Early Psychosis and the Prevention and Mitigation of Serious Mental Illness

Iruma Bello, Ilana Nossel, and Lisa B. Dixon

Schizophrenia spectrum disorders are psychiatric illnesses with a lifetime prevalence near 1%; they can cause extensive functional impairment and have for too long carried low expectations for recovery (Lieberman et al. 2013). This group of disorders typically includes schizophrenia, schizoaffective disorder, delusional disorder, and schizophreniform disorder. Hallucinations, delusions, and disorganized behavior constitute the hallmark symptoms of these disorders. In 2013, excess total costs of schizophrenia in the United States were estimated at $155.7 billion, including significant direct health care costs but mostly indirect costs related to losses to the labor market (Cloutier et al. 2013).

Specialized early treatment services for first-episode psychosis (FEP), now referred to as coordinated specialty care (CSC) in the United States, emerged during the last 25 years internationally and have proven effective for engaging clients in treatment and improving short-term and possibly longer-term outcomes. CSC can lead to improvements in symptoms, social functioning, quality of life, and treatment satisfaction (Dixon et al. 2018). In this chapter, we will discuss the scientific foundations for CSC, including describing the association between longer duration of untreated psychosis (DUP) and worse short-term and long-term outcomes. We will also describe the essential components of evidence-based CSC treatment and policy factors that led to the unusually rapid dissemination of FEP treatment throughout the United States.

Relationship Between DUP and Outcomes

DUP is defined as the time from onset of psychotic symptoms to effective treatment and is measured in months to years across psychotic spectrum disorders (Kessler et al. 2005). In the United States, schizophrenia-related disorders have an average DUP of over a year (Addington et al. 2015). Longer DUP has been robustly associated with poor outcomes across health-care systems (Howes et al. 2021; Marshall et al. 2005); however, there is not enough evidence to support causality.

Several meta-analyses have consistently indicated the negative relationship between longer DUP and outcomes. A meta-analysis conducted by Marshall et al. (2005) evaluated the relationship between DUP and a range of outcomes including depression, anxiety, social functioning, overall functioning, quality of life, positive symptoms, negative symptoms, rates of remission, time

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I. Bello (✉) · I. Nossel · L. B. Dixon
New York State Psychiatric Institute, Columbia University Vagelos College of Physicians and Surgeons, New York, NY, USA
e-mail: Iruma.Bello@nyspi.columbia.edu; Ilana.Nossel@nyspi.columbia.edu; Lisa.Dixon@nyspi.columbia.edu

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to remission, and relapse at baseline, 6, 12, and 24 months. The meta-analysis reviewed 26 studies with 4490 people over the age of 16 but under 60 with FEP. DUP was defined as the time from psychosis onset to neuroleptic treatment or hospital admission. The mean DUP for all studies was 124 weeks. There were limited significant correlations between DUP and outcomes at baseline (e.g., depression and anxiety, and quality of life); however, at follow-up time points, there were consistent negative correlations between DUP and an array of outcomes which support the idea that longer DUP is associated with worse outcomes. For example, at 6 months' follow-up, longer DUP was significantly correlated with greater levels of positive symptoms, negative symptoms, depression, and anxiety, as well as reduced overall and social functioning, and lower rates of achieving remission. At 12 months' follow-up, longer DUP was significantly correlated with more positive, negative, depressive, and anxiety symptoms, lower quality of life, and lower overall functioning, and individuals with longer DUP were not as likely to be in remission and took longer to achieve remission. While only two studies followed patients for 24 months, the link between longer DUP and greater positive symptoms, poorer quality of life, and overall functioning persisted (Marshall et al. 2005).

Results of the recent National Institute of Mental Health (NIMH) Recovery After an Initial Schizophrenia Episode Early Treatment Program (RAISE ETP) study provide information on the impact of DUP in a US-based early psychosis sample. In this study, DUP was defined as the time between psychosis onset and first-time antipsychotic medication treatment. The study included 404 individuals with first-episode non-affective psychosis between 15 and 40 years of age with a mean DUP of 193.5 weeks and a median DUP of 74 weeks. Using a cluster randomized design, outcomes of 223 participants receiving "NAVIGATE," the CSC program, were compared to 181 individuals receiving usual care after 2 years of treatment. Notably, DUP moderated the effects of NAVIGATE such that individuals with a DUP less than 74 weeks benefitted significantly more on quality of life and symptom measures compared to those with a DUP greater than 74 weeks (Kane et al. 2015).

