about it. – Meg, age 25

In this example, Meg describes how becoming a peer specialist was an option that she learned about after unsuccessfully looking for work with her employment specialist, and how she was able to parlay her lived experience into paid position. Two other individuals were in graduate education programs with direct pathways to a career such as healthcare and law, and chose those direct career pathways after being similarly frustrated with the secondary labor market. These findings have tremendous implications for the way that employment assistance by way of treatment programs approach re-entry to the labor market for those with a FEP.

### **University disability resource centers.**

For those individuals who were matriculating in, or planning to enter higher education settings, accessing university disability resource centers for needed accommodations were rated positively, and also appeared to play a crucial role in their ability to achieve and experience 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, my niche. 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, age 25

In this case, David is hoping to start a university degree program after taking online classes. David struggles with anxiety which often overlaps with his delusional thinking, so he worries 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 to have 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 of 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, presumably because [stressful event] and they were sympathetic to that, so they went so far out of the way, tutoring lessons every single week outside of class, every day I had 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, age 27

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 an incredibly 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, they can nonetheless have tremendous positive impact on assisting a young adult through the completion of their studies.

### **The Young Adult Leadership Council as Adjunctive Support.**

The final theme to arise regarding key moments to a pathway to employment and education was the Young Adult Leadership Council (YALC) function as an intermediary community through which young adults could gain skills and receive peer support. While the YALC formally served as a community of peers with responsibility for formal tasks such as advocacy, public speaking, and overall guidance for the state-based early intervention program, it also unofficially served as an intermediary between early intervention treatment settings and a career track.

I really appreciated the YALC, for a lot of good reasons, the opportunity to connect with other people, just that space that it provides for that support that it gives. And I don't think I've ever been in a room of people where I could talk as openly about feelings or experiences, not have to be so afraid of what an outsider might think, so

just that general support that I received from them I really appreciated. I think that they also have set it up in a way that creates a lot of opportunities for people, I was able to be part of those opportunities, when it came to public speaking...and I think that is what helped me to create a pathway into the peer support role.

– Mike, age 28

I think joining the council is really important, and like knowing that all the hard things I went through can be strengths, and you know, before I was thinking of becoming a peer specialist, I remember one of the other members of the council was...talking about going to a public speaking thing and shared her story, and I was like, what, you shared their story, people do that? It completely blew my mind (laughs), people want to hear that? 'This is a thing people do?'" – Meg, age 25

I'm using it all the way. I'm using it as security. I'm using it as purpose. I'm using it as my link to this university. – Evan, age 29

These descriptions of the positive experiences had through involvement in the YALC indicate that formal peer groups can serve as adjunctive support following early intervention programs. In this case, the YALC not only served as a bridge to the employment and education, it also included the built-in peer support, an important facet of recovering from a FEP as described in Part I.

This section is particularly compelling because it examines the themes encountered after leaving treatment programs, therefore revealing important information about a rarely-studied time period in the lives of young adults with FEP. This section highlights how young adults with a FEP navigated an ever-changing labor market after a FEP, including opting for career pathways with direct access such as becoming peer support workers, or entering educational trajectories with direct pathways to paid employment. It also highlights the importance of disability services departments within universities in their support to adults with FEP. Finally, the YALC is presented as an example of adjunctive support following early intervention programs, providing peer support and a link between involvement in the mental health system and eventual paid work.

## **Conclusion**

Part II covered how young adults with a FEP received support from family members and mental health professionals as well as messages about working or educational ideals. These ideals included those about ability and disability, and in particular, mental health professionals in the EASA early intervention program were found to “break the traditional mindset” that a psychosis diagnosis would result in a life lived in disability. Finally, part III described the contextual aspects of navigating the labor market and education pursuits after completion of the EASA program, and indicated that direct career pathways, the support of university disability services departments, and “buffer zones” such as the YALC are important structural pathways in the road to successful employment trajectories for young adults with a FEP.

## CHAPTER 6 – DISCUSSION

### Introduction

This study provides insight into experiences and messages that may affect pathways to employment, education, and disability for young adults with first-episode psychosis (FEP) by examining a critical case sample of FEP young adults who have self-navigated these pathways following their own treatment in an early intervention program. A review of the theoretical and empirical literature indicates that young adults are likely to experience poverty whether before, shortly after, or long after the onset of FEP, and that while good intentioned, supported employment interventions still lack robust employment outcomes that assist FEP young adults to a trajectory of earning potential (Baron & Salzer, 2002; Rosenheck et al., 2016). Furthermore, the negative labeling aspect of disability looms over young adults who may need to apply for temporary disability benefits during their early treatment, adding additional stigma to the personal recovery process. The young adult thus is navigating both an illness and their own self-concepts and aspirations, which are in turn heavily influenced by family, treatment staff, and society during this crucial time.

The results of this study reveal that the pathway between a FEP and employment within the labor market involves navigating a sea of new challenges, which are divided into three parts. Part I reviewed the key moments associated with the onset of a FEP and how they led to suspension of activities followed by forward progress. Part I begins with descriptions of the first hospitalization experience including first diagnosis and its associated labeling, and continues through overcoming initial regimens of psychotropic medications. Young adults then have to re-launch back into normal young adulthood, which was characterized as “getting back out there” where they essentially reconstruct their self-concept after the labeling experiences associated with their FEP, and reorient

themselves to feeling comfortable in public social situations outside of the mental health treatment system. Finally, peer support was seen as an integral part of coming to terms with the self-stigma of the early mental health treatment experiences and moving forward while struggles with ethnic identities created additional barriers to recovery. These key moments during and after psychosis onset are important as they illustrate how early experiences with psychosis and treatment begin to shape later self-concepts and capability for young adults with FEP.

