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# Measuring Success in First Episode Psychosis

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Measuring Success in First Episode Psychosis

by

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requirements for the degree of

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### **Abstract**

The first experience of psychosis can be hugely disruptive to a person's life. If left untreated, psychosis can gravely impact the long-term wellbeing and functioning of the person. In the last ten years in the U.S., the rise of the Coordinated Specialty Care (CSC) model for treating First Episode Psychosis is a hopeful development for addressing the unique challenges of those experiencing psychosis. The CSC model can potentially improve long term quality of life outcomes amongst people experiencing psychosis. There have been a range of empirical studies typically conducted at the state level that show a positive range of outcomes for participants that engage in the program. However, the rapid implementation of these programs and the use of slightly different models and components leaves challenges for accurately determining how effective these programs are. There are also a lack of qualitative studies that center the voices of the participants themselves. To determine potential areas of improvement within CSC programs, I conducted a scoping review of the literature to answer the following research questions: As described in the empirical research literature, what is the efficacy of Coordinated Specialty Care programs for treating first episode psychosis? As described by participants, what is the efficacy of Coordinated Specialty Care programs for treating first episode psychosis? Are there discrepancies between the empirical research literature and first-person accounts of participants? This scoping review highlights current scholarship on the efficacy of CSC programs within the United States and locates gaps in research and practice that could better these programs through additional research.

*Keywords:* coordinated specialty care, first episode psychosis, fep, csc, psychosis, early intervention

## **Introduction**

Ryan's transition from adolescence to early adulthood was marked with many challenges that his peers were unfamiliar with. He was no stranger to community mental health programs and had been seeing therapists and psychiatrists since he was 12. He had received a slew of mental health diagnoses including major depressive disorder, generalized anxiety disorder and most recently, bipolar disorder. Despite this, he kept a circle of close friends and did well in school. He graduated high school despite the challenges he faced and went on to attend his first term at college. It was here that Ryan began experiencing a shift in his perception that made it extremely difficult to fulfill the many new responsibilities and obligations of living on his own and attending class.

Ryan was forced to return home after his mental and physical health continued to decline. His parents noticed a shift in his personality and became very concerned for his well-being. Ryan returned to the community mental health center. His old diagnoses were reexamined, and he began taking medication prescribed by his psychiatrist. Despite treatment, Ryan's symptoms persisted and his health continued to decline. Ryan's many goals he had after high school began slipping away, and he became more isolated and stopped seeing his friends. Ryan began to see a new therapist that had heard of a program specifically designed for treating psychosis which seemed to match Ryan's symptoms. The therapist made a referral for him to complete an intake assessment.

Ryan met the qualifications for the program, received a diagnosis of first episode psychosis and got connected with the many services offered-- such as a job coach, a new therapist, a psychiatrist, and a peer mentor. Ryan's family also attended groups and educational sessions on psychosis. Ryan agreed to a low dose of medication and began attending groups and

appointments regularly in collaboration with his family. Ryan enrolled at the local community college and reconnected with his friends and made new connections within the program with his peer mentor and fellow participants. Ryan was encouraged by his progress, but he still encountered challenges related to his diagnosis and worried about how well he would do when he timed out of the program in a year and a half.

Psychosis is a condition that disrupts a person's perceptions and thoughts and makes it challenging for them to tell the difference between what is real and what is not. Symptoms can include delusions, hallucinations, trouble thinking clearly or concentrating, and behavior that is not appropriate for the situation. Schizophrenia, schizoaffective disorder, delusional disorder or even major depression and bipolar disorder can carry psychosis as a symptom. The first onset of symptoms typically occurs in people between the ages of 16 and 30, but it can happen at any age. First episode psychosis (FEP) is considered the early period of psychosis that occurs from the first onset of symptoms up to 5 years (SAMSHA, 2019).

It is estimated that 100,000 young people experience FEP every year. Given the time of life in which it typically occurs, first episode psychosis can present major problems for young people transitioning into adulthood. It can disrupt participation in school and work and also negatively impact social and family engagements. The longer it is left untreated, the greater the likelihood of the person experiencing hospitalization or legal challenges (Heinssen, 2014). The financial cost of psychotic disorders is estimated at \$155 billion within the United States annually (Westfall, 2020).