One of the most recent meta-analyses, which also included an umbrella review of available meta-analyses, examined the strength of the evidence supporting this proposition (Howes et al. 2021). They included 13 meta-analyses derived from 129 studies with a total sample of 25,657 individuals. Across the studies, the relationship between DUP and individual outcomes was classified as convincing, highly suggestive, suggestive, weak, or nonsignificant. Howes et al. (2021) found suggestive evidence for a relationship between longer DUP and more severe negative symptoms and greater chance of previous self-harm. At follow-up, they found highly suggestive evidence for a relationship between longer DUP and more severe positive symptoms, more severe negative symptoms, and lower chance of remission. There was suggestive evidence for a relationship between longer DUP and poorer overall functioning and more severe global psychopathology. Importantly, the effect sizes found in this meta-analysis were clinically meaningful. Using statistical analyses, the researchers were able to create a predictive model which calculated that a DUP of 4 weeks predicted >20% more severe symptoms at follow-up relative to a DUP of 1 week. This suggests that delaying treatment by 3 weeks would be associated with symptom outcomes that are 20% worse, and as the delay in treatment increases, so does the worsening of the outcomes.

One longitudinal study (Jonas et al. 2020) analyzed 20-year follow-up data for a cohort of individuals diagnosed with schizophrenia spectrum disorders. In their data, individuals, in general, had markedly deteriorating functioning either before or after hospitalization or treatment; DUP did not impact longer-term outcomes. The study has been critiqued because of the limited nature of the sample as well as the lack of adequate treatment provided after admission (Woods et al. 2020). Further investigation is needed.

Notwithstanding the study conducted by Jonas et al. (2020), evidence for the association between DUP and outcome is robust. At the same time, as mentioned before, a causal linkage has not been firmly established, and it is clear that more studies are necessary to fully understand the extent of any causal relationship between DUP and outcomes. In addition to understanding the causal relationship between DUP and outcomes, the ability to intervene early and reduce DUP is of paramount importance. In FEP, these delays to care can have detrimental consequences. Not only do they occur during periods of highest risk for self-harm and aggression, but even in the most stable circumstances, navigating the fragmented US mental health system and experiencing delayed access to the right treatment lead to increased suffering, trauma, and despair for youth and families who are trying to make sense of and cope with these experiences (Dixon et al. 2018). There is also evidence that the impact of social inequities and scarcity of resources for some groups compounds these delays.

Impact of Social Determinants of Mental Health Care on Pathways to Care in Psychosis

Many studies have attempted to elucidate the pathways to care for individuals with early psychosis. Cabassa et al. (2018) conducted a qualitative study to specifically examine pathways to care from symptom onset to CSC in individuals with nonaffective psychosis in the RAISE-Implementation and Evaluation Study (RAISE-IES). They were able to identify factors that shaped facilitators and barriers to care along the pathway. Their model illustrates the relationship between family, client, and health-care system factors and how these factors impact help-seeking decision-making and in turn may contribute to shortened or lengthened pathways to care. During the emergence of psychotic symptoms, the ways in which clients and families make sense of symptoms, level of stigma experienced, and ideas about self-reliance influenced help-seeking behaviors particularly, given the uncertainty that permeates all aspects of the experience. For example, during this initial phase, individuals and families are unfamiliar with symptoms, therefore making it difficult to accurately recognize them and the effects they are having on the young person's life. Individuals and their families also lack information and clarity about where and when to seek help, all of which can serve to delay engagement with treatment. Even when individuals and families connect with mental health services, Cabassa's model suggests that the pathway can be delayed if individuals and families have negative experiences and receive poor care, which is characterized as receiving poor treatment marked by inaccurate evaluations, feeling trapped in a hospital, receiving little information about treatment options and side effects, families feeling ignored or alienated during the process, not being referred to expert providers, and poor care transitions particularly from inpatient to outpatient settings (Cabassa et al. 2018). All of these experiences can be traumatizing and prevent the person and family from engaging further with mental health services.