Part II describes how regaining ground after the setbacks of a FEP experience was facilitated by mental health professionals and family. An engaging demeanor and positive prognoses from mental health professionals assisted towards employment and education pathways while a more traditional disability message from mental health professionals in non-early intervention settings sent complicated messages about capability for FEP young adults. Early intervention staff provided practical, tangible support in the form of navigating job searches, meeting with educational admissions departments, and teaching coping skills for employment. The presence of family support such as housing and help with practical support such as transportation to educational settings was seen as a facilitating factor while the absence of family support additionally hindered progress toward employment and education. Moreover, family messages about employment, education, and disability influenced the young adults' self-concept as a worker, student, or person with a disability.

Part III described forging pathways to employment and education including the ways in which contextual aspects of navigating employment and education channels influenced the actual uptake into these pathways. Young adults discussed foregoing the secondary job market and its high-stress, low-accommodation, part-time jobs, and instead pursued more direct pathways into employment. Examples included becoming a peer support specialist, or entering college programs with a specified career path such as healthcare or law school. For those in college settings, an active

university disability services center that was familiar with and sensitive to mental health issues was a major asset to the success of students needing temporary accommodations. Finally, informal support from the Young Adult Leadership Council (YALC) were invaluable to pathways towards career planning – even for those who were not currently employed nor in education, indicating that adjunctive support beyond the scope of early intervention is vital to the pathway to employment.

### **Relationship between Findings, Conceptual Model, and Literature**

These results illustrate key components of the conceptual model in Chapter 2 as well as the theoretical literature. The young adult with a FEP indeed had various intact self-concepts and aspirations for themselves before their first hospitalization, indicating that prior to FEP onset most were having a developmentally-normal progression into young adulthood. In all but three cases, the young adult was able to return to their pre-FEP onset aspirations following the period of regression into mental health treatment during a period of anywhere from three months to one-year post-FEP. Moreover, similar to developmental trends of young adults in the general population, these pathways were influenced by the structural realities of family SES, with more well-to-do families having the resources to support and encourage adults to stay the course with regards to higher education and the workforce, which those with less resources had struggled to provide. Being in a position of poverty with an absence of parental support presented almost insurmountable barriers to re-entering the labor market for FEP young adults. This study provided poignant evidence of the ways in which the more limited resources of low SES translated to negative messaging and more rigid expectations, while the context of a more affluent and educated family provided the hope and optimism that was facilitative of re-engagement and recovery.

Messages received from mental health providers encountered at various stages did influence whether the young adult and/or their family members chose or supported an employment,

education, or disability trajectory. In particular, psychiatric prognosis that offered hope or was presented as open-ended and sent a self-empowering message was perceived as helpful in moving forward, where very early communications about disability were difficult for both family and the young adult who was still coming to terms with the new diagnostic label. Finally, external structural realities influencing the young adults' pathways included family SES, treatment program ideology, and local labor market realities.

### **Employment & Education Trajectories.**

The key moments which were perceived as barriers to employment and education pathways were an early onset of psychosis, heavier early medication doses and the time to adjust, the labeling and overall professional demeanor of hospital staff, unsupportive family members, and secondary labor market jobs. Alternately, the key moments perceived as facilitating a pathway to employment/education pathways included becoming social again, finding peers, early intervention staff with self-deterministic demeanor and practical support, direct pathways of employment (peer specialist, exploring college programs), utilizing university disability centers, and the Young Adult Leadership Council (YALC).

### ***Barriers to employment & education trajectories.***

Similar to past studies, early-onset and hospitalization for FEP before the age of 18 created a more difficult path to employment or education, with the two participants with early onset still unemployed and not pursuing education six to seven years post-FEP. These cases are a compelling call for early intervention programs to take a different approach with individuals with early-onset if they are to help preserve the developmentally normal employment and education pathways for young adults.

Medications were felt to have had a negative effect on cognitive function and on the activities of daily living such as heavy sedation. It was presumed that symptoms of psychosis would be identified as a problem when returning to or initiating pathways to the labor market. However, when asked about the often pervasive, disturbing, and disruptive symptoms of psychosis and early schizophrenia or bipolar disorder, and how these impacted the young adults' pathways to working or maintaining success in educational settings, the participants instead discussed medications and how post-hospitalization, the road to normalcy was negatively impacted by the secondary effects of trial medication periods. Furthermore, when individual symptoms were discussed, they were brought up in the context of the actual lost time in the mental health system, such as during early hospitalizations or while receiving services from the early intervention program and less often discussed as a hindrance to working or education. Additionally, a historical trend of constrained funding allowing for only narrow treatment outcomes, such as medication, has also likely influenced the tendency toward heavy prescribing of medication early in treatment (Braslow, 2013; Teghtsoonian, 2009). These ideologies work in tandem to reproduce the idea possibly still held by early treatment providers, that psychosis leads more readily to disability than back to the labor market.