Due to lack of community education about psychosis and its varied symptoms, it can be difficult for those experiencing initial symptoms to be accurately diagnosed and enter a treatment program that is appropriate and effective for treating first episode psychosis. To address this

problem and improve quality of life and long-term outcomes for those experiencing FEP, programs designed specifically for treating FEP, known as Coordinated Specialty Care (CSC) programs in the United States, began to arise in the early 2000s at a grassroots community level. These programs typically offer the following components: supported employment and education, family therapy and support, peer support, case management, individual therapy, skills training, group therapy, skills training, and medication management. In the mid-2000s, several trials in the United States were conducted to test the efficacy of these programs. On the whole, they were shown to improve employment outcomes, education participation and reduction of symptoms. As a result of this, federal funding was issued to aid in implementing these programs nationwide. CSC programs have grown exponentially as a result of funding and empirical studies showing their effectiveness. In 2008 there were 12 programs nationwide and in 2016 there were 162 (Read & Khort, 2021).

The rise of the Coordinated Specialty Care model in the United States for treating First Episode Psychosis within the last 10 years is a hopeful development for addressing the unique challenges of those experiencing psychosis and potential for improving long term quality of life outcomes amongst this population. There have been a range of empirical studies, typically conducted at the state level, that show positive outcomes for participants that engage in the program. However, the rapid implementation of these programs and the use of slightly different models and components makes it difficult to determine how effective these programs are. There are also a lack of qualitative studies that center the voices of the participants themselves. To determine potential areas of improvement within CSC programs, I conducted a scoping review of the literature to answer the following research questions: As described in the empirical research literature, what is the efficacy of Coordinated Specialty Care programs for treating first episode

psychosis? As described by participants, what is the efficacy of Coordinated Specialty Care programs for treating first episode psychosis? Are there discrepancies between the empirical research literature and first-person accounts of participants?

## **Background**

The initial presence of psychosis often indicates the emergence of a persistent mental illness such as schizophrenia, schizoaffective disorder, or bipolar disorder that is associated with cognitive challenges and poor social functioning, which leads to poor quality of life in the long term. The rationale of early intervention programs such as CSCs is to shorten the duration of untreated psychosis (DUP) and thus to improve functional outcomes amongst this population. It has been shown that shortening DUP within the first five years, and preferably within the first 74 weeks, has the most substantial effects on positive functional outcomes (Dixon et al, 2018). Early intervention programs specific to treating first episode psychosis began to appear in the United Kingdom, Denmark and Australia over twenty years ago, with empirical studies showing positive outcomes for efficacy (Dixon et al, 2018). The United States lagged behind other countries in program development due to lack of policy measures and necessary funding. Despite this, early intervention programs in the United States such as the Early Assessment and Support Alliance (EASA) began to take shape at the community grass roots level in the early 2000s. The first empirical studies of the small number of programs in the United States began to be published from 2012-2015. With efficacy being shown abroad as well as in the states, the federal government mandated that 5% of the mental health block grant go to support implementation of CSC programs in existing community mental health settings (Read & Khort, 2021).

At nearly the same time that the block grant allotment was mandated, the National Institute of Mental Health (NIHM) published the first randomized controlled trial of early

intervention programs in the United States. This was known as the Recovery After an Initial Schizophrenia Episode (RAISE) study. The trial tested the Navigate CSC model, where Coordinated Specialty Care gets its name, and is applied when referring to early intervention programs in the United States. The Navigate model incorporated 4 components: psychopharmacology, individual resilience therapy, family therapy/psychoeducation, and supportive employment and education. The study implemented the Navigate model in 17 non-academic community mental health settings in 21 States. It compared outcomes at two years in a CSC to two years at a previously existing community mental health setting at 17 locations. At the two year mark, CSC showed improvements in quality of life, symptoms, engagement in treatment length, and improvement in engagement of work and school (Dixon et al 2018). As a result of the findings of this study and the feasibility of implementing Navigate in existing community mental health settings, the block grant allotment was increased to 10% in 2016 and then renewed in 2017 (Read &, Kohrt 2021).

As a result of a funding mechanism and a model that can be replicated in community mental health settings, CSC programs in the United States have expanded rapidly. They went from 12 Programs in 2008 to 162 in 2016 (Read & Khort, 2021). A number of empirical studies have examined the efficacy of these programs, typically at the state level. There have also been a number of fidelity studies and tools that have been developed to try to improve outcomes and accuracy of what components are accounting for positive outcomes. Despite this, there are many variations of CSC programs in the United States that have similar components but vary in program length, qualifications for entry, and discharge planning. As a result of this, it is challenging to attribute positive outcomes to specific intervention components. There is also a lack of qualitative data that centers the voice of the participant in assessing measures of efficacy.