The relationship between risk for psychosis, social determinants of health, and DUP is complex and worth examining. In communities of color, henceforth referred to as BIPOC (Black, Indigenous, and People of Color), pathways to care are delayed even more due to social and environmental inequities experienced across the life span conceptualized as social determinants of health. Social determinants are defined as community and population-level economic and social conditions that negatively impact people's behaviors, limit help-seeking, and are associated with poor access to care (Compton and Shim 2014). At the societal level, they can include prejudice, discrimination, and social exclusion based on race, ethnicity, and sexual orientation. At the environmental level, they can include factors such as unemployment, housing instability, and food insecurity. Elevated risk factors experienced by BIPOC communities are typically associated with increased risk of mental illness and a worsened, more persistent illness course (Compton and Shim 2014).

At the neighborhood level, disparities create increased stress as individuals in BIPOC communities struggle to meet basic needs and have limited access to opportunities. This environmental stress may be a driver for increased risk of psychosis; particularly given the established association between stress, adverse childhood events, and schizophrenia (Rosenberg et al. 2007). For instance, studies have found that immigrant communities are at greater risk of developing schizophrenia and other psychotic disorders compared to native-born communities possibly due to socio-environmental factors, such as urbanicity, discrimination, or socioeconomic deprivation (Bourque et al. 2011). Narita et al. (2020) examined the relationship between social stressors in the neighborhood setting as a risk factor for psychotic experiences in a general population sample of individuals residing in New York City and Baltimore. They specifically focused on perceived neighborhood disruption and gentrification. Results indicated that individuals who perceived greater neighborhood disruptions (i.e., characterized as feeling pushed out of the neighborhood, perceiving a disruption of social ties and neighborhood connections, and observing changes to the sense of community in the neighborhood) tended to endorse psychotic-like experiences more often than other members of the community. However, they did not find significant differences for the gentrification construct. Anglin et al. (2020) examined whether perceived ethnic density from childhood was associated with psychotic-like symptoms in a sample of young urban adults. Results indicated that individuals from racial and ethnic minority groups raised in neighborhoods perceived as primarily racially or ethnically different from their identity tended to report higher rates of psychotic-like experiences compared to individuals raised in White, mixed, or racially concordant neighborhoods.

In terms of diagnosis of psychosis, there is evidence that individuals from Black and Latinx communities are disproportionately diagnosed with psychosis, and this is in part due to clinicians misinterpreting and misattributing the clinical presentation (Schwartz and Blackenship 2014). We use Latinx as a gender-neutral term to describe the heterogenous group of people living in the United States of Latin American origin or decent. In the United States, BIPOC communities which have faced sustained systemic racism are under-resourced, segregated, and disenfranchised. Community members live under stressful conditions that limit their ability to overcome poverty and have limited access to stable housing, health care, and education. Frequently they experience increased discrimination and are exposed to higher rates of violence, all of which are associated with decreased access to care and poorer health outcomes (Feagin and Bennefield 2014). Studies have found structural disparities experienced by racial and ethnic minoritized groups such as limited access to care, lack of insurance coverage, and experiences of implicit bias when engaging in care (Alegría et al. 2007). As such, it is probable that all of these disadvantages and stressors serve to increase risk for psychosis while complicating and delaying pathways to care.

Ku et al. (2020) examined the relationship between neighborhood-level characteristics and age at onset of psychosis and DUP. The study included 143 participants between the ages of 18 and 30 diagnosed with a schizophrenia spectrum disorder; 86% of the sample was African American. In addition to collecting individual-level data, they characterized the neighborhood using census tract-level data. Of the neighborhood-level factors they examined, they found that neighborhood-level residential instability was associated with earlier age of onset of psychosis even when controlling for individual-level residential instability. They also found that perceived neighborhood disorder, measured by the Neighborhood Disorder Scale, was associated with longer DUP. The Neighborhood Disorder Scale asks individuals to rate 15 statements related to how much they perceive the presence of several neighborhood qualities such as drugs, crime, noise, graffiti, etc. This study potentially points to the increased distress that individuals living in these communities might experience and how this impacts their ability to access supports and mental health care.