The labeling and overall professional demeanor of hospital staff was identified as another major barrier to the individual's self-perception regarding their re-entering a career trajectory. Hospital staff were more likely than early intervention staff to be rated as illness-centered with an ideology of presuming a pathway to disability. As discussed in Chapter 4, this labeling of psychosis in the hospital was perceived as the beginning of self-stigmatizing thoughts about the label of psychosis for the young adults, and this was intensified by feelings of being treated differently by staff in the inpatient situation. While utilizing disability income as a temporary form of financial aid through a FEP can provide some relief to a young adult, the problem lies with the acceptance of

living on SSA benefits as an alternative to employment within the mental health system which “removes focus from attempting to re-enter the labor market” (Hansen et al., 2014, p. 82). Finally, the process of coming to terms with the label of “mentally ill” and “disabled”, with its internalization of a deviant identity and lifestyle, has a lingering impact on the future productivity of the person (Goffman, 1973; Gove, 2004).

Having unsupportive family members with little encouragement toward maintaining a trajectory towards employment or education solidified disability trajectories, which was similar to the findings of Estroff, et al., (1997). This was intensified when combined with an early onset of psychosis. Since schools provide little guidance in the transition to adulthood and the post-high school outcomes of students with disabilities is even more pronounced (Smith & Routel, 2010), those individuals with an early onset of FEP in high-school may not receive support from their school system, and thus may rely more on family and mental health professionals for transition to adulthood.

Finally, part-time jobs in the secondary labor market, which were traditionally accessed by low-skilled, younger workers, were experienced to not be conducive to working while in recovery from psychosis, a critique also emphasized by Baron & Salzer, (2002). During their decision processes, these young adults described the typical application-interview process of the secondary labor market to be unsuccessful, and the jobs to be high-stress, with one now very successful graduate student going so far as to perceive that a job in a big-box electronics store led them to a psychotic break. Disclosure of having a psychosis diagnosis and needing an accommodation was an additional issue to grapple with, which was also found by Basset, Lloyd, & Basset, (2001) and Forchuck et al., (2017). Young adults either opted to become trained as mental health peer specialists, a para-professional job category employed by mental health centers (2), worked in a family business (1), opted for a full-time office job (1), or entered graduate college programs with a

specific training such as healthcare, law, or social work (4). At the time of the interviews, it was remarkable that none of the sample were currently employed in the secondary labor market.

***Facilitators to employment & education trajectories.***

Key moments that were reported to be conducive to facilitating pathways to employment or education included the process of becoming social again and finding peers at the early stages of recovery. Individuals found that becoming social again was a necessary task used to integrate their new sense of self post-diagnostic label with non-peer friends, and the public, and that this was an important part feeling “normal” in society again. In addition, finding peers with lived experience who served as a model of having psychosis and returning to work or school was perceived as invaluable during the early intervention program as well as after completion.

In contrast to the perceived experience of negative labeling and treatment from hospital staff, some participants highlighted how early intervention staff with a self-deterministic demeanor and willingness to provide practical support assisted them towards employment or education. The ways in which early intervention staff presented options for prognosis, rather than a permanent disability ideology, and avoided pursuing Social Security benefits if the person had a prior work history, were seen as key moments that facilitated their trajectory towards pursuing employment or education.

These early intervention staff also provided support for young adults to pursue direct pathways of employment. After not having success interviewing for part-time jobs in the secondary labor market, young adults received guidance from early intervention staff to become trained as mental health peer specialists or entered graduate college programs with a specific training such as healthcare, law, or social work. This shows promise for the unique position of early intervention programs to indeed assist in the development of career trajectories at earlier developmental stages.

Two participants pursuing post-secondary education rated university disability centers as integral to their success as they were able to receive accommodations such as extra tutoring or planning to cope with symptoms if they became troublesome in the classroom environment. Finally, the YALC itself was rated highly as a form of support outside of treatment that provided peer modeling and access to employment through others. The internal social capital generated by participation in the YALC was seen to be invaluable to this group.

In total these findings illustrate how a range of key moments were highly determinant in assisting or hindering a young adult's progress toward an employment and education trajectory. While some of these key moments including messages from mental health providers and family, and overcoming stigma were previously discussed in qualitative studies (Bassett, Lloyd, & Bassett, 2001; Estroff, et al., 1997), the balance of these findings are not discussed in the quantitative literature on pathways to employment or disability. This indicates that these key moments are not only likely transferable to similar FEP contexts, they are also integral to further research on pathways to employment.

### **Theoretical Connections: Social Causation, Drift, and Disability.**

#### ***Social causation.***

Several aspects of the participants' stories aligned with elements of social causation theories. First, most of the participants recalled experiencing high stress situations when the FEP onset began, though in very different socioeconomic situations. Patty was struggling with a chaotic home life, with little parental supervision or support and existing mood disorder and medications when she began hearing voices. However, the balance of the sample was either in college or working when they first experienced psychosis, which is not associated with the impoverishment or neighborhood stress outlined in the social causation literature. This does reflect aspects of the Stress-Vulnerability

Model, where exposure to any normal life stress can act as a trigger to psychosis for those already biologically predisposed to the illness (Mueser, 2004; Nuechterlein & Dawson, 1984) regardless of context.