**Reflexive Statement**

I became interested in this topic through working in a group home that served as a step down program for individuals under the jurisdiction of the Psychiatric Security Review Board. These were people who had plead guilty except for insanity for felony crimes and entered this program with the ultimate goal of community integration and more independent living rather than serving out their sentence in an institution. Many of the individuals were diagnosed with schizophrenia which carried psychosis as a symptom. I became interested in the experiences of their earlier lives and what would be required to prevent the effects of institutionalization. Many of the individuals with whom I worked expressed displeasure with their required strictly regimented lives, medication adherence, clinical mental health services and groups. They formed strong connections amongst themselves.

I was aware of an Early Intervention Program in Central Oregon known as EASA. (Early Assessment Support Alliance). I became very interested in this program because I could see the potential for positive life outcomes for people experiencing psychosis if it was treated early. I remembered how the individuals at the group home did not feel as though they were benefiting and were frustrated with some of the services designed to treat their mental health and other co-occurring disorders. They felt as though they were jumping through hoops to complete the program and were required to continue despite not feeling the benefit from the treatment or having options for different providers. They seemed to gain strength from forming connections with their peers who had similar life experiences.

These experiences encouraged me to look deeper into early intervention programs specific to treating First Episode Psychosis, as I could see how persistent mental illness related to psychosis can have detrimental impacts to quality of life. I think about the experiences of those

in the group home and the systems they had to navigate such as jails, prison, and the state hospital and how their lives may have been positively impacted if they received treatment and education earlier. Another thing that stuck with me was that in spite of the many mental health services they were mandated to partake in, the connection amongst themselves seemed to provide the most hope in challenging times. This has led me to take note of the peer connection component that is emphasized within some CSC programs.

## **Methods**

This thesis is a limited scoping review of the available literature to determine the efficacy of CSC programs in the United States using three databases available to me. This scoping review seeks to map the available literature and determine gaps in research and practice.

## ***Research Questions***

The way I conducted research and thematic analysis was guided by the three following research questions: As described in the empirical research literature, what is the efficacy of Coordinated Specialty Care programs for treating first episode psychosis? As described by participants, what is the efficacy of Coordinated Specialty Care programs for treating first episode psychosis? Are there discrepancies between the empirical research literature and first-person accounts of participants?

## ***Search Strategy***

A search of the Pubmed, Psycinfo and Portland State University Library databases was conducted. I also located literature within the Substance Abuse and Mental Health Services Administration (SAMHSA) and National Institute of Mental Health (NIMH) websites to provide additional background information and definitions specific to first episode psychosis and coordinated specialty care programs. The data bases were recommended from a social work and

social services librarian as they would be most relevant for my topic. The SAMHSA and NIMH were chosen because SAMHSA administers block grant funding to CSC programs and the NIMH standardized the CSC model through their RAISE study and implementation of the Navigate program.

I searched for two terms “Coordinated Specialty Care” and “First Episode Psychosis.” I chose to search for “Coordinated Specialty Care” as a way to limit the scope of the articles to the United States, as CSC is used specifically within the US and was piloted as part of the RAISE study. “First Episode Psychosis” was chosen to access material that was specific to this population and the intervention systems that are used to treat them. All articles that were located and met the initial criteria were stored in the Mendeley reference database. Mendeley is a citation management program that checks for duplicates and is useful for generating bibliographies and citations.

### ***Eligibility Criteria***

The general inclusion criteria for this thesis were: 1) studies occurred from 2000 to 2022, 2) within the United States, and 3) contained at least three treatment interventions specific to treating FEP. The rationale for including studies from 2000 on was that the first program that resembled a CSC program, the Portland Identification and Early Referral and Resilience Program in Maine, was implemented in 2000 (Read & Khort, 2021). Studies that occurred within the United States were included due to the focus of efficacy of CSC programs specifically. Studies had to include at least three components specific to treating FEP to make sure they fell within the parameters for what could be considered a CSC program.

The criteria for including quantitative articles specifically was that they were empirical, used measurement tools, and were reproducible. The additional criteria specifically for qualitative articles was that they included the voices of the stakeholders group: staff members, family members, and ideally, participants themselves.

Selection criteria for exclusion from the scoping review included: 1) programs that are focused on a single component such as therapy or medication, 2) programs that treat psychosis but not FEP specifically, and 3) programs that are located outside of the United States.

### Screening process

Step 1 of the screening process was to scan the titles of the studies for relevance. I created an Excel spreadsheet that broke the results of each database into quantitative and qualitative sections. This assisted me in keeping track of what I had analyzed and where it had come from.