Studies conducted in Latinx communities consistently support the notion that social determinants of mental health impact recognition and help-seeking in racial and ethnic minoritized communities. There is evidence that poor Latinx groups, for instance, tend to access specialized mental health services at a disproportionately lower rate than non-Latinx White individuals, possibly due to language fluency, a cultural value placed on access to affordable services in their neighborhoods, differences in recognition of mental health problems, and lower quality of mental health care (Alegría et al. 2007). López and colleagues (2018) studied psychosis literacy among Latinos, primarily of Mexican origin, with FEP and their caregivers and found that young people with FEP had generally low psychosis literacy. Their caregivers had significantly better levels of literacy but still demonstrated significant gaps in knowledge which likely directly impacts help-seeking. A qualitative analysis of a sub-sample of this cohort indicated that stronger family relationships characterized by open communication and disclosure of symptoms that facilitated awareness and direct action by family caregivers were associated with shorter DUP (Hernandez et al. 2019). When considering DUP, it therefore becomes important to contextualize the pathway to care and to take into account the unique barriers and facilitators present across communities. Although national studies provide information on aggregate-level delays, they do not provide a detailed perspective on the unique issues that BIPOC communities face and specific cultural and neighborhood-level factors that need to be considered and targeted to reduce DUP.

Strategies for Reducing DUP

Internationally, efforts have been made to reduce DUP using a variety of strategies. The Treatment Intervention in Psychosis Study (TIPS) conducted in Norway demonstrated that a multi-pronged public information campaign focused on building community awareness and providing clear instructions on how to access specialized services was able to reduce DUP by 50% in a large sector of the community (Friis et al. 2005). Lloyd-Evans et al. (2011) evaluated 11 DUP intervention studies to determine strategies for effective reduction of DUP. They included eight interventions which targeted increasing early detection of psychosis and connecting people to treatment. Three of the interventions included education campaigns for general practitioners to identify early signs of psychosis and encourage timely referral to care; the remaining initiatives involved a multi-intervention approach. These multi-element interventions included large-scale public service announcements across various media outlets, outreach to schools, face-to-face and written contact with general practitioners and other health care providers, and a telephone line for the public to call for advice. They concluded that the most effective way of reducing DUP consisted of taking a multi-focused approach which targeted multiple audiences through diverse modes of communication.

In the United States, several studies have focused on identifying strategies to shorten DUP by improving early detection and referral pathways. Srihari and colleagues (2020) used a quasi-experimental design to examine the impact of a 4-year early detection (ED) campaign (Mindmap), adapted from the Scandinavian TIPS approach, across ten towns in Connecticut. They used mass and social media messaging, professional detailing, and rapid triage of referrals and measured DUP as the time between the onset of psychosis and initiation of antipsychotic treatment and CSC. The comparison DUP group was derived from a CSC program in Boston during the same time period as the campaign. Results indicated a reduction in DUP at specific timepoints, measured in quartiles. For example, a time-series analysis revealed a cumulative effect of the campaign over time, i.e., for each year of campaigning, a 46-day reduction was achieved for connecting with their CSC program (Srihari et al. 2020). However, there are limitations to these findings since the overall differences between groups were not significant.

Other projects have focused on testing a variety of strategies for different populations. For instance, Kane and Birnbaum (2017) developed Internet-based strategies to reach young people through social media and concluded that young people with psychosis use the Internet and social media platforms such as Facebook frequently throughout the day and indicated that they would be okay with proactive outreach via the Internet as symptoms emerged. Additionally, the researchers found that their algorithm was able to accurately differentiate between psychotic disorder, mood disorders, and healthy controls 67% of the time (Kane and Birnbaum 2017). New York City has taken a public health approach and now requires all individuals hospitalized with first-episode psychosis to be identified and reported; the city also offers a critical time intervention model staffed by a peer and a professional, called NYC START, aimed at enhancing optimal follow-up care and facilitating connection with appropriate services 3 months post-discharge from an inpatient unit.