Two individuals who identified as people of color reported experiencing discrimination which exacerbated their symptoms in a way that added a feeling of despair to overcoming their illness. They added that it felt like an additional weight on their shoulders, above and beyond the illness. In other words, young people who are on a low SES trajectory and/or are racial and ethnic minorities, face additional barriers to the labor market regardless of early psychosis. This fits into a larger context about mental disability and employment where social and demographic variables that help individuals into the labor market (such as being white, male, and having a college degree) have a more significant influence on their actual labor market success than having a mental illness (Hegelstad et al., 2017).

### ***Social drift.***

As mentioned in the introduction, all but three individuals regained their traction in regards to previously planned or initiated education programs or employment after their initial inability to complete these daily activities. David experienced true downward drift from his parents' middle-class SES after having a FEP during high-school and not regaining ground until recently when he decided to pursue a college degree. Sandy was working full-time when she developed psychosis and had inconsistent part-time jobs until recently deciding to apply for disability benefits. Patty has stayed at relatively the same income level of her mother. Despite this being a critical case design, it is still compelling that (70%) have rebounded back from temporary lost time to early onset of FEP.

Finally, Patty's situation mirrors the medicalization of poverty where conditions brought forth by living in impoverished conditions are classified as psychiatric problems rather than

addressed as secondary effects of poverty (Hansen, Bourgois, & Drucker, 2014). While a school-aged Patty felt depressed from the stress of a financially-strained household, Patty's mother, strapped for financial and emotional resources, reached out to medical professionals to assess her daughter's difficulty adjusting to school. As a result, Patty was medicated at a very early age for mood disorder, and subsequently felt that some of her disorganization related to her first psychosis diagnosis stemmed from the early medication. In addition, due to early onset of psychosis, coupled with a family environment with limited capacity to provide care, support, or positive messages about employment and education, Patty's disability status was solidified before she completed high school. Today, Patty, once a high-school honors student, depends primarily on the adult mental health system for her needs and struggles to find a niche into the workforce, supporting the empirical data that social drift is linked to earlier onset (Kuruvilla & Jacob, 2007).

The structural realities of the labor market had profound effects on the employment trajectory of the young adults, with none having been successful entering or remaining in the part-time jobs of the secondary labor market. Finally, the type of community also impacted pathways to employment with relatively resource-rich Portland offering many channels to employment, particularly through a progressive community-oriented public university and the YALC, while smaller communities offered a limited array of entry-level jobs in the primary labor market such as in Sandy's case. The structural aspects of the modern labor market have rendered the entry-level jobs of the secondary labor market to often be high stress environments and unaccommodating to a psychotic illness. In addition, these jobs do not pay enough of a living wage to lift an individual out of poverty, nor do they generally provide a ladder to advancement (Baron & Salzer, 2002; Newman, 1999).

*Labeling/stigma & disability.*

Of particular importance in this study is that there was range of interpretation of disability which seemed to vary by the messages received by mental health professionals and of course, current ability to maintain employment. As reviewed in the previous section, participants recounted a distinct difference between the messages received about disability benefits from hospital staff involved in early phases of the illness and those of the early intervention program, with more traditional messages about applying for disability coming from those hospital staff. In contrast, early intervention staff did not automatically pursue disability benefits, instead first assessing the existing work history and educational plans of the FEP young adult. This shift in planning from a disability mindset to an employment mindset kept individuals moving towards their employment and education goals while involved in the two-year program, rather than having the young adult spend that time languishing in the lengthy disability approval process. Interestingly, this shift between discussing disability benefits as an automatic part of treatment, and holding off, indicates that the ideology of early intervention programs may be leaning toward prevention and therefore are not completely steeped in the medical model of disability.

Two additional themes about treatment staff were a positive demeanor and receiving tangible support. Many of the young adults reported being treated as “less than” or in stigmatizing ways by inpatient hospital staff, which they partially attribute to their difficulties adjusting to life after the FEP period. In contrast, they experienced some early intervention staff as warm, friendly, and treating them more like a person than a diagnosis. This positive demeanor theme came up multiple times as a key moment for the young adults. These experiences reflect the structural realities of the mental health system in that it is likely that front-line psychiatric staff operate from an emergency treatment ideology while an early intervention program is tasked with re-integration and

is thus better poised to instill hopeful messages and assist with the pathway to employment or education.

The process of overcoming self-stigma and the lost time during mental health treatment occurred through an iterative process where the young adult worked to re-construct their self-concept after the fragmentation of the hospitalization and diagnostic labeling experience. Self-stigma refers to the individual response to the negative labeling and oft-accompanied discrimination felt by others (Crocker, 1999). This can include those attitudes and social distance experienced at the hand of mental health professionals (Lauber, Nordt, & Rossler, 2005), which was echoed by the young adults who described feeling as though they were treated as “less than” by inpatient hospital staff in general. Finding natural peers, or others who had experienced psychosis and were returning to navigating young adulthood were perceived as helpful to this process. In addition, learning to be “normal” in social environments again was described as step in overcoming the FEP experience. Young adults described a loss of confidence to interact with the public both related to worries about being further stigmatized by the public and after having not used their social skills in hospital and treatment settings.