Step 2 of the screening process was to read the abstracts of the articles. If inclusion criteria were met I uploaded the article into the Mendeley database. As articles were uploaded I checked for duplicates by seeing which articles were already stored in the database. Duplicates were excluded.

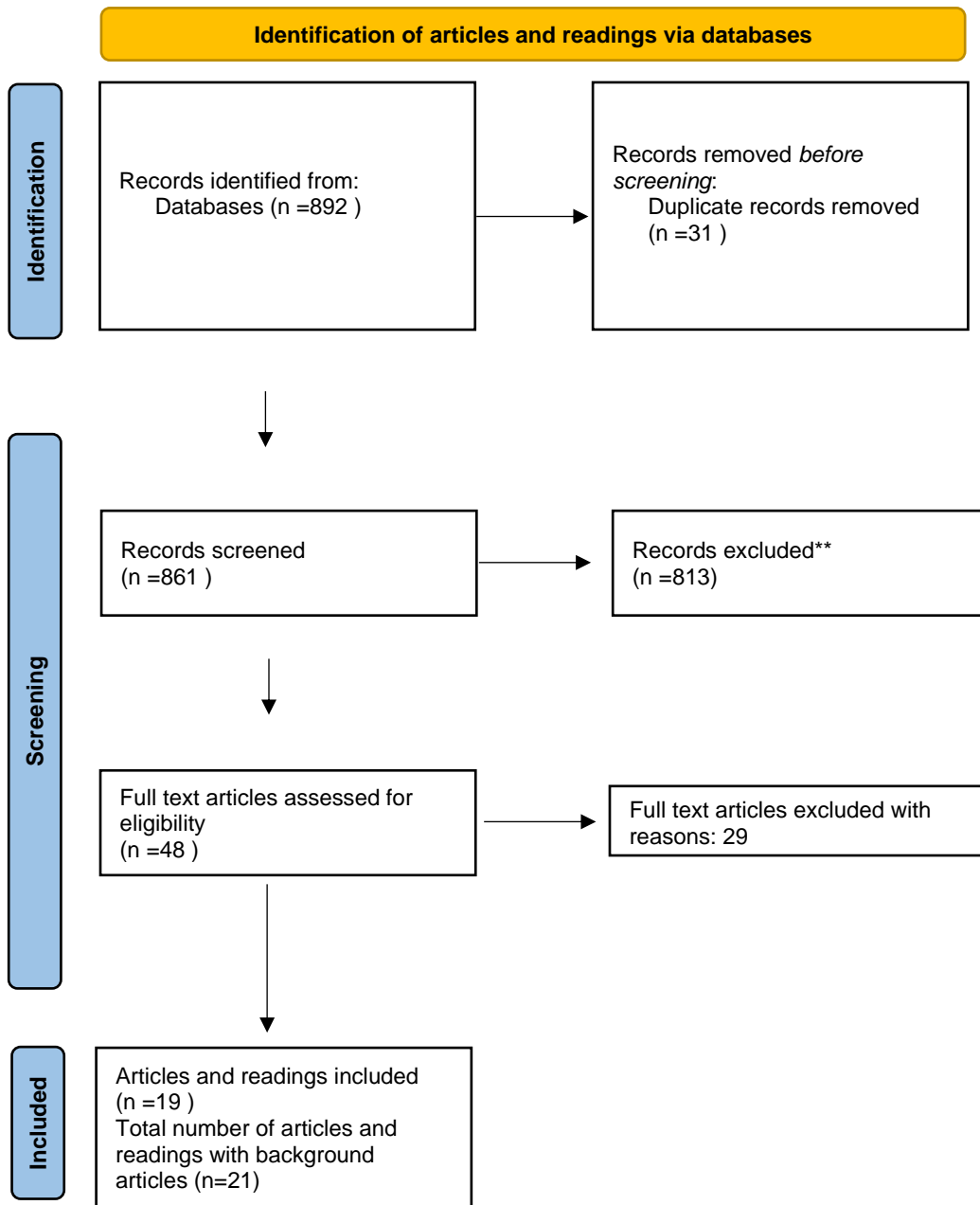
Step 3 of the process was to skim the entirety of the articles. A separate spreadsheet was created for the skim process with notes on the articles to highlight what they contained, and important information relevant to thematic analysis.

Step 4 was to make the final selection and print out the articles for a full read including thematic analysis. Several articles were weeded out at the final stage as I missed certain exclusion criteria such as some data occurring outside of the United States or evaluating only one component of the program. For the final selection I made a word document for each article that included categories such as title, year, methods, outcomes and notes among others. This was to

assist in the final analysis and make it easier to reference articles without needing to scan through them.