A significant limitation of current attempts to reduce DUP is that, for the most part, they lack attention to how social determinants of mental health limit access to care in BIPOC neighborhoods. Employing generalized population-level strategies for reducing DUP may prove insufficient, as these population-level strategies do not address the differential limitations that some communities experience when accessing health care and fail to account for the lack of capacity of current CSC programs to meet the population-based need for CSC services. A public health campaign that raises awareness about psychosis without considering and changing neighborhood-level deprivation, discrimination, and inequities that delay pathways to care will likely have limited effectiveness for a heterogenous group. Furthermore, if there is limited availability of CSC programs in a given area, then increasing awareness without providing adequate services could compound frustrations and mistrust toward the mental health system. More research is needed to understand whether engaging communities using individualized messages and strategies that have cultural resonance and that work to address disparities can more effectively reduce DUP in BIPOC communities. Overall, more work is needed to develop approaches to shorten DUP, to clarify the relationship between DUP and outcomes across various groups, and to consider the actual resources available to provide treatment. It is important that young people be connected to evidence-based treatment services as quickly as possible after developing psychotic symptoms to increase the probability of recovery and building a meaningful life; a more individualized, culturally informed approach might be more effective for achieving this goal.

Evidence for the Early Treatment for Early Psychosis

Early intervention services (EIS) for FEP have been supported by a combination of international research studies and implementation efforts carried out during the past 20 years. EIS have been broadly implemented in Australia, the United Kingdom, Scandinavia, and Canada (Heinssen et al. 2014). Studies have focused on specific treatment components (i.e., single-element studies), as well as multi-element team-based approaches. Multi-element services that combine each of the single elements (e.g., medications, supported employment and education services, cognitive behavioral therapy for psychosis, family therapy) have consistently demonstrated better short-term outcomes (Dixon et al. 2015; Craig et al. 2004; Petersen et al. 2008; Srihari et al. 2015). The most recent studies conducted in the United States have led to the creation of the label, “coordinated specialty care” (CSC) to represent these team-based approaches which encompass a package of evidence-based treatment modalities. We will review the literature that has established the evidence base for EIS services, focusing on describing foundational studies.

A study conducted in Denmark was the first randomized control trial (RCT) of multi-element care for early psychosis (Petersen et al. 2008). It recruited 547 individuals ages 18–45 with psychosis who had no more than 12 weeks of exposure to antipsychotic medications and randomly assigned them to either multi-element care (named OPUS) or treatment as usual (TAU). Individuals randomized to OPUS received services for 2 years based on the assertive community treatment model, which included individualized case management; family groups; low-dose antipsychotic medications and, when indicated, cognitive behavioral therapy (CBT); and social skills training. OPUS clinicians preferred to see individuals at their homes, and the client to staff ratio was 10:1. In contrast, individuals in the TAU group had monthly meetings with a psychiatric nurse in a community mental health center, consultations with a social worker, and medication when indicated. Home visits were infrequent, and participants consulted psychiatric emergency departments for care after office hours. In this group, the client to staff ratio was 25:1. OPUS participants had lower levels of positive and negative symptoms of psychosis, reductions in substance use, and increased engagement in, and satisfaction with, treatment compared to individuals in the control group (Petersen et al. 2008).

In the United Kingdom, the Lambeth Early Onset (LEO) study was the second RCT to test the impact of multi-element care for early psychosis. It included 144 individuals living in London, ages between 16 and 40, diagnosed with non-affective psychosis who had sought mental health services less than two times prior to study enrollment (Craig et al. 2004). Individuals randomized to multi-element care received atypical antipsychotic medications at low doses, CBT, family therapy, and vocational services for 18 months. Individuals randomized to standard care were treated by teams untrained in specialized services for early psychosis at a local community mental health center in the Lambeth section of London. Individuals who received the specialized intervention had fewer hospital readmissions, better medication adherence, and better occupational functioning and quality of life compared to those in standard care and were more likely to stay in the study (Craig et al. 2004).

The largest multi-element study to date was conducted across ten clinical sites in China by Guo et al. (2010). The study enrolled 1268 individuals aged 16–50 with an onset of psychosis within 5 years. Participants were randomly assigned to the control condition which focused on antipsychotic medication management or specialized treatment which included monthly visits consisting of medication management coupled with 4 straight hours of psychosocial groups, which covered individual and family psychoeducation and support, skills training, and CBT for 12 months. In total, 406 individuals received the multi-element intervention and 338 individuals received medication alone. After 1 year, individuals who received the psychosocial interventions had significantly greater improvement in insight, social functioning, obtaining employment or education, activities of daily living, and quality of life in addition to lower rates of "clinical relapse," which was defined by worsening symptoms, hospitalization, need for increased level of psychiatric treatment, self-harming behaviors, or violent behaviors (Guo et al. 2010).