Previous studies on stigma and on career development processes of FEP young adults have found that individuals go through similar distinct stages as the young adults in this study. Gove (2004) proposed that the “In-Patient Phase” was characterized by moving through the labeling of “becoming a mental patient,” while the “Post-Patient Phase” was characterized by making sense of the new label when returning to normal societal roles. This staging framework is similar to that in this study. In a similar study on FEP young adults and career processes, Boychuck, Lysaght, & Stuart (2018) found that pre-illness self-concept was temporarily suspended by the decline brought on by the onset of FEP, but that a process of re-engagement followed, during which individuals

were able to regain some of their pre-illness self-concept. The authors also found that social support in combination with labor market realities further directed career development.

### **Implications for Services**

The results of this study have major implications for early intervention programming, as well as for the mental health system in general. These include better targeting of early-onset FEP with an anti-poverty lens, and improvements to the Supported Employment & Education (SEE) model used by early intervention programs that encourage a philosophical shift to primary labor market career planning as opposed to traditionally navigating the challenging world of the secondary labor market.

Next, given the positive effects of locating peers with lived experience and in the usefulness of the YALC as adjunctive support, FEP programming should assist with linking young adults to adjunctive support with an employment and education slant. Finally, this paper calls to challenge the professional discourse from one of accepting disability for this population to one that instills messages to encourage individuals to an employment or education trajectory.

#### **Target early-onset FEP with an anti-poverty lens.**

These findings implicate mental health services in becoming more effective in reducing poverty trajectories for young adults with FEP. Similar to other studies (Boychuck, Lysaght, & Stuart, 2018; Mellor-Marsa et al., 2017), this study found that the earlier in life that the initial hospitalization period struck, the worse the employment/education outcome. Two of three individuals who were not employed nor in education activities had not worked prior to onset during their high-school years. Coincidentally, while in the early intervention program, they did not receive specific, targeted support to enter the labor market nor college as they were recipients of the two-year specialty program at an earlier developmental age.

Special consideration and intervention for those with early onset (before age 18), low family SES, racial and ethnic minority populations, and those not having had working experience prior to FEP onset will allow for targeted engagement of those young people who are not yet on an employment or education trajectory and who may face additional structural barriers related to poverty and discrimination. This includes both training for early intervention programs regarding structural barriers to employment and instilling a social justice ideology for the more vulnerable members of this population, and improvements to employment programming.

Assessment of structural barriers to employment and education should be completed at or shortly after enrollment into the early intervention program so that these become a living part of the participants' treatment plan. Following this initial assessment for an early onset subpopulation, a longer period of engagement should commence, allowing early intervention staff, and employment specialists in particular, the time to motivate these younger individuals while they are receiving other treatments for their symptoms. Additionally, since not all progress will be able to be made during the typical two-year duration of an early intervention program, discharge plans should include individual tasks toward entering education or employment as well as linkages to community sources of support such as college counseling centers and peer support, if expansion of the length of services are not possible.

**Shift Supported Employment & Education (SEE) programming  
to the primary labor market.**

Supported Employment & Education (SEE) is a modified IPS supported employment model intended to target young adults by focusing on both employment and maintaining or initiating formal education (Killackey, Jackson, & McGorry, 2008). SEE employment specialists are integrated within a number of early intervention programs and range from part to full-time in their

dedication to this specialty within a team (Rosenheck, et al., 2017). Baron & Salzer, (2002) have studied causal links between poverty and SMI and implicated the mismatch between the traditional “train, place, support” IPS Supported Employment model and the changes to the labor market that have rendered the secondary labor market inadequate to lift an individual out of poverty.

Additionally, Baron & Draine (2013) called for a “refocusing on primary labor market jobs” within employment programming targeted at those with SMI. A direct entrance into the primary labor market for career development is important, particularly for young adults with mental health disorders who are not negatively impacted by living with years of disability and are poised to do so.

Taking this into account, supported education & employment specialty (SEE) services, as a developmentally appropriate version of the IPS model for early intervention programs, should create engagement plans to work with those NEET (not in education, employment or training) youth with early onset psychosis (Iyer et al., 2018). This includes attention to the first recommendation about targeting NEET youth who present with a first episode with a working knowledge of the adverse impact of structural inequalities on those with disadvantaged backgrounds. Even if symptom severity is the major barrier to returning to employment or education, career planning for earning potential should be a main point of discussion for this group.

These two approaches will impact the professional mental health discourse about employment vs. disability trajectories for those young people who encounter the mental health system at early ages, instilling a sense of positive future-orientation in day-to-day practice of mental health providers, including those in hospital settings. They will also address the 40% of FEP young adults who are not engaging in work or educational activities (Rosenheck et al., 2017) as a normal part of treatment, rather than an afterthought.

**Develop and promote adjunctive peer-based support for FEP programs.**

Adjunctive support such as an advocacy group or other peer-based non-professional social setting offered support to young adults for staying the course, even when unsuccessful at entering the labor market. Included within the natural peer support theme of this study was the function of the Young Adult Leadership Council (YALC), which all participants had at one time been involved with. The YALC was described as a place to gather, be responsible for handling important tasks, a place where young adults could find their own voice, and even practice using their voice through public speaking engagements about recovering from psychosis. The YALC was a gateway to employment or education through its model of peer interaction and was utilized as such even for the individuals who were not actively working nor in educational programs.