### ***Thematic Analysis***

Once I completed the full read to determine final inclusion and exclusion of articles, I developed a system for completing the thematic analysis. I assigned a highlighter color to each theme to be further explored: green for measures of success, pink for flexibility in program length, yellow for stigma/assuming the role of the patient, orange for the importance of natural support and success, and finally, blue for gaps in practice and research. I then completed a thorough re-read of each article, highlighting themes as I came across them and making notes to reference them for the thematic analysis. I charted the inclusion/exclusion process using a Prisma Flow Diagram that is located on the following page.



From: Page M.J., McKenzie J.E., Bossuyt P.M., Boutron I., Hoffmann T.C., Mulrow C.D., et al. (2021) The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 372:n71. doi: 10.1136/bmj.n71

## **Findings**

The database search yielded a result of 892 articles and readings relevant to the topic of first episode psychosis and coordinated specialty care programs. Removing duplicate articles left 861 articles and readings. During the screening process 813 articles were excluded due to the title, abstract and other information lacking relevance to the topic. This left 48 articles to read. After full text articles were read and analyzed, 29 articles were excluded due to not meeting inclusion criteria such as occurring outside of the United States, focusing on a specific treatment and not having a qualitative focus related to CSC programs. This left 19 articles to be included in the final analysis. I included one article from SAHMSA and one article from NIHM for background information. The final number of articles included in this review was 21.

## ***Themes***

**1. Measures of Success in Coordinated Specialty Care.** In analyzing both the quantitative and qualitative studies evaluating CSC programs, the common measures for determining outcomes that show up consistently were: 1) rates of engagement with school and work, 2) rates of hospitalization, 3) medication adherence, 4) service engagement, and 5) symptom presentation. Quantitative studies evaluate a range of common outcomes while qualitative studies tend to have a narrower focus on outcomes and information with the exception of one study that looked at a range similar to quantitative material. Quantitative studies use a range of measurement tools with data being collected by employees most typically in intervals of three months up to one year. Qualitative used interviews to answer questions pertaining to the focus of the study.

Quantitative studies have very similar measures throughout; they often employed similar evaluation protocols, many of which have stemmed from the RAISE trials. They also show

similar outcomes: 1) a drop in hospitalization rates, 2) reduction in symptoms, 3) increased medication adherence, and 4) increased school and work engagement. The majority of the studies measured outcomes at baseline upon program entry and proceeded in three month increments up to one year. A common challenge was in retaining participants long enough to complete outcome measurements past one year of program participation.

Qualitative studies tended to incorporate some similar measures of success but typically focused on one to two measures rather than a battery as found in the quantitative studies. Measures explored were program engagement, decision making, experiences prior to CSC engagement, work and education participation, discharge planning, family member experiences, and stigma. As the methods of the studies took the form of interviews, the results were more challenging to measure directly compared to quantitative studies, but they highlighted nuance and pulled apart individual components of CSC programs to explore program efficacy more in depth. An example of this was in one study, participants were asked what changes occurred, which were most important, and how this change was enacted. The most common category of change was a reduction in symptoms and the most commonly cited cause of changes experienced was participation with clinicians such as therapists or other team members (e.g., psychiatrists and peer specialists) (Daley et al, 2020).

Quantitative studies always incorporated more than one CSC program, were typically within the same state, and had similar funding mechanisms typically in the form of the mental health block grant. They most frequently occurred across a range of service settings like community mental health centers, universities, and hospitals. Some occurred using the same implementation model (such as RAISE), while others incorporated different implementation



models but offered a range of common CSC services. All quantitative studies examined similar programs, and none took the form of a randomized controlled trial.

Qualitative studies always included one or more participants from a group of “stakeholders” including program participants, staff (from clinicians to administrators), and family members. Three studies centered the voices of program participants alone. Three studies included participants alone, one included family members alone, one included participants and staff, two included participants and family, and two studies included family and staff.

**2. Flexibility in program length.** The majority of the CSC programs evaluated had a program length of 2-3 years. There is some contention within the studies for what an ideal program length would be based on the initial and ongoing needs of participants. Large variation among participants with regard to initial functioning and ongoing needs were cited as reasons for flexibility within program lengths. A lack of discharge planning and options also appeared in studies and factors into program lengths.