In the United States, Srihari et al. (2015) compared their comprehensive early psychosis program (STEP) in Connecticut, which included antipsychotic medications, CBT, family education, and case management to help individuals access education and employment supports. Treatment received in the TAU condition varied because it was determined by the participant's current provider or by an outside treatment provider to whom they were referred. The sample included 120 individuals who had an onset of psychosis of less than 5 years before entry into the study and fewer than 12 weeks of exposure to antipsychotic medications. After 1 year of treatment, STEP participants had fewer total hospital admissions, fewer hospital days, and a greater likelihood of being employed or in school (Srihari et al. 2015).

Additionally, the National Institute of Mental Health (NIMH) funded the Recovery After an Initial Schizophrenia Episode (RAISE) initiative. Launched in 2008, RAISE aimed to develop and test a treatment model to reduce relapse and long-term disability for individuals experiencing early schizophrenia. NIMH required that the model be ready for rapid deployment if found effective (Heinssen et al. 2014; Bello et al. 2017). Two RAISE studies, the RAISE Early Treatment Program (ETP) and the RAISE-IES, laid the groundwork for larger-scale implementation of CSC programs (Dixon et al. 2015; Kane et al. 2015). The RAISE ETP study, a cluster-randomized control trial, enrolled 404 individuals who were between 15 and 40 years of age, diagnosed with non-affective psychosis, who had only experienced one episode of psychosis and were treated with antipsychotic medications for less than 6 months. The study was conducted across the United States in 34 clinics, half of which were randomized to the NAVIGATE condition and the other half to TAU. The NAVIGATE multi-element treatment was comprised of evidence-based prescribing of antipsychotic medications, family psychoeducation, and supported employment and education services. The individual therapy component entitled Individual Resiliency Training consisted of CBT-based strategies for symptom management, skills training, and substance abuse treatment utilizing shared decision-making with a focus on promoting individual resilience, recovery, and goal attainment. TAU included available community services as determined by clinicians within community clinics. Individuals receiving NAVIGATE remained in treatment longer, had more improvement on quality of life measures, were more likely to have a job or be in school, and experienced greater symptom reduction compared to participants in the TAU clinics after 2 years of treatment (Kane et al. 2015).

The RAISE-IES study (Dixon et al. 2015) focused on developing training materials for rapid deployment and implementation of CSC. The study recruited 65 participants at two sites, in Baltimore and New York City. Participants received multi-element treatment for up to 2 years which consisted of evidence-based pharmacology, case management, supported employment and education, family support and education, and a flexible CBT-based psychotherapy approach which offered psychoeducation, social skills training, substance use treatment, and an emphasis on reducing suicide risk. The model was delivered using the principles of cultural competency, shared decision-making, and with an emphasis on individualized recovery trajectories which were guided by a person's strengths and goals. Results indicated high retention rates in the program; 91% of individuals stayed in services for as long as they were offered. Study participants also demonstrated improved social and occupational functioning, decreased symptoms, decreased rates of hospitalization, and increased rates of remission. Furthermore, they found significant increased participation in competitive employment and degree granting educational programs (Dixon et al. 2015). The materials developed by the RAISE-IES study were later adapted to the OnTrackNY model. OnTrackNY and NAVIGATE are two of the leading models used in the United States to train specialized teams on the implementation of CSC.

Evidence-Based Treatment for Early Psychosis

In the United States, coordinated specialty care (CSC) became the umbrella term to describe multi-element approaches for delivering evidence-based early intervention treatment for young adults experiencing early psychosis. As described in the literature review above, the multi-disciplinary CSC team approach encompasses a suite of evidence-based practices that have been shown to reduce relapse and improve outcomes for individuals experiencing schizophrenia spectrum disorders. The services are recovery-oriented and emphasize shared decision-making, assertive outreach and engagement, and cultural competency in an effort to effectively engage young people and their supports. Furthermore, CSC is offered utilizing a person-centered, collaborative, and youth-oriented framework, to help people achieve meaningful goals and reduce disability. The CSC team strives to convey hope for recovery and views the person diagnosed with early psychosis as the central member of the team's efforts. Individuals' life goals, aspirations, and ambitions drive treatment planning; therefore, none of the treatment components are mandatory. In general, CSC teams have low client to staff ratios typically in the range of 10:1 (Heinssen et al. 2014).