Studies on FEP and employment suggest additional adjunctive interventions to assist with maintaining employment (Abdel-Baki et al., 2013; Alott et al., 2013) beyond those provided by early intervention teams. Examples of adjunctive peer-based support exist in the SMI world, the most famous of which was the clubhouse model (Doyle, Lanoil, & Dudek, 2013) which began as Fountain House in New York City, and has been disseminated globally. While the original purpose of Fountain House was to provide a place of social engagement, it morphed into an opportunity for vocational life as well.

Given that early intervention programs are time-limited, the benefits of peer support can last beyond the ending of formal treatment programs. Since formal adjunctive support in natural settings are not routinely available, they will need to be addressed at the community level, possibly through local mental health task force groups that can identify and strategize their development.

**Implement a change in the professional discourse about disability.**

As a final note, while the early intervention programs referenced in this study were described as being very pro-employment and anti-disability to an extent, this is not the status quo of mental health treatment programs in general (Baron & Salzer, 2002). This was evidenced by receiving more traditional messages about disability from the hospital where first response staff likely see people at their worst, and perhaps operate under the more traditional ideology that mental illness leads to permanent disability. The success of many participants in this study in the entry to career settings illustrates that psychosis symptoms which are present and severe at first diagnosis, may not have the same impact on a working/education trajectory within three years and beyond, particularly for young adults.

A change in professional discourse will likely only occur through a disability rights advocacy campaign and subsequent policy development. For example, education on a critical social model of disability in the context of mental health recovery (Drake et al, 2012) would likely challenge lingering notions about disability driven solely by diagnosis. This type of campaign could originate through social media and move through media channels of national advocacy groups. Local mental health task force groups could also provide a formal point of education about the shift in disability ideology to the continuum of mental health service providers in a given community.

**Limitations of the Study**

There were several limitations for this study. This is a cross-sectional study that relied on a single critical case sample drawn from a unique environment. The drawback of starting from a critical case for sampling is the limitation for broad generalization since the group is relatively homogenous through their experience with a specific model of early intervention and their advocacy work. In particular, the study sample is selectively comprised of young adults with FEP that

possessed the capacities 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 the longer a participant had been out of the early intervention program, the more they offered perspectives that had emerged over time, which would not have been the case had this study occurred with participants currently in treatment programs. All participants were functioning high enough to volunteer for the study and complete interviews. Social desirability could have been an issue as those who volunteered wanted to share their story to improve services for future FEP programming. Lastly, this study was retrospective to a degree – participants were able to identify the key moments in their pathways by looking back to past events – and thus lacks prospective data about their future.

### **Implications for Research**

The results of this study indicate that more research is needed on the 40% of FEP young adults who do not enter employment and education following early intervention programming including gaining a better understanding of the ways in which low SES and disability functions as a barrier to re-engagement with the labor market or career track as well as on engagement interventions. A proposed next study design would be an exploratory study on the ways in which this subsection of FEP young adults struggle and try to overcome these barriers to the labor market, and the determinants in the disability trajectory that could be points of intervention. Following this exploratory study, a larger quantitative study that examines these determinants and that can eventually provide knowledge to underpin intervention development is critical. Intervention that enhances the knowledge and ability of early intervention programs regarding the needs of those NEET young people as it relates to their education and labor market liabilities is crucial, leading eventually to intervention testing research. Additionally, longitudinal studies are needed on FEP

young adults and employment and education to assess what helps to “stay the course” in the years post-early intervention programs.

## **Conclusion**

In conclusion, the FEP young adults in this study, described a series of major moments that directed their pathway toward employment, education, or disability trajectories, which were additionally influenced by messages from mental health professionals and service providers. Those with early onset psychosis struggled more than those who had already entered educational settings or held part-time jobs prior to a FEP, as did those coming from a low SES background. Overcoming the hospitalization and medication processes and accompanying self-stigma, were assisted by the location of peers, dealing with issues of ethnic identity, and by encountering early intervention staff who communicated hope and self-determination. Structural realities of the labor market, such as changes in the characteristics of entry-level jobs, meant that more success was found through pursuing a direct pathway into paid employment such as becoming peer support specialists or entering a career track through college channels than working in part-time jobs. Finally, young adults found additional support and practicing of employment skills through their involvement in a leadership council. These collective stories shed more light on the ways in which poverty impacts and can possibly be averted for FEP young adults, including progressive ideals about avoiding the disability trap and underscoring difficulty with initial psychiatric medication processes and program ideology. These conclusions have significant implications for early intervention programs, including targeting early-onset FEP, shifting programming to the primary labor market, promoting adjunctive peer-based support, and challenging the professional mental health discourse about disability. Implications for research include the need to better understand the pathways of the 40% of FEP

who are not in education, employment, or training (NEET) and face additional barriers to accessing employment programs and the labor market after a FEP.