A challenge that was well highlighted throughout quantitative articles was service engagement and attrition before the suggested length of 2-3 years. These articles typically exhibited 30% disengagement rates before the program timed out (e.g., Dixon et al, 2015). This made it challenging to collect data beyond one year of program engagement. An explanation for this rate of attrition rate was different severity of psychosis among participants and those with less needs timed out of the program sooner as they did not need services for the full duration. Another explanation was that people with more social support tended to engage at higher rates, which would indicate that lower social support would equal lower rates of engagement (Marino et al, 2015).

There was mention of needing to remain flexible in treatment length as people experiencing FEP have a different level of needs based on severity of symptoms, natural supports and baseline functioning. One side of the argument is that too much treatment could increase dependency on services and contribute to the person engaging feeling like a patient not participant (Jones et al, 2020). The other side of the argument is that CSC services would be more useful if extended to 5 years (Dixon et al, 2018). Another topic within the literature examined was continuing CSC specific services on an as needed basis past the date of completion depending on the needs of clients (Jones et al, 2020).

One qualitative article explored discharge planning within CSC programs. There were not uniform measures implemented across the programs and it was shown that services were lacking. Some programs discontinued all services indefinitely despite a remaining need among participants, while other programs were still able to retain some of the same services through therapists and psychiatrists, as they also operated out of the community mental health setting (Jones et al, 2020).

**3. Stigma and assuming the role of the patient.** The stigmatizing effect of being diagnosed with psychosis is discussed in both quantitative and qualitative articles. The concept of stigma and its impacts are presented differently across these two study methods. In quantitative studies, stigma is typically not discussed in depth but measures within CSCs that are intended to counteract stigma are often highlighted. In one qualitative article, by contrast, stigma is discussed at greater length. This study pointed out the way in which stigma is assigned to the participant as part of the process of engaging in treatment and navigating services rendered by CSCs. This article argues that counteracting the effects of stigma can be accomplished through greater levels of peer support and peer advocacy (Blajeski et al, 2021). Both quantitative and

qualitative articles highlight stigma as being potentially detrimental to those experiencing psychosis. A need for further community education on psychosis is presented by both types of studies to combat the effects of stigma.

An undesirable effect that is also related to the process of ascribing a label to a participant is assuming the role of the patient. This is discussed in qualitative studies that address the idea that the length of CSC services should be variable based on the unique needs of the participant. If participants rely too heavily on services and assume the role of somebody who will always need this care, rather than establishing their own identity and desired outcomes, they may be at risk of creating a dependency that inhibits their ability to grow (Jones et al, 2020). It is argued that having a set program length or longer program length could create this dynamic. Another qualitative study referenced the number of participants that were on disability services and how this qualification led to a mindset that they would not be able to return to school and work; this could generate poor long-term outcomes (Blajeski et al, 2021).

In quantitative studies, the impact of stigma on the wellbeing of participants is typically not described at length and is something that is encountered before entering the program. CSC programs are described as emphasizing participant choice and having a collaborative decision-making process to promote independence and support the outcome desired by the participant. Educating the participant and their family members about first episode psychosis is also of great importance. Centering participant choice, independence, and also providing education are all measures that are mentioned as counteracting the impacts of stigma.

On the other hand, qualitative studies, especially the one that took place at EASA in Oregon argues that one experiences stigma once the diagnostic label of psychosis has been placed on people experiencing psychosis-- whether in medical, mental health, or CSC settings.

The effects of stigma can have detrimental impacts especially for those who have goals of gaining/maintaining employment and returning to school (Blajeski et al, 2021). Participants who were interviewed mentioned that they felt they lost social skills after initial diagnosis and treatment and were having struggles readjusting with the new label. Jessica who was an EASA participant expressed her feelings here, “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 lie 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 the situation and try to interact with other people...” (Blajeski et al, 2021, p. 4). Participants believed the experience of having psychosis would hinder them from achieving their vocational goals. Participants said peer support helped counteract the effects of stigma. They were able to connect with peers who had achieved success in school or work settings and saw that it was possible to have this diagnosis and have positive outcomes.

Stigma was referenced in both quantitative and qualitative studies as having a negative impact on participants seeking services initially. The detrimental effects of DUP are also regularly discussed when mentioning barriers to engagement. Community education on psychosis is presented as being an area of focus that would present better outcomes for reducing stigma through education and improving earlier engagement which would decrease DUP and improve long term outcomes.