Evidence-based treatments provided by CSC programs include (1) evidence-based psychopharmacology which emphasizes prescribing the lowest effective dose of antipsychotic medications with the fewest side effects; (2) health, wellness, and primary care coordination meant to address cardiometabolic factors associated with antipsychotic medications by providing education on nutrition and exercise, assessing health with routine lab work, and coordinating with other medical professionals; (3) case management aimed at helping individuals and families meet concrete needs and connect to outside resources; (4) psychotherapy that is generally supportive, focused on engagement, collaboration, and enhancing resiliency coupled with cognitive behavioral treatments to target symptoms of psychosis and related comorbidities; (5) family support and education consistent with individual and family preferences, to promote family involvement across all treatment components and address family needs; (6) supported education and employment using the individual placement and support model to assess work and school interest, facilitate rapid placement, and provide supports as needed; and (7) peer support services which are also included in some programs to help enhance engagement, peer connections, and promote self-advocacy (Heinssen et al. 2014).

These services are provided in a flexible, developmentally sensitive way for an average of 2 years – although sometimes much longer. Within the CSC model, participants are not required to engage in any of the interventions in order to maintain enrollment, although everyone is connected to a primary provider who serves as the point person for the participant and family member. It is the participant's and family's ability to engage with the team in a flexible way that allows the interventions to be tailored specifically to each individual and his/her set of circumstances to promote achievement of school, work, and relationship goals. Similarly, families have access to the team of providers and receive individualized services to help them navigate this precarious time and support the young person in their recovery journey.

At the outset of treatment, teams focus on forging highly collaborative and engaging alliances with participants and family members through the use of specific assertive outreach and engagement strategies (Bennett and Bellack 2017). For instance, successful teams are able to remain proactive in connecting with participants and family members throughout all phases of treatment, and this might include the use of various forms of communication (phone, texting, email, and in-person meetings). The time and location of sessions are flexible and responsive to the needs and preferences of the participants and family members (e.g., in the home, community, or clinic with increased or decreased frequency, as needed). Considerations of transportation, work schedules, and other caregiving are critical, as well. Especially in areas that are geographically spread out where public transportation may not be readily available, the flexibility of team members to be creative in communication and scheduling is critical to developing a solid working alliance. Teams typically have the flexibility to keep the participant's file open in the program for longer periods of time than in traditional clinical settings, even when there is little contact with the participant.

Teams are also able to provide important information for participants to consider all relevant treatment choices rather than dictating treatment recommendations and, therefore, ensure that treatment decisions are guided by pressing concerns expressed by participants and family members – not the priorities of the team. Providers maintain a flexible and consistent stance toward treatment, which allows them to respond sensitively and practically to the range of situations that might arise on an as-needed basis. At the same time, they focus on demonstrating to the participant and family members that the team will remain a consistent presence by behaving in a reliable manner and offering support, empathy, and trustworthiness (Bennett and Bellack 2017). This therapeutic alliance usually serves to ensure treatment engagement remains across time and serves as the foundation for introducing and delivering the pharmacological, psychosocial, and other treatments offered.

National Expansion of Coordinated Specialty Care

The creation and dissemination of CSC programs across the United States and the contribution of the RAISE projects can be understood as the intersection of trends in both science and policy that converged to create the foundation for changes in care and care delivery (Dixon 2017a, 2017b). In 2014, House of Representatives Bill 3547 provided an increase of 5% to the Community Mental Health Block Grant program, an allocation targeted at evidence-based programs for individuals experiencing early psychosis. The funds were maintained in 2015 and doubled in 2016. This funding allowed for the widespread national implementation of CSC programs (Heinssen et al. 2014; Bello et al. 2017). At this point, every state has at least one CSC program. However, many challenges remain. First, there is no standard CSC program and no well-validated measure of fidelity, although some researchers are developing this process (Addington et al. 2016). This complicates the ability to train the workforce and the financial sustainability of CSC continues to be a challenge (Dixon 2017a). Furthermore, the fragmented US health-care system has contributed to a variety of experiences regarding how to implement CSC programs across diverse contexts.