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- Wilkinson, R., & Pickett, K. (2018). *The inner level: How more equal societies reduce stress, restore sanity and improve everyone's well-being*. London: Allen Lane.
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**Shannon (M) Blajeski*****Curriculum Vitae***

University of Washington School of Social Work  
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 Seattle, WA 98105-6299

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**EDUCATION**

PhD	<b>University of Washington</b> PhD Candidate: Social Welfare Dissertation: On the Cusp: Early Psychosis and Employment Trajectories UWQUAL Certificate	April 2019
MSW	<b>University of Washington</b> Blajeski, S. (2005). Young adults with mental illness: An investigation of subjective experience and peer support. Unpublished master's research. University of Washington, Seattle, WA.	June 2005
BA	<b>University of Wisconsin – La Crosse</b> Psychology	June 2000

**AWARDS, HONORS, GRANTS, & FELLOWSHIPS**

J. Scott Briar Dissertation Award	Spr 2018
UW Graduate and Professional Student Senate Travel Award	Fall 2016
Boeing Endowed Fellowship	Fall 2013

**RESEARCH INTERESTS & EXPERIENCE****Interests**

- First-episode psychosis and prevention of negative social outcomes (poverty, unemployment, disability) through early intervention.
- Reducing disparities in psychosocial treatment outcomes within EBPs.
- Qualitative methods and community-based participatory research in intervention development.
- Applying critical frameworks to traditional mental health treatments.

## Experience

### **University of Washington School of Social Work**

Predoctoral Research Associate

April 2016 –

Sept 2017

Conduct literature reviews and synthesize findings on social needs for the SMI population as part of Many Minds Center of Impact in King County. Identify behavioral health educational models at the graduate and undergraduate levels and contribute to BASW and MSW curriculum development for community mental health settings.

### **Portland State University**

**Regional Research Institute**

**EASA Center for Excellence**

Predoctoral Research Study Assistant

Sept 2013 –

Sept 2014

Designed and facilitated study of the Duration of Untreated Psychosis (DUP) with Oregon's Early Assessment and Support Alliance (EASA) program including IRB application, sample recruitment, interviews and grounded theory data analysis using Dedoose software.

### **University of Washington**

**Department of Psychiatry and Behavioral Sciences**

**Division of Public Behavioral Health and Justice Policy**

Consultant and Project Manager

Selected projects include:

#### New Journeys Early-Psychosis Treatment Pilot

Led design, data collection and analysis activities of qualitative study of Washington State's first early-psychosis treatment program in Yakima, WA. Supervised two research assistants in sampling, interviewing and data analysis.

March 2016

– Dec 2016

#### PACT (Program for Assertive Community Treatment)

Provided ongoing technical assistance to teams in ACT model, Supported Employment, Motivational Interviewing, Integrated Dual Disorder Treatment and Illness Management & Recovery. Complete team fidelity evaluations with new Tool for Measurement of Assertive Community Treatment (TMACT).

Aug 2008 –

Dec 2018

#### Illness Management & Recovery (IMR) Pilot Project

Lead trainer and consultant to three IMR pilots in the Yakima, WA area. Collect and interpret yearly outcomes.

2011-2013

**University of Washington**  
**School of Social Work**  
**Behavioral Medicine Research Group**

Oct. 2004 –  
 June 2005

Graduate Student Research Aid

Worked on a four-person research team running two NIH behavioral medicine projects. Responsible for timely scheduling of subject interviews and maintaining database integrity. Assisted with grant preparation.

## **PUBLICATIONS & PRESENTATIONS**

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**Blajeski, S.** & Lindhorst, T. (manuscript in submission). Addressing Social Isolation in Schizophrenia: A Critical Review of Dominant Individual-Level Language and Ideology within Recovery and Evidence-Based Treatment. *Social Science & Medicine*.

**Blajeski, S.**, Marcenko, M., & Schaper, E. (manuscript in preparation). Mental health case management for integrated care teams: implications for social work practice. *Research on Social Work Practice*.

Melton, R. & **Blajeski, S.** (in review). Understanding individual and family experiences associated with duration of untreated psychosis. *Community Mental Health Journal*.

Leickly, E., McDonell, M., Monroe-DeVita, M., Peterson, R., Oluwoye, O., Hughes, M., **Blajeski, S.**, Roskelley, J., Kopelovich, S., Moore, C. & Blair, T. (2017). Washington State New journeys program for young adults experiencing first episode psychosis: pilot results. *Schizophrenia Bulletin*, 43(Suppl1), S258.

Pruitt, A. & **Blajeski, S.** (2016). Data trends: seeking help for family members

experiencing their first episode of psychosis. *Focal Point*, 30, 16-18, Pathways Research & Training Center: Portland State University, Portland, OR.

Sale, T. & **Blajeski, S.** (2015). Steps and decision points in starting an early psychosis program: information guide. *National Association of State Mental Health Program Directors*.  
[https://www.nasmhpd.org/sites/default/files/KeyDecisionPointsGuide\\_0.pdf](https://www.nasmhpd.org/sites/default/files/KeyDecisionPointsGuide_0.pdf)

Manthey, T., **Blajeski, S.**, Monroe-DeVita, M. (2012). Motivational interviewing and assertive community treatment: A case for training ACT teams. *International Journal of Psychosocial Rehabilitation*. Vol 16(1) 5-16.

## Presentations

**Blajeski, S.**, (2018, October). On the cusp: Early Psychosis, Employment & Disability. IEPA 11<sup>th</sup> Annual Conference on Early Intervention in Mental Health, Boston, MA.

**Blajeski, S.**, Devylder, J., Lukens, E, & Wotjiak, J. (2017). Preventing severe mental illness: a grand challenge for social work. Society for Social Work & Research Conference, New Orleans, LA.

**Blajeski, S.** & Melton, R. (2016, October). A model of DUP in Northwest Oregon, USA: recognition, interpretation and intermediaries. 10<sup>th</sup> Annual International Early Psychosis Association Conference. Milan, Italy.