**4. Importance of natural support and success.** Family support and inclusion and peer support-- often in the form of a peer specialist-- are two components of the CSC model that are referenced as being important to engagement in services as well as supporting positive long-term outcomes. Services including family such as education, therapy, collaborative decision making, and community support are often referenced in quantitative studies (Dixon et al, 2015). Family

involvement is also referenced as being critical to supporting engagement to services while in CSC programs. Qualitative studies focus on the experiences and roles of family members prior to services and initiating services for their loved ones experiencing FEP.

Family members' roles are regarded as crucial within quantitative studies as their involvement with the participant at baseline often indicates better outcomes in several domains. Participants often reside with their family and remain there throughout the CSC program. Family involvement often equates to lower DUP rates, higher engagement of services, and serves as a strong indicator of connection to services after the CSC program times out. Family members are also often the ones that connect the individual to services initially. Those without family are at substantially higher risk for longer DUP (Melton et al, 2020). Longer DUP translates to less service engagement and poor long- term outcomes.

Community participation is not a component within the CSC models regularly mentioned; however, the need for community education on psychosis is noted throughout articles to decrease DUP and increase engagement. One qualitative study examined current CSC involvement in community participation and inclusion. The article argues that community participation is a “medical necessity” to people with persistent mental illness as it can have benefits to physical, mental health, and cognitive outcomes. The article argued for further community participation and found that the stakeholders placed a high value on involvement (Thomas et al, 2021).

Peer support in the form of groups and peer specialists employed through the CSC are not commonly referenced in quantitative studies. One qualitative study that took place at the EASA program in Oregon stresses peer support’s importance in improving vocational and educational outcomes, as having shared experiences combat the effects of stigma. It also discussed how the

Young Adult and Leadership council that is involved in community education, advocacy, and peer support could be beneficial to maintaining positive functional outcomes after the completion of the CSC program (Blajeski et al, 2021).

**5. Gaps in research and practice.** There are numerous gaps in research and practice that are noted throughout this thematic analysis. The first is a lack of fidelity. Many of the quantitative studies used CSC programs that were located in the same state and utilized federal block grant funding. These programs were often located across settings--most typically hospitals, universities, and community mental health settings. CSC programs, according to the RAISE initiative, would be best implemented in existing community mental health settings. Also most of the common CSC services were offered but there was variation within services offered. Program duration also varied. Standardizing implementation such as within the RAISE initiative could improve fidelity.

The second gap is that there were only three qualitative studies that I found that center voices of participants. This is important because it shows that there has been a lack of studies that use the voice of participants to measure program efficacy and highlight gaps that could be improved upon.

The third gap in practice that was located was a lack of discharge planning. There is no design for discharge planning that is recommended for CSC program implementation in the data I collected. One qualitative study was conducted interviewing program staff, participants and family on the topic of discharge planning. Discharge planning varied greatly and was non-existent in some programs. Oftentimes it was a return to community mental health which is shown to have less beneficial outcomes when compared to CSC programs in the RAISE trials.

The fourth gap was lack of community education. Duration of Untreated Psychosis was a theme prevalent in quantitative and qualitative studies. Lack of community education on psychosis and the stigma that resulted created treatment barriers, which decreased program engagement and ultimately led to poorer long-term outcomes.

The fifth gap was program retention and how it impacted quantitative studies. The majority of quantitative studies measured outcomes up to one year despite most programs having a length of two to three years. There was a high rate of attrition amongst program participants. Hypothesized reasons included poor engagement as a lack of family supports and lower psychosis severity.

The sixth and final gap is the lack of randomized controlled trials. The only randomized controlled trial that took place was the RAISE Trial that concluded in 2015. More RCTs would result in more reliable program efficacy data.

## **Discussion**

For this scoping review, I examined available literature on the efficacy of CSC programs for treating First Episode Psychosis in the United States by analyzing quantitative and qualitative data and determining if there are any discrepancies between the two. After eligibility criteria was applied, I located six quantitative studies and nine qualitative studies. Amongst the quantitative studies there was a very similar structure to how they were conducted and methods for determining program efficacy and results. Qualitative studies differed in that they used different groups of stakeholders as participants and often only looked at one to two measures of efficacy or another area of the program experience that was not directly measurable. I used a thematic analysis to explore the measures and common themes within these articles to highlight their similarities, differences, and where the known and unknown gaps in the literature exist.