As the implementation of CSC programs has been expanding throughout the United States, the differences across implementation efforts have become more evident. Decisions regarding specific implementation practices appear to be influenced by population density and incidence of FEP, community-based needs, available workforce, involvement of state-level leadership and coordination efforts, and financial circumstances. Even though clinical trials have demonstrated the effectiveness of CSC treatment for individuals aged 15–25 diagnosed with non-organic, non-affective, non-substance-induced psychotic disorders, who have started experiencing symptoms within 5 years of receiving care, some programs try to reach a broader sector of the population. Some programs have decided to expand the age range and others to focus on any transition aged youth demonstrating high levels of service use, and others have broadened the diagnostic criteria for program inclusion. One important permutation is the expansion of the eligibility criteria to include individuals experiencing affective psychosis, as a way of addressing the real-world needs of participants in certain communities and enhance the sustainability of the programs. It is yet to be determined whether these adaptations and permutations will preserve the effectiveness of CSC models. However, it is evident that there needs to be a balance between maintaining fidelity to the key elements of the model and being able to deploy a program that is responsive to the needs of the population in a given community.

There needs to be further consideration of community-level factors that impact the ways in which individuals and families relate to and utilize CSC programs. One way to do this might be to systematically include the conceptualization of the impact of social determinants of mental health into the fabric of the CSC interventions. CSC models need to go beyond delivering culturally competent care. They should explicitly incorporate a focus on social justice that encompasses an anti-racist framework. This is fundamental to being able to really alter the short- and long-term outcomes of young people diagnosed with psychosis across communities. At this time, there is limited guidance within these models on how to conceptualize the impacts of population-level economic and social conditions that negatively impact people's behaviors.

OnTrackNY developed a guide for delivering culturally competent care to individuals with early psychosis (Lewis-Fernandez et al. 2018). This guide describes key concepts and principles, best practices, and case examples to help individuals with FEP; their supports and providers work together to implement culturally competent early intervention services. Specifically, it guides teams on how to think about and work with areas such as religion and spirituality, family culture, language barriers, gender and sexuality, youth culture, and the team's own culture. At the individual level, these are important things to consider and incorporate particularly if they are salient to the individual and family. However, teams also need to be able to consider the impacts of the broader systemic, structural racism associated with significant disparities in most aspects of life in the US for BIPOC individuals. Individuals cannot be separated from their skin color, backgrounds, or the systemic oppression that these characteristics guarantee in society. CSC providers would benefit from training on a model that includes a specific understanding of the effects of discrimination, social exclusion, and neighborhood-level disadvantage that their BIPOC participants experience. Furthermore, training on delivering evidence-based interventions that are adapted to include and respond to the effects of discrimination, stigma, and community-level disenfranchisement would benefit young people and their families and likely have long-standing effects. Failure to address these barriers in treatment limits the team's ability to truly understand, connect, and help the individuals they serve. For example, understanding that certain communities have been harmed by mental health systems and acknowledging the well-founded level of mistrust that participants and families might have toward the team from the outset could help build a more genuine, stronger relationship. Recognizing that some BIPOC participants live in communities where their friends in families experience police brutality, are disproportionally incarcerated, and face food insecurity could help shape where providers focus their interventions and modify the way they work with participant and family members, as well as communities.

It is insufficient to deliver a high-fidelity CSC intervention that does not acknowledge and address the disparities that people face in their daily lives and lack of resources they and their families have for meeting basic needs due to their race or ethnic background. The flexibility and time afforded within the CSC model provide a unique opportunity to deliver care that is able to meet unique individual needs while at the same time work toward dismantling racism. As a field, we have achieved a great deal in a relatively short amount of time by continuing to study and develop strategies for reducing DUP and providing evidence-based CSC treatments to young people as quickly as possible. More work remains to be done to make these programs responsive to the specific needs faced across communities and understand how these programs could be shaped to provide improved long-term outcomes and even have an impact on changing policies to create systemic change.

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