**Blajeski, S.** (2016, January). Schizophrenia, social networks & community life: an analysis of the discourse of recovery and treatment. 20<sup>th</sup> Annual Society for Social Work and Research Conference. Washington D.C.

**Blajeski, S.** (2015, March). Does recovery discourse impact the social aspect of living with schizophrenia? 19<sup>th</sup> International Congress on Psychological and Social Approaches to Psychosis. New York, NY.

Melton, R. & **Blajeski, S.** (2014, November). Understanding individual and family experiences associated with duration of early psychosis (DUP). International Conference on Early Psychosis. Tokyo, Japan.

**Blajeski, S.**, Ray, A. & Aubol, G. (2013, June). Illness Management & Recovery (IMR). Washington State Behavioral Healthcare Conference. Yakima, WA

**Blajeski, S.** (2013, May). Community assessment and EBP implementation:

Illness Management & Recovery (IMR) & Integrated Dual Disorder Treatment (IDDT). Seattle Implementation Research Conference. Seattle, WA.

**Blajeski, S.** & Monroe-DeVita, M. (2011, May). Implementing EBP's in ACT: Training and Technical Assistance. Assertive Community Treatment Association National Conference. Huntington Beach, CA.

## Invited Talks:

University of Washington Disability Studies Program – *Graduate Student Roundtable* – May 2019

University of Washington School of Social Work – Advanced Social Work Research & Evaluation, *Qualitative Data Analysis*, April 2017

University of Washington School of Social Work – Child & Adolescent Mental Health, *Early Intervention for Psychosis*, February 2017

University of Washington School of Social Work – Advanced Recovery Practice, *Early Intervention for Psychosis*, April 2016.

University of Washington School of Social Work – SOC W 505 – Foundations of Social Welfare Research, *Understanding Individual and Family Experiences Associated with Duration of Untreated Psychosis*, February 2015.

## TEACHING INTERESTS & EXPERIENCE

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### Interests

- Evidence-Based Practice in Social Work
- Applied Research Methods
- Historical Foundations of Social Welfare
- Historical and Sociological Foundations of Mental Illness in the U.S.

### Experience

Sole Instructor – 20 MSW students – *Foundations of Social Welfare Research* – Winter 2019

Sole Instructor – 40 BASW students – *Evidence-Based Practice in Social Work* – Winter 2018

Sole Instructor – 40 BASW students – *Evidence-Based Practice in Social Work* – Winter 2016

Sole Instructor – 22 MSW students – *Foundations of Social Welfare Research* – Fall 2015

Sole Instructor – 23 MSW students - *Advanced Social Welfare Research and Evaluation* – Spring 2015

Teaching Practicum – 25 MSW students - *Historical and Intellectual Foundations in Social Work* – Fall 2014

Teaching Assistant – 40 BASW students – *Evidence-Based Practice in Social Work* – Winter 2014

Teaching Assistant – 40 BASW students – *Evidence-Based Practice in Social Work* – Winter 2013

Trainer – *Mental Health First Aid* – various locations – 2009 – 2012

Trainer & Program Manager – *Co-Occurring Disorders Case Management Training Academy* – 2009 – 2011.

## COMMITTEE WORK

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Health Sciences Library Committee, University of Washington 2015-2017

Doctoral Students Social Justice Committee, University of Washington 2016-2018

## ADDITIONAL PROFESSIONAL EXPERIENCE

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SAMHSA – Peer Grant Reviewer

April 2018

Reviewed six homelessness mental health grants.

**SAMHSA – Peer Grant Reviewer** May 2017

Reviewed four Integration of Behavioral Health and Primary Care grants.

**SAMHSA – Peer Grant Reviewer** June 2013

Reviewed six Homelessness-to-States grants.

**Dartmouth College - RAISE Grant** October 2009

Member of clinician panel reviewing new project targeting young adults with psychosis.

**SAMHSA – Peer Grant Reviewer** July 2009

Reviewed six grants for Integration of Behavioral Health and Primary Care.

## CLINICAL SERVICE EXPERIENCE

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**Downtown Emergency Service Center** Aug. 2005 – March 2007  
*Intake Specialist & Mental Health Case Manager* Seattle, WA

**Sound Mental Health** Sept. 2004 – June 2005  
*MSW Counseling Intern* Seattle, WA

**Oregon State Hospital-Portland** Dec. 2003 – June 2004  
*MSW Intern* Portland, OR

**Outagamie County Community Support Program** Dec. 2001 – July 2002  
*Mental Health Technician* Appleton, WI

**CareerPros, Inc.** Aug. 2000 – Aug. 2002  
*DHS Employment Specialist/Resource Specialist* Oshkosh, WI

**Pnuma Healthcare, Inc.** June 1999 – Dec. 2001  
*Tenant Assistant* Neenah, WI

## REFERENCES

Dr. Gunnar Almgren, PhD  
Professor  
School of Social Work  
University of Washington

Dr. Taryn Lindhorst, PhD  
Associate Professor  
School of Social Work  
University of Washington

Dr. Greg Townley, PhD  
Assistant Professor  
Department of Psychology  
Portland State University

Dr. Robert Mugerauer, PhD  
Professor  
College of Built Environments  
University of Washington