This scoping review answered the proposed research questions showing efficacy in quantitative studies using specific and replicable measures. Qualitative studies shown impact, but they were less specific in measuring program outcomes. There are considerable differences between the two methods. In exploring these varied measures of success there were known and unknown gaps in research and practice that were highlighted throughout. Quantitative studies highlighted the limitations of measuring efficacy as the variability of program settings, length and specific treatment components. As the CSC model is designed to be implemented in existing community mental health settings with specific components, this variability makes it challenging to determine what components are responsible for positive outcomes. The lack of randomized controlled trials other than the RAISE study also limits reliable data on the specifics of program efficacy. It would be difficult ethically to conduct more RCT trials, as the efficacy of CSC versus community care or other methods is widely shown. Another limitation or gap that is explored is the lack of engagement and program retention to the standard program length of two to three years. Most studies used the final measurement of one year. There seems to be a wide range of hypothesized causes such as lower family involvement, longer DUP times and less need due to higher functioning upon program entry. As engagement is critical to determining efficacy (and also ideal program length and services), more studies would be helpful in this area. A vitally important area that was acknowledged but not well explored was if the positive outcomes experienced during the typical one year of the study were sustained after program completion.

Qualitative studies evaluated specific components of CSC programs or the impact of FEP on stakeholders who were in CSC programs. This included studies that examined the impacts of stigma on vocational outcomes and self-identity while in CSC, differing perceptions of all stakeholders on CSC programs, family member engagement, routes to CSC and stakeholder



perspectives on discharge planning. The nature of these studies being more varied than quantitative methods exposed more gaps in knowledge and practice through more detailed accounts of individual experience while also highlighting a need for more specific qualitative studies to show efficacy for CSC programs on a component by component basis.

Qualitative studies focused on uncovering areas for improvement or gaps such as a need for community education to lower DUP times through better family knowledge in symptom type and recognition. Community education would also have the potential to lower stigma which was another well documented barrier to program entry and positive vocational outcomes. The importance of peer support was also highlighted in combating stigma through having shared experience. Peer support also has the potential to improve long term outcomes especially if support would continue to be used past CSC completion. Qualitative studies showed key differences in how stakeholders viewed the program and for shared decision making to be most effective these varied perceptions would need to be further explored. A very important gap that was highlighted was a lack of uniform discharge planning and step-down practices and a general lack of services post CSC that would be as effective. This poses serious challenges as it is not well researched if the positive impacts of CSC hold and how rates of remission would occur post program.

There were several areas where overlap occurred between the two study methods. These included: the importance of family involvement in connecting to services and engagement during CSC participation, the efficacy of therapy and peer support for improving cognitive outcomes, and a need for further community education for decreasing the impacts of stigma and DUP to improve long term functional outcomes.

## **Practice Implications**

I believe the findings of this scoping review highlight several pressing needs to improve the long-term functional outcomes for those experiencing FEP who use CSC programs.

Challenging areas to address are: 1) ideal program length, 2) discharge planning/care after program completion, 3) increasing community education and 4) adding additional peer support.

There are an increasing number of quantitative program evaluations showing efficacy of components treating FEP. There is a clear lack of qualitative studies exploring participant experience in CSC settings. Highlighting the unique experiences of participants through qualitative studies could help determine what would be most appropriate for program lengths and how to accommodate the varied needs within this population. These studies could also be used to inform discharge planning practices tailored to the unique needs of participants.

EASA has a very interesting model in the Young Adult Leadership Council. I believe exploring expanding peer support groups that also focus on advocacy and community education could improve program practices as well as serve as effective community education from the voice of participants themselves. I believe this would be vital to combating stigma as it would not be from the provider perspective and could encourage program entry/retention and benefits after completion through continued participation.

Further quantitative analysis with studies exploring if CSC programs hold positive outcomes for the duration of the two to three years and beyond completion would also be useful. Determining step down programs and possibly continued service utilization at the CSC seems to be useful for retaining positive outcomes.

**Limitations**

This review was limited due to the use of only three databases, an inability to locate all studies within the search, and time constraints related to finishing my undergraduate degree. I do not believe limiting the search to the three databases captured all of the studies related to CSC programs, especially as studies have increased dramatically since 2016 with the emergence of the block grant and an increase in monitoring outcomes for funding protocols. I located a number of studies that I could not find the full text for in time to complete my thesis. These quantitative studies could have provided more valuable data for determining how success is measured in CSC programs. Finally, my study is limited in its replicability, as I did not provide charts showing commonalities and differences between articles/studies.

**Conclusion**

Coordinated Specialty Care programs have shown to be effective in limiting the pain and suffering of those experiencing psychosis and those involved in their lives. This thesis highlighted some of the gaps in research and practice. Ideally, the results of this scoping review can be used to encourage further research into refining CSC programs to improve outcomes and promote wellbeing for clients during and after program completion.

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